The concept of total pain: a focused patient care study

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Abstract

This article considers the care of a patient admitted into a hospice environment for pain management and respite care. The concept of 'total' pain is discussed together with the need for a multidimensional assessment of pain to enable effective management to be accomplished. A multiprofessional approach to care along with inclusion of both the patient and her husband in decision making achieved the best possible quality of life for them both. A palliative care approach requires healthcare professionals to focus on the achievement of quality of life for all patients whose disease is not responsive to curative treatment. This is achieved by providing relief from pain and other distressing symptoms, including psychological, spiritual and social aspects of care, together with the acknowledgement of patient and relative autonomy. Hence, the study also exemplifies contemporary palliative care in action.

Similarly, although care affecting pain management is delivered holistically, in order to explain the complexities of the concept of total pain it is helpful to use the same four-fold specification (Figure 1). To ensure both confidentiality (UKCC, 1992) and anonymity a pseudonym has been used for the patient throughout.

CARE STUDY

Hannah was admitted for both symptom management and respite care. She was in her early fifties and had a history of colonic cancer and currently of metastatic lung disease. Concurrent disorders included arthritis, which had resulted in bilateral knee arthroplasty, as well as pulmonary embolism resulting from chemotherapy for lung cancer. Initially, Hannah’s most significant symptom was pain in her left knee. She was shocked when this was investigated as being potentially the result of bony metastases. She was therefore relatively relieved when the diagnosis of chronic osteomyelitis requiring surgery was made.

However, Hannah was considered unfit for surgery. The consequent ramifications generated psychosocial and spiritual challenges, alongside physical pain, exacerbated by increasing breathlessness. These problems exemplify the need to view pain in a ‘total’ (Saunders, 1995) or holistic way.

THE CONCEPT OF TOTAL PAIN

Morse (1997) claims that the focus of nursing is on the human response to disruption in health, and that nursing focuses on care rather than cure. Provision of care must start with the assessment of need based on a comprehensive understanding of the concept of pain.

Pain is described by Turk (1993) as being a complex, subjective and perceptual phenomenon with several dimensions, all of which are uniquely experienced by each individual. He goes on to suggest that consideration of mood, attitude, coping efforts, resources, responses of
family and the impact of pain on individuals' lives need to be included, alongside the somatic or sensory component when assessing pain. Twycross (1999) groups these components into four dimensions — physical, psychological, social and spiritual — which collectively contribute to 'total' pain (see Figure 1).

In order to relieve total pain, care needs to be comprehensive encompassing all four dimensions of pain. Physical pain cannot be treated separately from other aspects, nor can patients' anxieties be properly addressed when patients are suffering physically (O'Neill and Fallon, 1998). Hospice documentation for nursing assessment reflected the four dimensions of this concept and hence provided an appropriate framework for analysis of the assessment of Hannah's pain.

**PHYSICAL PAIN**

The physical discomfort in Hannah's left knee was attributed to the stimulation of nociceptive afferents within the bone surrounding the site of arthroplasty. Such pathological or organic pain within the musculoskeletal system is known as somatic pain (Twycross, 1995). Since the periosteum has a rich nerve supply any damage as a result of inflammation or cancer metastases is very painful (Hawthorn and Redmond, 1998).

Observation and measurement are important assessment strategies (Hawthorn and Redmond, 1998). Hannah described her pain as one exacerbated by movement of the limb and this was supported by observation of behaviour and non-verbal expression on movement. Such pain is known as incident pain and can impair severely a patient's functional ability (Sykes et al, 1998).

The subjective nature of pain has made the measurement of the amount of pain suffered by an individual difficult and has hindered pain research (Diamond and Coniam, 1991). However, Harlos and Dudgeon (1998) suggest that pain assessment tools are useful in obtaining a quantitative assessment of the degree of a patient's pain and that response to treatment can be more objectively followed.

A commonly used tool is the visual analogue scale on which a patient is able to mark his/her degree of pain on a continuum ranging from no pain to agonizing pain (Seers, 1994). Diamond and Coniam (1991) argue...
that even if patients understand the use of this tool, this means of measurement is crude and they question its accuracy.

