

# Doing our bit to ease the pain

**P**SYCHOLOGISTS and others have long recognised that the experience of loss, especially through the death of important people in your life, represents a challenge (Bowlby, 1980; Parkes, 1996). Even the much-criticised Life Events Scale developed by Holmes and Rahe (1967) categorised loss of a spouse as the most stressful event a person is likely to encounter. Dealing with patients and their families facing the end of their life and the loss of important relationships is a central part of the work of psychologists working in palliative care.

This article is about the potential of psychology to contribute to improving care for adults with advanced disease who are nearing the end of their life. We will define palliative care and briefly describe the range of services available to very ill and dying people and their families. We show how psychologists can contribute to improving care by working directly with patients and families doing psychological assessment and therapy, working with health and social care professionals and volunteers, and developing research.

Currently it is predominantly clinical and counselling psychologists that are involved in direct patient services. However, we are aware of professional developments within health psychology with Society accreditation of practitioner status that may increase their role in healthcare services. In this article we refer collectively to psychologists whatever their specialist background.

What is palliative care?

Palliative care is 'the active total care of patients whose disease is not responsive to curative treatment' (World Health



**SHEILA PAYNE and REBECCA HAINES** describe the potential contribution of psychology to palliative care.

Organization, 1990, p.11). It includes terminal care but is not synonymous with it, as it also includes the management of difficult symptoms at an earlier stage of illness. There has always been an emphasis on the control of pain through the use of drugs, especially opioids (morphine and other analgesic medication), and the medical control of distressing symptoms such as breathlessness, fatigue and nausea (Doyle *et al.*, 1998). But from the early days there has also been a recognition that dying patients have concerns not only over their physical care but also over their social, psychological and spiritual well-being.

Such concerns may be addressed within a palliative care approach provided by any doctor or nurse working in primary care or a hospital. Doctors, nurses and other health professionals with additional education and expertise provide specialist palliative care services in hospitals, in the community and in hospices (National Council for Hospice and Specialist Palliative Care Services, 2001).

In Britain the hospice movement arose out of perceived inadequacy in the care of dying patients, in particular concerns about pain control and symptom management (see box opposite). The hospice movement did not really take off with the opening of the first hospice in 1967, St Christopher's in south London. It was a more gradual process of change and consciousness

raising, with powerful charismatic leadership by Dame Cicely Saunders and others (Clark, 1999). The terminology of end-of-life care has undergone a number of transitions: from hospice care and terminal care in the 1960s and 1970s, to palliative care being the common term now (Clark & Seymour, 1999).

Palliative care and the modern psychologist  
Palliative care has now spread worldwide and has developed in diverse ways. Such trends have been born out of necessity. The last century saw dramatic changes in public health, medical technology and science – the pattern of disease has shifted from young babies and children dying rapidly of acute infections to older people dying slowly of chronic diseases.

New standards for specialist palliative care services have recommended the provision of psychological services (Department of Health, 2000a). This means that psychological expertise is increasingly being regarded as a core component of good-quality care, and that psychologists are beginning to be viewed as part of the multidisciplinary team. The NHS Cancer Plan (Department of Health, 2000b) outlines proposals to significantly increase investment and to ensure equitable access to specialist palliative care services. Within the Cancer Plan a supportive care strategy for cancer (encompassing information, communication, psychological support and palliative care) is being developed and will be of particular importance to the development of psychological care and specialist psychological services.

## WEBLINKS

Sheffield Palliative Care Studies Group: [www.sheffield-palliative.org.uk](http://www.sheffield-palliative.org.uk)

National Council for Hospice and Specialist Palliative Care Services: [www.hospice-spc-council.org.uk](http://www.hospice-spc-council.org.uk)

Hospices have largely cared for people dying of cancer, but the trend now is to extend care to people with other conditions. This represents a challenge in terms of resources and skilled staff (Addington-Hall & Higginson, 2001). Structural changes in patterns of chronic end-stage illness and dying in British society represent a challenge to psychologists and others working in palliative care. Demographic trends with a rising older population indicate that cancer deaths and those from other chronic illness, for which palliative care will be needed, are likely to rise. More people have chronic diseases that progressively limit their functional (and, for some, cognitive) abilities. Thus people, especially older people, are increasingly dying slowly over a long timespan, punctuated by episodes of acute illness and partial recovery (Froggatt, 2001), which may be unlike the normal disease trajectory of most cancers.

Psychologists can make a contribution to the understanding of the psychological effects of chronic progressive disease. Much health care is based on assumptions about the availability and willingness of families and friends to provide care. But social change such as geographical mobility, changing patterns of female employment, and changing patterns of partnership relationships and divorce, make this problematic. Healthcare services need to take account of these social trends in planning interventions and working with practitioners in providing end-of-life care.

