

## TOTAL PAIN: A MULTIDISCIPLINARY APPROACH

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*Abstract: Through two distinctive case studies the author illustrates the complex nature of total pain. He describes how the physical, psychological social and spiritual elements of what it is to be human are so intertwined that they need the skills of a team of gifted professionals to help the patient and the family in their suffering. The discussion explores the pitfalls for professionals who retreat into their professional boundaries, and the benefits of a multidisciplinary approach.*  
*The Editors*

*Key words: good communication, multidisciplinary team working, total pain, palliative care, suffering*

### Introduction

Many patients think that cancer and pain are synonymous. However one third of patients' with cancer do not experience severe pain

Several studies have shown that approximately 88% of cancer pain responds in a predictable way and should be adequately controlled by the application of basic principles of pain management including the prescription of regular opiates such as morphine (Zech DF 1995). Using these methods pain relief may be sustained for the duration of the illness.

However, there is evidence of poor pain control in around one third of patients in a generalist setting (Addington-Hall 1995). The main reason for failure is lack of knowledge of the simple principles of analgesic use. Even in specialist units around 10% of patients pain proves difficult to control. The use of analgesic drugs does not always lead to pain relief. Increasingly, cancer pain management guidelines are referring to the need for multi-professional input and utilising a range of skills to best meet the needs of patients with cancer (SIGN 2000).

Pain may be only one of several symptoms suffered by a cancer patient. A thorough assessment, by a multidisciplinary team, may achieve a better understanding of the impact and meaning of pain for the individual. There is a challenge for all professionals in teasing out the psychological and spiritual com-

ponents of distress. Good communication between members of the team is vital to achieve this end.

Pain is not simply a physical experience. It is the sum of the physical experience and the patient's interpretation of that experience, taking into account personality, mood, understanding, past experiences and social relations. Dame Cecily Saunders first used the term "total pain" to describe the physical, mental, social and spiritual components to distress and suffering in terminally ill cancer patients (Saunders 1978).

The following case studies serve to highlight the non-physical elements of "total pain" and the team approach to management.

### Case Study 1

Jane, a 67 year-old lady with the diagnosis of pancreatic carcinoma was transferred to the hospice from a local hospital for Symptom control. She had received her diagnosis at Christmas time some two months before. She had been reviewed by the hospital palliative care team who had found her struggling to come to terms with the diagnosis and unrealistic about her ability to cope at home. Her main problem in hospital was a complaint of poorly localised abdominal pain.

Jane was married without children. Unfortunately, her husband John had recently been detained under section 18 of the mental health act (six-month detention order) following a period of paranoia and an attempt at self-harm, subsequently diagnosed as

frontal lobe dementia. He possessed little insight into his wife's condition. The circumstances under which Jane's husband had been committed to the Psychiatric Unit were dreadful for her. He was removed from home by the Police around the time of her diagnosis, and leading up to this point she had been coping with his mood swings and the change in his personality. She saw her diagnosis of cancer as "the last straw".

Jane's problems on admission were assessed as follows:

- Continuing abdominal pain,
- Nausea and poor appetite
- Low mood
- Lack of motivation
- Reluctant to mobilise

She demonstrated an awareness of her diagnosis and prognosis. She felt shattered by the news and she felt that her husband was "burying his head in the sand." One week before admission she had been commenced on the antidepressant (mirtazepine 15mg daily) and started on a sub-cutaneous syringe driver consisting of following combination of drugs running over 24hrs:

- Diamorphine 15 mg for pain control
- Metoclopramide 30 mg for nausea
- Dexamethasone 4 mg for pain control, appetite and mood elevation.

She was observed to be sleepy and lethargic in the ward. She favoured lying on her bed in the foetal position and attempts made by various members of the palliative care team to talk to her met with a polite refusal.

Unfortunately the abdominal pain persisted. Diamorphine was increased in stages to 60 mg over 24 hrs and buscopan was introduced to treat colic. Her bowel continued to move regularly. The situation was complicated by Jane's sensitivity to opiates, producing drowsiness. It was observed that the pain was difficult to localise in the abdomen and varied in intensity. It was felt that her pain was more severe following contact with her sisters and other family members. At one point she became agitated and suffered hallucinations overnight and the Dexamethasone dosage was reduced (we had seen no benefit from the drug thus far) the syringe driver was discontinued and a switch to oral morphine and metoclopramide was made.