Although rather disparaging of the cognitive ability of most adults, their argument concerning accuracy warrants reflection. They claim that there is often a tendency to mark certain divisions of the scale more than could be expected at random. They also question the ability to remember the intensity of pain so that even if pain is reduced by treatment, the patient is still drawn to the same point on the scale. Perhaps if treatment lessens the intensity of one aspect of pain, e.g. physical pain, and not others, the perception of total pain to patients in these situations may not be reduced.

The hospice documentation did not include a visual analogue scale to facilitate the collection of data for assessment of Hannah’s physical pain. The assessment tool used incorporated a visual analogue scale similar to those used in The London Hospital Pain Observation Chart (Figure 2; Carr and Mann, 2000) which enabled Hannah to illustrate the site of pain.

It also included a menu of descriptive terms similar to those suggested by Hawthorn and Redmond (1998), encouraging the identification of the intensity, duration, nature, incidence and factors that might influence pain. This helped Hannah to describe her pain as a deep stabbing pain on movement and when in an uncomfortable position. A high dose of opioid analgesia was required to control her pain at rest adequately. This was administered as a modified-release form of morphine, 460 mg given every 12 hours. Change of position helped reduce incidence of pain further.

**PSYCHOLOGICAL PAIN**

In considering the psychological perspective of the experience of pain, McGuire (1992) points out that pain affects and is related to mood, outlook, sense of wellbeing and other emotions. On admission to the hospice, apart from suffering chronic pain in her left knee, Hannah was tearful and frightened by the rapid progression in her illness, especially her dyspnoea. Fear exacerbates pain further in that it contributes to lowering pain threshold (Twycross, 1999).

The psychological implications of the information Hannah received regarding the cause of the pain in her knee are significant when assessing her total pain. Morse and Penrod (1999) use the term ‘enduring’ to describe the way a person ‘gets through’ an extraordinary physiological or psychological challenge. Endurance is characterized by a suspension of emotions allowing energy to be focused on making it through the situation at hand and remaining in control.

Hannah and her husband expressed confusion at what they considered to be conflicting information by the hospital consultants dealing with her knee pain and lung disease. The irritation and anger, so often a consequence of such emotion, is a signal that circumstances have become, even momentarily, beyond the individual’s skills to endure (Dewar and Morse, 1995). Morse and Penrod (1999) also describe suffering as the time when individuals move out of emotional suspension into an acknowledgement of the impact of the situation on their past, present and future. Without a goal to resolve the issue, the individual feels buffeted by the event, out of control and suffers emotionally.

When Hannah was told of the potential diagnosis of metastatic cancer as the reason for her knee pain she was shocked and suffered emotionally as the implications regarding the spread of her disease became apparent. This suffering was relieved on hearing the final diagnosis of chronic osteomyelitis, a potentially treatable disorder.

However, Hannah’s deteriorating lung function rendered her unfit for the necessary knee surgery, and her unresolved chronic infection of bone rendered her unfit for any further chemotherapy to reduce the progress of her lung cancer. Her response to this situation was one that Montes-Sandoval (1999) describes as anguish, with the unmistakable realization of the meaning of her painful situation as one that would continue and contribute to a poorer prognosis.

**SOCIAL PAIN**

Family and carers need to be included in the social perspective of assessing total pain because the effects of an individual’s chronic pain extend to family and friends (Seers and Friedli, 1996).

As a consequence of her ill health, Hannah was unable to work and her husband had chosen to take early retirement to look after her. Hannah’s increasing problems of immobility as a result of knee pain, exacerbated by increasing dyspnoea, limited her activity even more. This increased her dependence for care...
and eroded her role within the family further. Research by Seale and Addington-Hall (1995) suggests that patients in their last year of life fear dependency more than they fear pain.

Worries about the family can affect adversely a patient's perception of total pain (Twycross, 1999). Although Hannah's daughter and son-in-law lived with her the relationship was difficult and her husband asked them to leave during her stay in the hospice. Hannah became quite depressed and her change of mood may well have lowered her pain threshold (Twycross, 1999) as her requirement for analgesia increased at this time from 460 mg to 540 mg of modified-release morphine every 12 hours.

Severe and chronic pain isolates; it captures concentration and is insistant in its demand for attention. Such preoccupation may render the patient unavailable to engage in social interaction or activities (Fordham and Dunn, 1994).

**SPIRITUAL PAIN**

Spirituality is often mistakenly equated with religion (Greenstreet, 1999). It is better seen as a broader notion, an umbrella under which religion and the needs of human spirit are found (Herriot, 1992). Examples of themes associated with spiritual need are the meaning and purpose of life events, meaningful relationships, and the need to give and receive love (Greenstreet, 1999).