### What can psychology contribute?

Palliative care is an exciting area for a psychologist to be involved in. Multidisciplinary teamwork and a 'holist' philosophy lie at the heart of the hospice philosophy, so psychologists should be welcomed. In theory they should not be 'battling' against a biomedical model and a traditional dominant medical hierarchy. In practice we have indeed found that palliative care can be one of the few truly multidisciplinary areas in health care. As it is a relatively new area, there are lots of opportunities to develop innovative clinical practice and many interesting research questions to be posed. We have highlighted a few areas in which we believe psychologists can contribute.

### Theoretical models and understandings of human behaviour

Psychology has a rich heritage of theories that attempt to explain how people

## HOSPICE FACTS

Hospices arose out of a desire to provide better-quality services for dying patients and their families, and largely occurred outside statutory health services. By the beginning of 2001 in the UK and Ireland there were 3222 in-patient beds and 364 homecare teams providing palliative care (Hospice Information Service, 2001).

Hospice developments in Britain have traditionally emphasised:

- in-patient care
- care for cancer patients
- pain management
- teamworking in ways that challenged established medical hierarchy, especially with the use of volunteers drawn from the local community (James & Field, 1992)

Patients may be admitted to in-patient hospices for:

- control of difficult symptoms
- respite (to enable their caregivers to rest)
- terminal care

Patients tend to stay for a limited period and are then discharged. In many places patients are helped to live at home and die there, if they and their families choose (Thorpe, 1993).

approach loss and death (for a fuller account see Payne *et al.*, 1999). Theories that fall into the group variously classified as coming from lifespan, developmental or psychosocial transitions perspectives are good examples (e.g. Bowlby, 1980; Erikson, 1963; Parkes, 1996). These are based on an assumption that there are normal patterns in human life cycles in which there is 'a time to be born and a time to die'. Therefore changes or transitions are regarded as a normal part of human experience. These experiences permit psychosocial development and growth as people learn how to cope successfully with change and loss.

An alternative approach to understanding the effects of loss and bereavement on individuals has been derived from theoretical models of stress and coping. This assumes that bereavement and loss function as stressors to which individuals are required to adapt. The transactional model described by Lazarus and Folkman (1984) has formed the conceptual basis for a recent model of bereavement proposed by Stroebe and Schut (1999). They suggest that people oscillate in their styles of coping between focusing on the emotional expression of grief and the need to continue with everyday living (called restoration-focused coping). This model has been used to guide bereavement support, so that people can be helped to achieve a balance between being overwhelmed with distressing emotions and getting on with practical activities.

The social-cognitive transition (SCT) model of adjustment (Brennan, 2001) offers a broad conceptualisation of adjustment to cancer and other progressive

diseases. Adjustment is regarded as the psychological processes that occur over time as the individual seeks to manage, learn and adapt to the multitude of changes associated with the illness pathway within a number of social contexts. The SCT model attempts to account for the huge diversity of experiences that people with cancer report – from psychological disorders to positive personal growth. The model may also aid clinical formulations and generate interventions whether someone is at the time of diagnosis or is terminally ill.

### Direct psychological interventions to support patients and families

At a practical level, while multidisciplinary teams may welcome a clinical psychologist, you will need to explain the skills that you bring and consider how such skills can be integrated into existing services. Practitioners may have little experience of clinical psychology. A recent review showed that experienced doctors and nurses working in palliative care remain uncomfortable and uncertain about how to assess their patients for depression (Lloyd Williams, 2001). A survey in Britain showed that some specialist palliative care nurses were concerned about perceptions of stigma associated with mental illness and labelling their patients (Lloyd Williams & Payne, in press). Thus they were reluctant to refer patients for assessment and treatment. Some nurses also made assumptions that psychological distress and depression were to be expected, and so regarded this as normal. Psychologists have much to do in assisting in removing the stigma associated with mental health

problems. They can also legitimise the expression of difficult emotions as normal and adaptive. They can suggest 'safe' ways to express these emotions and support problem-solving skills.

Psychologists have a clear contribution to make to the psychological care provided to patients and families by palliative care services, but the particular specialist contribution of the clinical psychologist is a thorough understanding of varied and complex psychological theories and the ability to apply these to problems and generate specific interventions (National Council for Hospice and Specialist Palliative Care Services, 1997). Specialist psychological services may be required to address a variety of clinical issues including:

- abnormal grief reactions, such as prolonged or excessive grieving;
- adjustment disorders, such as fear of leaving the hospice;
- psychological morbidity, such as anxiety and depression;
- relationship and communication problems, such as excessive dependency; and
- symptom management, such as control of anticipatory nausea associated with chemotherapy, or non-pharmacological pain management such as relaxation.

