Patient information for pain control in palliative care

In this article the author argues that written information about pain and its control should be given routinely to patients and carers. This would be in line with guidelines for palliative cancer care, would relieve distress for patient and carer, and promote best practice.

Date of acceptance: June 12 1997.

Pain is one of the most feared consequences of cancer. Yet there appears to be a lack of knowledge and understanding of the nature of pain or analgesia amongst patients and carers in the community. Offering written information to patients and carers could help to reduce their fears about analgesic drugs. It could also lead them to understand that drugs are not the only form of pain control available.

The Palliative Cancer Care Guidelines for Scotland (SOHHD 1994) state that 95-98 per cent of patients could die pain-free. However, in 1982 Twycross and Fairfield estimated that 30,000 patients die in unrelieved pain in the UK each year. Much has changed since that study, but patients' and carers' fear of pain remains. Informal discussion with nurses in several settings suggests that nurses still do not offer written information to patients on pain and its treatment. The use of booklets, such as that produced by BACUP (Jackson 1991), is rare, in spite of the fact that BACUP's booklet is available free to patients.

**PATIENT PARTICIPATION IN CARE**

Providing patients and their carers with written information on pain and its control will allow them to participate in their care (Dougherty and Stuttaford 1993).

The Palliative Cancer Care Guidelines for Scotland (SOHHD 1994) clearly state that the focus should be on the patient: 'Palliative care is concerned with the whole person - a person's body, mind, emotions, social and family context and spiritual values.' The guidelines quote the Lothian Health Board Patients' Charter: 'You are entitled to be involved in so far as is practical in making decisions about your own care, and whenever possible to be given choices.'

This point is given greater emphasis elsewhere in the guidelines: 'At the heart of palliative care is the belief that the involvement of the patient and family is an essential prerequisite to the planning and provision of care. In this context the uniqueness of each individual patient can be understood and respected to the point where an individual's choices about care can be identified and, wherever possible, met. Palliative care should follow the patient's chosen path and accompany the patient at his or her pace.'

Other authors have emphasised the subjective nature of pain. According to McCafferty (1983): 'Pain is what the patient says it is and exists when they say it does.' Gooch (1989) suggested that: 'The nurse has a duty to learn as much as he or she can about the nature of every individual patient's pain.'

Patients need to know that their experience of pain is accepted without question or criticism. Such unconditional acceptance will itself give a foundation of hope upon which patient, carer and nurse can build. Specific matters can then be addressed.

The subjective nature of pain means that responses to it can be affected by a wide variety of factors. Factors which can lower or raise the threshold to pain are listed in Box 1.

Factors that lower the threshold to pain cannot be countered without the active involvement of patients. For example, patients with past experience of uncontrolled pain need to be encouraged to express their current fears. As long as their fears remain, the efficacy of any analgesia will be reduced. Staff and carers may guess that fears exist, but only the patient can express exactly what these are. The gentle persistence of caring staff can encourage the patient who is introverted to open up, and so discover the causes of that introversion. Anger, fear and sadness must be expressed before they can be healed. All these factors are very real in the experience of the patient, but they are subjective and their relief requires the patient's active involvement.

**NEED FOR WRITTEN PATIENT INFORMATION**

To help them cope, patients and relatives need information that encourages them to participate in their own care (Hiromoto and Dungan 1991). Providing adequate information can help patients to cope with their illness and give them a sense of control (Clark and Sims 1988). They need to be able to absorb and retain information, but the fear often associated with cancer can prevent them from doing this. Many patients forget what they have been told or are unable to retain facts (Webb 1987).
Box 1. Factors affecting the pain threshold

Lowering factors:
- Insomnia
- Sadness
- Depression
- Fatigue
- Anxiety
- Mental isolation
- Introversions
- Anger
- Past experience
- Fear

Raising factors:
- Sleep
- Elevation of mood
- Analgesics
- Diversion
- Antidepressants
- Understanding
- Anxiolytic drugs
- Sympathy
- Rest

Dixon (1992) stated that: 'Inadequate information can lead to patient frustration and ultimately the vitiation of nursing efforts.' She used the example of non-compliance with drug regimens because often patients cannot see the point of continuing to take drugs once they feel better. The advantage of written information is that it is available for patients to consider, review, absorb and share as they are ready, at their convenience.

Cancer patients themselves have expressed favourable attitudes towards receiving written information (Ley 1990, Lilley 1991). Providing patients with information opens the way for truly informed consent, increased patient understanding and satisfaction, and increased compliance with treatment (Ley 1990).

Dougherty and Stuttaford (1993) found that relatives also considered it useful to have information written down, particularly if they had not been present when information was shared, or if the patient was too anxious to remember all that was said. Hinds (1992) commented that misconceptions were sometimes evident in carers' understanding of disease: 'The continuous worry anticipating an experience that may never occur was a source of suffering to the care giver.' Patients and carers may need constant reassurance that pain can be controlled, and the relief of uncertainty and anxiety caused by anticipating situations may itself relieve some pain (Hayward 1975). Disseminating accurate, reliable information about pain control may also dispel unnecessary fear based on hearsay.

Dixon (1992) found evidence that some patients have a selective memory, and may rationalise what they are told to suit themselves. They may also readily revert to previously held views once they are away from a medical setting. Using printed information that they can refer to in their own time means that patients, relatives and friends will have an accurate record of information on pain control. Moreover, nurses and doctors in different settings will know what information has already been given to patients.

THE ROLE OF COMMUNICATION

The implications of unrelieved pain are evident in the misery and suffering of patients, their carers and staff. As Latham (1991) pointed out: 'Pain is a burden... a drain on the resources of all.'