Throughout this period Jane was reluctant to engage in conversation apart from to state that she wished to be at home with her husband. She continued to suffer from drowsiness and some two weeks after her admission, following a gradual reduction in dose, regular Morphine was discontinued in favour of a weaker analgesic without a change in the pattern or severity of pain. This coincided with the arrangement of a weekend pass for 24 hours. Sadly, her husband was not allowed to stay with her overnight due to the section order. She returned to the ward exhausted and immediately complained of colicky abdominal pain with nausea. On this occasion Jane was distracted from her symptoms by talking at length about her sense of frustration with her situation. However, the following day, she experienced a panic attack with chest pain and tachycardia. This episode quickly settled with diamorphine and a small dose of diazepam. She spoke with some anger about "being detained in the hospice against her will"

The following day Jane had a long discussion with the hospice chaplain discussing her hopes of getting home to die. A case conference was arranged. At this stage Jane's family were unaware of her hopes. In previous discussions they were of the opinion that she should remain and be cared for by the hospice and they had communicated this to Jane. They found the home situation, particularly with John in the same house, too much to contemplate. A couple of shorter passes of a few hours each were arranged and Jane found these easier to cope with.

Unfortunately the case conference proved to be acrimonious with the family feeling unable to provide any input and insisting on 24hr care from the various caring agencies. Sadly this proved impossible and a compromise plan was arranged with passes for the weekends together with a few hours here and there. Jane suffered occasional panic attacks before going home and frequent attacks of abdominal pain with vomiting on her return.

After a month as an inpatient and six weeks on the antidepressant mirtazepine(now up to 45mg daily) we were still having problems with tiredness, exhaustion and drowsiness, felt to be due to medication. Therefore the antidepressant was discontinued. Blood results at this stage were essentially normal. Jane agreed to complete the Hospital Anxiety Depression Scale, consisting of a fourteen-part ques-

tionnaire. Seven questions relate to anxiety and seven relate to depression. The anxiety score was 7 and the depression score was 20 (both out of a possible 21). Following discussions with a Psychiatrist, a decision was made to treat Jane with the central nervous system stimulant drug Methylphenidate (Ritalin®).

On the day that Ritalin was started the note entered in the case record was as follows: *No headway, extremely "flat", lacks volition. Any attempt at activity produces abdominal pain and the need to lie down and rest.*

Two days following the introduction of Ritalin in a dose of 2.5mg twice daily, Jane began to mobilise around the ward. She was able to get dressed and even managed to get out to the shops with members of staff. The abdominal pains abated. Ritalin was increased to 5mg bd after one week. Potential side effects such as paranoia, elevated blood pressure, anxiety and agitation were not seen however she did develop a tachycardia of 120/ min and the dose was therefore reduced to 2.5mg bd. Jane developed a positive outlook. She felt able to and enjoyed attending mass in the hospice. She was keen to go home for week-ends and at the same time became much more content within herself and as a hospice patient. Jane completed the HAD Scale two weeks after starting Ritalin. On this occasion her anxiety score was 6 and her depression score was 9 showing a considerable improvement.

Three weeks after Ritalin was commenced, Jane became jaundiced and immediately understood that this signified a deterioration. Unfortunately this coincided with the death of a friend she had made in the same ward. This was a hard day for Jane, she admitted to a personal loss of faith. She managed to rally her spirits over the next couple of days although physically much weaker she became adamant about going home to die. As Jane was in the terminal phase of her illness, a full care package was arranged quickly and she was discharged home the following day. John's condition had improved with treatment to the extent that he was discharged home under supervision. Jane died peacefully at home a couple of weeks later.