**Working with teams and organisations** At an organisational level, psychologists could be more involved in examining how multidisciplinary teams

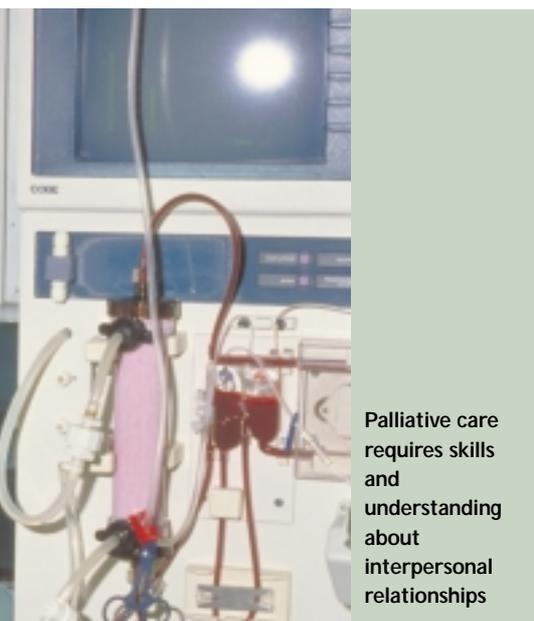


function. The rhetoric in health care is that teams are a good thing. But they require skills and understanding about interpersonal relationships, a recognition of the different disciplinary languages and cultures (for example, between medicine and social work). Specialist palliative care teams increasingly work in complex networks such as the new Cancer Networks, and their work crosses organisational, geographical and service boundaries. Drawing more explicitly on models from organisational psychology, psychologists can facilitate teams in preparing for and implementing change.

Working with patients and families making major life transitions is both rewarding and challenging. Psychologists also have a role in helping to shape organisational structures to support and contain staff distress. For example, post-death debriefing sessions can be used to facilitate open discussion which does not accuse or blame others in the team when a difficult death has occurred. Clinical supervision of the psychological elements of care is essential to the protection, maintenance and development of skills of the caregivers. Skilled communication by staff at all levels, tailored to their

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Palliative care requires skills and understanding about interpersonal relationships

needs, enhances the possibility of caring for patients and their families, and also has implications for training and supervision. Clinical psychologists have a role to play in the training and supervision of others as well as having a responsibility for their own continuing professional development.

**Research expertise** Psychologists may function as links helping to bridge the gap between 'biomedical' research and social science paradigms of research. These are important skills in health services in which multidisciplinary research teams need to collaborate to tackle complex research questions.

There is much debate about what constitutes appropriate methods in clinical and health psychology and in palliative care. There are very few randomised controlled trials to evaluate the effectiveness of palliative care. Substantial practical problems and ethical debates surround research with this group of frail and potentially vulnerable people (Barnett, 2001; de Reave, 1994). The methodological problems include recruitment difficulties, an anticipated sample attrition (through death and increasing frailty) and restricted physical and cognitive abilities (Jordhoy *et al.*, 1999).

There seems to be a tension in the basic philosophy and focus of research: on the one hand, is it to study small elements of human experience; or on the other, the total experience of patients? Approaches combining quantitative and qualitative methods are increasingly popular. But is

it justified to combine research methods when they are based on fundamentally different notions of truth, reality and causality? In our view, qualitative methods may offer exciting possibilities in understanding the lived experience of terminal illness. Action research methods may offer participatory models where patients and carers can be involved in setting the research agenda. Although it is fashionable to talk of user involvement in healthcare services (Gott *et al.*, 2000), how can this be achieved in palliative care when patients are so ill and carers may be distressed and bewildered by events? Are psychologists ready for collaborative methods such as action research?

### The future role of psychologists in palliative care

There is an increasing recognition of the value of psychological perspectives and interventions in the care of patients with advanced disease and the support of their bereaved families. Recent government policy has acknowledged the place of psychological services in providing high-quality cancer and palliative care. In this article we have highlighted a number of ways in which psychologists may contribute. There has been a long tradition of scholarship and critical commentary on palliative care from social scientists, such as sociologists (e.g. Clark, 1993; Clark *et al.*, 1997) and anthropologists (e.g. McNamara, 2001). Arguably psychologists have not yet sufficiently contributed to this area.

'Critical' health psychology, which offers an analysis derived from constructivist theoretical and methodological paradigms, is a potentially exciting development (Crossley, 2000). This approach challenges many of the theories and practices that have formerly defined mainstream psychology and suggests alternative, perhaps more collaborative ways of working. In our view, clinical and health psychology can contribute not only practical expertise but the insight to ask challenging research questions.

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