Unrelieved pain throws patients into a vicious cycle of anxiety, loneliness and fear. This isolates them and places additional strain on the bonds of mutual care and support which should exist between the patient, carers and staff.

Poor communication, whatever its cause, may result in pain being unrelieved. Communication may be clumsy, distant (due to poor-person-to-person interaction) or non-existent. In her Booklet Of Hope, written as a result of her own cancer experience, Prince-Stoltenberg (1993) wrote: 'It is important to communicate with others during your cancer experience.' At a time when emotions can be overwhelming and many difficult issues have to be faced, fear and embarrassment can obstruct communication between patients, carers and staff.

Anxiety, fear and loneliness can all have an adverse effect on the response to pain. Providing a patient with information on pain control which can be shared with carers may provide a 'safe' opportunity for communication. This may open the way to communication on more sensitive areas. As Wells (1988) indicated: 'Freedom from pain ensures trust, facilitates continued interaction with those who are meaningful, and enables dignity to be maintained.'

In their study of referral to an inpatient hospice, Seamark et al (1996) found that pain was a feature in 60 per cent of cases, but only 8 per cent of referring GPs reported frequent problems in achieving pain control in patients. One suggested reason for this discrepancy was the stoicism of patients; many did not wish to complain to their family doctor. Another was that pain rating scales were not used in either medical or nursing notes. Interestingly, the study also showed that coping with the emotional distress of patients and their carers consistently appeared to give GPs more problems than dealing with their own emotions.

The availability of information on pain control is no panacea, but patients and carers might have experienced less distress if they had understood the many factors affecting the perception of pain. Similarly, the use of pain assessment tools might have assisted the health professionals in caring effectively for patients and carers. Actively encouraging the involvement of informed carers could also alleviate the professionals' own distress.

NURSING RESPONSIBILITIES

In view of the many factors influencing responses to pain, nurses must use all their powers of observation and communication to assess and bring effective and acceptable relief of pain. Many factors affect nurses' assessment and interpretation of a patient's pain (Davitz et al 1980, Gooch 1989), and they often inadvertently under- or overestimate a patient's pain. Wilkinson (1991) commented that much of what nurses do is based on assumption and that they are never able to understand fully true emotions and anxieties. Marks and Sacher (1973) and Hunt et al (1978), working with patients with protracted pain, produced evidence that pain and site involvement are often underestimated, and pain inadequately relieved.

Relatives or other people significant in the patient's life can help patients to communicate their pain. Helplessness is often expressed by those close to a terminally ill patient (Hinds 1992), Cameron and Parkes (1983) commented that 50 per cent of a group of bereaved relatives referred to memories of the dead person's unrelieved pain as the worst thing they had to bear, even a year after bereavement.

Carers often spend more time with the patient...
than anyone else. Given the appropriate tools they could help to resolve their own helplessness and distress — and help the patient — by providing accurate, current information about the patient’s pain. Suitable written information with appropriate encouragement and help from professional carers could be that tool.

CHARACTERISTICS OF USEFUL INFORMATION

Information given to patients and carers should cover a wide range of topics in the broadest way possible. However, it is estimated that one in eight adults in the UK have reading and writing difficulties (Dixon 1992). Information should therefore be presented in a readable, but not condescending, way.

Although the topics covered should be discussed broadly, it is worth providing detailed information on means of describing and locating pain. If this is not done there will still be too much scope for staff to make assumptions about the level of pain and appropriate treatment. Written methods have been devised to achieve comprehensive descriptions of pain using drawing, scales, diaries and shading on ready-drawn outlines of the body.

When producing something from scratch, thought can be given to costs and formats. Booklets are useful. But it is worth considering a loose-leaf folder, into which information on other topics could be included as appropriate. One centre produced such a folder and included information about the specific disease, treatments and their side effects, and so on (Dougherty and Stuttford 1993). This could be extended to include some hand-written record of staff interaction with patients. Such a patient-held record could encourage openness and further enhance communication between staff in different care settings.

Patients should always be encouraged to ask questions, and staff should never use written information to avoid responsibility. Nothing can replace the interest and concern of open and caring staff.

If all patients have access to the broadest possible, readily understandable written information about pain control, they can gain enough knowledge to be able to take part, and be helped to make informed choices in pain control. If the patient knows that there is a plan for and means of coping with increased pain, anticipatory fear might be relieved (Hayward 1975).

Trusting patients with this information and including them in decision making restores their dignity by implying a respect for their ability to make choices. Showing that there are more means of removing pain than purely medicinal ones, and that many can be instituted by the patient or carers, encourages some self-reliance and autonomy in a situation where a patient may be progressively robbed of these things.

Broad channels of communication may gradually be opened between patient, carers and staff allowing discussion of other sensitive matters. The existence of such information may ease communication between care settings.

Adequate information and pain assessment tools can aid good nursing care, because patients have the means of giving a more accurate assessment of their pain. In addition, the danger of nurses underestimating the degree of pain is minimised, and nurses are given a tangible means of informing doctors of a patient’s changing need for analgesia.

CONCLUSION

The provision of the fullest and most accurate possible information on pain control — supported by thoughtful reinforcement and care and taking into account each patient’s ability to assimilate information — is a means by which patient, carer and nurse can work together. They can learn to understand the components of the pain and plan care measures for its best relief. Neither party can do this successfully alone, because it is only through the exchange of knowledge that proper identification of the actual problem and its solution will be found.

REFERENCES

Scottish Office Home and Health Department (1994) Palliative Cancer Care Guidelines. Edinburgh, SOHHD.