#### **Case reflection**

This lady's cancer journey is set in the context of an already stressful family situation. It was made more

difficult by the conflicting family views expressed on 'what was best for Jane'. It illustrates the dilemma a team can sometimes face in looking after someone who wishes to be left alone and undisturbed and yet there is a feeling that more could be done. Various factors played a part in Jane's fatigue. Physical weakness due to disease progression and attendant anorexia and cachexia was clear. Mental weakness too was significant, partly as a result of depression, partly due to the 'loss' of her husband and in part frustration in her attempts to get home and to die at home.

#### **Case Study 2**

Andrew, a forty-one year old male, married with three young children was referred to the palliative care service by his General Practitioner for pain and symptom control. He was diagnosed with squamous-cell carcinoma of the tonsil two years previously and had developed widespread bony metastases. He was found to be cachectic and his mobility was significantly impaired by pain. Other problems included impaired speech due to the primary tumour and poor appetite. His drug therapy included MST 80 mg twice a day, which caused him nausea and a feeling of detachment. In addition he was receiving Dexamethasone 2 mg daily, Methotrimeprazine 25 mg daily and Diclofenac 50 mg three times a day.

It became clear that, although he and his wife were very close, they had not talked openly about Andrew's steadily failing health and acknowledged to each other the fact that he was dying. This was clearly having the knock-on effect of poor communication with the children. Andrew himself was very much focused on his symptoms and did not show any emotion at this stage.

His drug therapy was modified. Dexamethasone was increased to 8 mg daily in an attempt to improve his appetite and energy in the short term. Palladone was substituted for Morphine in the hope of reducing the opiate side-effects he was experiencing. Arrangements were made for his admission to the hospice the following week. Andrew had agreed with this plan. In the week leading up to the admission Andrew's pain had increased dramatically, his General Practitioner had commenced a syringe driver containing Diamorphine 80 mg and Ketorolac 60mg. On admission he was drowsy and detached. He was

reluctant to communicate. However he did say that he knew what it meant to be in the hospice, he had only come in of the sake of his wife and he wished to go home. A visual Analogue Scale (VAS) revealed score of eight out of 10 for severity of pain.

On closer questioning about his pain he described a generalised aching. He was offered massage to his limbs, back and face with good effect. Slowly over the next few days he began to talk openly with staff about his disease and prognosis. He was able to talk about the various losses he had experienced:

- the loss of his job,
- the loss of his ability to play with his children,
- the loss of enjoying food
- the loss of his physical and mental stamina.

He also managed to express his anger at what he perceived as the late diagnosis of his disease. This process gradually enabled Andrew and his wife to discuss the future together and face his death. Andrew's wife received the support of the hospice children's drop-in group. This group provides support for pre teenage bereaved children and children of hospice patients. This group is supported by a social worker, a psychologist and trained volunteers. Age specific reading material is also provided which deals in a sensitive way with the loss of a loved one.

The pain level dropped significantly (3 out of 10 on VAS) and we were able to reduce the analgesic medication. Unfortunately, a few days later, Andrew's daughter was admitted to hospital with a viral illness. Fortunately she recovered quickly and was able to be discharged. Andrew's pain returned over this period requiring several breakthrough doses of morphine causing drowsiness without totally alleviating pain

Andrew managed to get home the following week, physically weaker but the pain had subsided. Unfortunately he was admitted to hospital one week later in renal failure. Transfer to the hospice was quickly arranged. The situation was discussed with him and he took in the news very calmly. Andrew died in the hospice four days later. The opiate doses were reduced in view of renal failure and a small dose of Midazolam was introduced to combat anxiety. He did not complain of pain during this period.

### **Case reflection**

This case illustrates the effect that communication difficulties within the family, coupled with unresolved feelings of anger and loss may have on physical symptoms such as pain. Andrew and his family required time and skilled multi-professional input to first acknowledge then address these issues.