Carson and Mitchell (1998) link quality of life with being concerned with the meaning one gives to life at any moment in time; this changes and unfolds in relationships with others. Loss of meaning and lack of purpose in life is a form of spiritual pain (Saunders, 1995). Hannah's spiritual practices were documented as a non-practising Anglican but her sources of strength and hope were not formally identified. Many find meaning outside of religion, e.g. a career, family or money (Harrison and Burnard, 1993; Oldnall, 1996). Hannah appeared to find her meaning and source of strength in the close, open relationship she shared with her husband.

**MANAGING PHYSICAL PAIN**

Chronic pain can often be difficult to eradicate, and hence minimizing such pain to facilitate optimal function is often a more realistic goal (Hawthorn and Redmond, 1998). The principles central to the pharmacological management of pain are those advocated by the World Health Organization (WHO) (WHO, 1996). The first of these is that medication should preferably be given by mouth, and this was the case for Hannah who had no difficulty in managing to swallow her medication.

Two further principles are: first, that medication should be given regularly and prophylactically and not as needed; and, second, that doses should be titrated upwards until pain is relieved (WHO, 1996). This approach aims to maintain plasma levels of analgesia within a therapeutic band maintaining pain relief rather than administration of analgesia when pain occurs.

Hannah's analgesic medication was given regularly. Initially, this was a modified-release form of morphine (British National Formulary (BNF), 2001) given 12-hourly; however, the degree of breakthrough pain became such that Hannah's analgesia was changed to a normal-release form (Twycross, 1999) given 4-hourly to facilitate titration of the dose until effective pain relief was achieved. No adverse effect occurred following increased dosage and so Hannah resumed taking the equivalent dose in a modified-release form of morphine every 12 hours.

A further principle of pain management advocated by WHO (1996) is the three-step analgesic ladder (Figure 3). This provides guidance in 'stepping up' analgesia from non-opioid to weak opioid and eventually stronger opioid analgesia with or without...
non-opioid and/or adjuvant medication. Hannah’s analgesia was already third step in that she was being prescribed a strong opioid.

Nocteceptive somatic pain is typically treated with non-steroidal anti-inflammatory drugs (NSAIDs) (Twycross, 1999). Although this was considered when Hannah was admitted, NSAIDs were contraindicated as Hannah was still being prescribed an anticoagulant as continuing treatment following her pulmonary embolism. NSAIDs enhance the effects of anticoagulants and thus would have increased the chance of haemorrhage (BNF, 2001).

Following diagnosis of chronic osteomyelitis, adjuvant medication to enhance pain relief was prescribed. This included a corticosteroid to reduce inflammation of the knee. A 2-week course of intravenous antibiotics was also given in an attempt to promote comfort and further pain relief in the left knee, albeit short term.

Some consideration of the side-effects of analgesia is necessary to ensure the benefit is not outweighed by the burden of treatment (Twycross, 1999). Laxatives to both soften the stool and stimulate bowel activity were prescribed prophylactically to counteract the constipating effect of opioid medication. These were effective in helping Hannah maintain regular bowel evacuation. The depression of respiratory drive as a side-effect of opioids is actually beneficial in reducing the subjective sensation of dyspnoea (Dubose and Berde, 1997). Hence, morphine was also indirectly able to contribute to reducing Hannah’s total pain by relieving a concurrent distressing symptom that affected pain threshold (Twycross, 1999).

Non-pharmacological interventions to reduce further Hannah’s pain included the use of a brace to immobilize her knee joint and crutches to ensure Hannah did not place weight on her left leg when mobilizing. The reduction of movement and pressure on the left knee helped to reduce incident pain. Hannah’s leg was supported and elevated on pillows when she rested on her bed and a reclining chair facilitated elevation of her leg when she sat out. Elevation constitutes an attempt to reduce inflammatory oedema and its associated pain. These interventions are all measures suggested by Judd (1997) as appropriate when caring for a patient with osteomyelitis.

RELIEVING PSYCHOLOGICAL PAIN

Melzack and Wall’s (1965) gate control theory attempts to explain the complex process of pain perception. This theory acknowledges the influence of sensory, affective and cognitive dimensions of pain (Montes-Sandoval, 1999) and, in so doing, supports interventions dealing with pain as needing to be multidimensional.

