

Rod MacLeod MBChB MRCGP FACHPM



A black and white portrait of Robert A. Hines, a middle-aged man with short, light-colored hair, smiling. He is wearing a light-colored dress shirt and a dark, patterned tie.

It is also useful to identify what significance the pain has for each individual and how much of a nuisance the symptom is. Following this methodical approach, examination and investigation should lead to documentation and repeated review.¹ Because most clinical medicine is based on the biomedical model it may be hard for some to recognise all the dimensions of pain. Dame Cicely Saunders, over 30 years ago, identified the importance of seeing pain in its totality – that is, a symptom having physical, psychological, social and spiritual components. It is relatively easy to identify the physical causes of pain (the actual tissue damage of the IASP definition) and for some it is possible to identify early, the psychological elements of pain (the potential or real losses

associated with a terminal illness). But how good are we at identifying the other elements of pain? How good are we at recognising the social or spiritual aspects of pain?

Frances Sheldon² recognises that the *'losses experienced by people with advanced cancer in relation to their social world are concerned with their engagement with the world outside home and with the roles and relationships within the family'*. Who better to help to unravel the complexity of this issue than the family physician?

Financial hardship often accompanies serious illness and puts additional strain on an already challenging situation for a family. The inability of individuals and families to maintain their previous levels of social engagement can create additional burdens that can be manifest as pain. It is not hard to recognise that persisting pain, especially if associated with approaching death, can be a wearying prospect. It is not hard to recognise that some people will experience the pain of therapeutic failure. Imagine the pain of loss – loss of role, loss of independence, loss of a future. Imagine too the pain associated with sadness and worry – worry about family and friends and about the future. The pain of fear is very real – the fear of pain or of suffering, the fear of dying or of death itself.

Suffering is a uniquely individual experience that is quite different from the presence of pain. Suffering is intensely personal and again can be multidimensional. Relief of pain on its own will not always relieve suffering and, particularly in the man-

agement of people near the end of life, attention to the relief of suffering by all members of the team will ease this considerable burden.

Many people may also experience a spiritual pain – a pain associated with a lack of understanding, an inability to make sense of what is happening to them at that time. And for many the sense of hopelessness that is associated with persisting pain is all pervading.

For most people, the concept of hope involves a sense of future. In order to experience hope one must foresee a future for oneself. Eric Cassell³ has written that, *'for many people who are dying, any notion of time stands still while it continues to move forward for the rest of the world'*. In studies that have looked at the maintenance or rekindling of hope in people who are dying, patients identified as their 'highest rated' interventions, hope enhancing strategies. These include strategies such as providing comfort/pain relief, assisting in the development of goals, facilitating a sense of connectedness with others

that have also been identified as being useful in qualitative studies with elderly, critically and chronically ill people.

The maintenance of hope is essential to well-being. Paradoxically it has also been suggested (and this is borne out by professional experience) that hope-damaging incidents remain with the individual for a prolonged period of time, if not until death.⁴

The maintenance of hope should not just be concentrated on the patient either. Family and carers will find themselves with similar fears,

worries and sometimes a sense of hopelessness.

The aims of management⁵ then can be seen as:

- To recognise and assess pain promptly;
- To recognise psychosocial and spiritual influences on pain perception and management;
- To maintain maximum possible quality of life and independence;
- To relieve current and future fears about pain;
- To provide support and encouragement to carers.

The principles of management are:

- Patient and family participation;
- Collaborative multi-disciplinary approach by health care professionals;
- Use of appropriate medications, tailored to each patient individually, given regularly to relieve and prevent pain, and with minimum side effects;
- Continued regular follow-up;
- Access and early referral to specialist services if pain control is not achieved.

Overlooking this last point may be one of the reasons why so many continue to live with pain. Referral to specialist pain services or palliative care teams should be considered early if the pain is not responding to 'standard' measures. With meticulous attention to detail, it is possible to reduce pain in almost all cases. Over 90% of cancer pain can be alleviated. Meticulous attention to detail is the hallmark of good palliative care and with that detail employed by a multi-disciplinary team, pain as a major symptom should be alleviated for the vast majority of people with advancing disease.

Suffering is a uniquely individual experience that is quite different from the presence of pain

References

1. MacLeod RD, Vella-Brincat J, Macleod AD. The palliative care handbook. Wellington: NZIJ; 2002.
2. Sheldon F. Social impact of advanced cancer. In Lloyd Williams M, editor. Psychosocial issues in palliative care. Oxford: Oxford University Press; 2003. p.37–47.
3. Cassell E. The Healer's Art. Cambridge, Massachusetts: MIT Press; 1976.
4. Rustoen, T. Hope and quality of life, two central issues for cancer patients: A theoretical analysis. Cancer Nursing, 1995; 18:355–361.
5. Royle D, MacLeod RD. Management of malignant bone pain. New Ethics Journal. 1999; 2(11):23–29.