### **Discussion**

Multidisciplinary team working is evident in most hospices in Scotland. Integral to the success of these teams is that each person's contribution to patient care is valued and that the patient and family are very much a part of the team. The challenge for all staff in dealing with this type of patient is to be able to understand the nature of suffering. Suffering is experienced by people not merely by bodies. It extends beyond the physical and has its source in threats to the intactness of the person (Cassel 1982). A person has many dimensions and roles. The presence of advanced cancer may cause the loss of many of these facets of the person such as breadwinner, capable parent, socialiser, friend, and may be expressed by sadness, grief, isolation and, in some cases, intractable psychogenic pain. The incidence and severity of pain tends to increase as death approaches requiring an increase in analgesic medication. Also, pain problems later in the course of the disease seem to be predictable in those patients with higher scores emotional disturbance and in those who expected a loss of control (McKegney 1981) Those with pancreatic cancer run a higher risk of depression (Pomara 1984). The cause is unknown but may be a paraneoplastic syndrome related to the secretion of products by the cancer cells (McDaniel JS 1995).

Pain is a subjective symptom. It is a cardinal sign of disease and has real meaning for the patient. For a patient with cancer it is often interpreted as advancing disease. Doctors have to learn to step outside their usual role in the medical model of seeking a cure in order to adequately listen to and care for patients with the distressing symptoms of a terminal illness. Likewise, members of the clergy may need to step outside their own system of faith and worship in order to consider and address spiritual needs of this group of patients. By spiritual in this context I refer to the search in the individual, for understanding, meaning, self worth and identity while at

the same time coping with distressing symptoms and facing death.

Total pain, although relatively uncommon, is not selective. It affects the young and the old although in my experience it is commoner in young people, atheists, agnostics and people with profound religious beliefs. Indeed, on several occasions our team has struggled to manage total pain in an individual generally regarded as having a strong faith. Can anyone say they have a strong faith until it is tested in extremis?

The pitfalls for all professional groups are similar. It is easy to avoid good-quality communication with palliative care patient at a time when they most need it:- by retreating behind a professional wall ignoring cues from patients, giving false reassurances, changing the subject and generally not giving enough time. Time is required to build a trusting relationship with patients. However much can be achieved in a relatively short time period if the professional is prepared to listen and accept the feelings of the patient as the hard currency of communication. Most dying patients are looking for openness and honesty. However honesty must be used with intuition and cannot be used as a blunt instrument!

In a recent American study (Kristella Jean L 1999) looking at how oncologists and oncology nurses address spiritual distress in cancer patients in a generalist setting, a substantial proportion of both oncologists (37.5%) and nurses (47.5%) identified themselves as primarily responsible for addressing spiritual distress in their setting. However, they gave such concerns very low priority in the face of competing demands even when the prognosis was poor. Over 85 per cent of both doctors and nurses felt that ideally chaplains should address such issues. A majority of practitioners identified that the chaplain is readily available but they are often not contacted. The paper concludes that spiritual distress experienced by cancer patients may be under-addressed due to time-constraints, a lack of confidence in effectiveness, and role uncertainty.

There is a greater challenge in a general setting such as hospital and primary care. Specialist Palliative Care Teams exist in many hospitals. However they are of variable composition and often under-resourced. They usually consist of doctors and nurses but not all have regular Chaplaincy input.

There is evidence that pain is better controlled when patients have access to such a hospital palliative care service. (Edmonds P.M. 1998)

Marie De Hennezel (Hennezel 1995) a psychologist working in a hospice in Paris, refers in her book "Intimate Death" to the distress of a visiting oncology nurse from a provincial hospital:

*In the oncology unit there is a constant feeling of unease around the patients for whom all treatments have failed. The doctors are no supporters of the truth, they limit themselves to informing the families, who in turn feel duly condemned to keep everything a secret. The nurses are subject to the same sentence and cannot share the journey of the dying.*

This account is of a French hospital. However the situation in UK hospitals was very similar until recently.

### Conclusion

These case studies demonstrate that, in order to meet the complex needs of patients and their families, Specialist Palliative Care should be delivered by a multi-professional team containing practitioners with a broad mix of skills. Good communication within the team is important as is an understanding and respect for everyone's role and expertise.

The Clinical Standards Board for Scotland has produced generic clinical standards (CSBS 2001), and is currently producing standards for Specialist Palliative Care. They refer to the need for good patient/staff communication and the requirement for effective team working. These standards may go some way to ensuring that the problem of intractable suffering due to cancer related pain is recognised earlier and addressed more effectively.

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