Massage and aromatherapy influence senso-

ry and affective psyche resulting in a sense of wellbeing (Brownfield, 1998) which helps close ‘the gate’ to nociceptive somatic pain. However, it is important that nurses acknowledge the limitations of both their skills and remit of the role in which they are employed to practice when considering complementary therapy for patients.

Similarly, distraction is of value in reducing the perception of pain (Hawthorn and Redmond, 1998), resulting in an altered cognitive focus. McGhee (1998) gives anecdotal evidence of laughter contributing to pain relief. He attributes partly to the theory that laughter results in the production of the body’s natural analgesia, endorphins, although he acknowledges there is no scientific evidence to support this view.

However, most experienced nurses are likely to intuitively support his further claim that humour contributes to a more positive frame of mind. Hence, laughter, both as a means of distraction and enhancing a sense of wellbeing, can be used as a strategy to alter pain perception.

The hospice’s complementary therapist used a variety of aromatherapy oils, including grapeseed, lavender and camomile, to massage Hannah’s lower legs and feet. The outcome of these sessions was very positive leaving Hannah relaxed and in a positive frame of mind. Sources of distraction for Hannah included her husband’s company, access to television, radio, sitting room, refreshments, garden, patio and the presence of nursing staff.

Although Hannah’s morale was very low at times she was amenable to humour. A ‘toe in the water’ approach (McGhee, 1998), i.e. starting with a light remark, determined whether Hannah was receptive to humour or not at that moment in time.

SUPPORTIVE MEASURES TO REDUCE SOCIAL PAIN

Smith and Friedemann (1999) considered the family dynamics in relation to the person with chronic pain and cite Friedemann’s
(1995) work as of value in this context. Friedemann (1995) believed that families had to pursue targets to adjust successfully. The target of control-reducing anxiety as a result of vulnerability and practicalities of family activity had largely been achieved as financial support had already been arranged.

The target of stability, reducing anxieties concerning family disintegration, was a greater challenge given the fact that Hannah's daughter and son-in-law had been asked to leave her home. The importance of dialogue (Widdershoven, 1999), both in expressing a point of view and achieving a change of stance, became evident when Hannah's daughter visited; the outcome of dialogue with her daughter left Hannah in good spirits.

**STRATEGIES TO ALLEVIATE SPIRITUAL PAIN**

Friedemann's (1995) target of connectedness changes this discussion from one of managing social pain to managing spiritual pain. This target involves strategies conveying love, affection, commitment, purpose and meaning. Hope moves patients on from suffering towards purpose as they once again are aware of others and life outside their source of anguish (Morse and Penrod, 1999). Hope is enhanced by holistic care and inspired by effective nursing practice. Active participation in their care gives patients some control over circumstances which threaten their future (Cuthcliffe, 1995). Taking time to attend comfort measures and talking with patients contributes to pain relief (Pediani, 1998).

Rapport between hospice staff and Hannah was excellent. She was always a participant in the decisions made concerning the way forward as the nature of her pain unfolded and management was planned. Her choices were made real by honest and realistic explanations of the options and expectations regarding outcomes. The hospice environment and staffing levels enabled time to be spent ‘being with’ Hannah, providing what Carston (1989) refers to as presence. The commitment and affection of Hannah's husband clearly demonstrated the degree of connectedness he had with Hannah.

**CONCLUSION**

In exemplifying the complexity of the experience of pain this care study highlights the importance of a comprehensive understanding of the concept of pain by all who contribute to palliative care. Accurate assessment requires a truly holistic approach encompassing not only the physical effects of pain but also the consequences of psychological endurance on the perception of pain, preoccupation in relation to social interaction, and ultimately the challenge to the worth of life itself. Similarly, effective pain management utilizes a global approach incorporating pharmacological measures alongside intuitive and innovative means to relieve physical pain, together with supportive measures to allay psychological, social and spiritual pain.

Implications for practice that stem from this care study include the need for education for nurses in any setting to enhance their ability to understand, assess and manage their patients' total pain. There is also a need for the acknowledgement by those who manage environments in which palliative care is delivered that assessment and delivery of psychological, social and spiritual care requires additional time alongside fulfilling physical need. This is an issue that has to be addressed if holistic care is to provide quality of life for those who are dying.
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