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Challenging the representations of cancer pain: Experiences of a multidisciplinary pain management group in a palliative care unit

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ABSTRACT

Objective: This article describes how a Multidisciplinary Pain Management Group was set up in a palliative care unit, and outlines the ways that the group works with different patients. We place these comments in the context of the wider representations of pain.

Methods: Our observations of patients seen by the multidisciplinary team.

Results: We tentatively propose that where the patient's pain has certain characteristics it may require a different approach. Patients who are older, with a lengthy treatment history, may require a different input than younger patients, who may have a number of factors that further complicate their experience of pain. We use our extensive experience with mesothelioma patients to draw a further important distinction between this patient group and other patients.

Significance of research: Our observations suggest the need to allow sufficient time for intensive psychological work to be done with mesothelioma patients in order for pharmacological interventions to be effective.

KEYWORDS: Cancer pain management, Psychosocial, Mesothelioma, Representations of pain, Multidisciplinary approach

INTRODUCTION

There are currently two dominant representations of cancer pain in existence. The first is the lay representation that cancer and pain, particularly in the latter stages, are inextricably linked (National Council for Hospice and Specialist Palliative Care Services, 2003). The second representation that can be seen, more particularly in many medical contexts, is that by following the World Health Organization (WHO) guidelines, cancer pain can be reduced and managed (Perron & Schonwetter, 2001). For the staff at one hospice, the reality fell somewhere in between; WHO guidelines may adequately address physical pain, but existential suffering needs additional approaches. Although many patients are successfully treated for pain and other symptoms of cancer and proceed to their deaths in a manner that many would term a "good death," a smaller number of patients can be identified as experiencing a degree of suffering, expressed as pain, that is more difficult to relieve and may not be relieved before death.

There are a number of situations when we might see patients in pain, despite advances in pharmacological, physiological, and psychological pain relief techniques. A primary factor in the patient's experience of poorly controlled pain rests on the multi-

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factorial nature of cancer pain and suffering: physiological, sensory, affective, cognitive, behavioral, and sociocultural elements (Higginson et al., 1995; Cherny et al., 1994; Jacobsen & Breitbart, 1996). Patients with cancer may continue to experience pain at the end of their lives because pain consists of more than just physical and pathological sensations. These components may be less straightforward to assess and treat and this aspect of pain may remain underexplored due to time constraints and unfamiliarity of staff with this perspective of pain.

Much of the research investigating unrelieved pain in cancer patients focuses on barriers to adequate pain relief, often suggesting that these may be patient related. Pargeon and Hailey (1999) reviewed some of the patient barriers to adequate pain relief, noting that patients may have a number of misconceptions about medications, a fear of analgesic use and the potential unpleasant side effects. Paice et al. (1998) investigated fear of tolerance and addiction, noting that fear of tolerance is another significant factor. Potter et al. (2003), using the Barriers Questionnaire, noted similarly that patients might have concerns about analgesics and be hesitant to discuss their pain; in these cases, patients were likely also to have poorer pain control (e.g., Ward et al., 2000). A further related barrier is that patients may feel that "good" patients do not bother the physician by complaints of pain or, indeed, that such complaints may prevent them from dealing with the disease (Gunnarsdottir et al., 2002).

One of the more difficult corollaries of this is that despite being offered various different interventions, the patient may say he does not have pain, may delay telling anyone about it, or underreport it. This dissonance between the physical effects of disease in the body and the reporting of pain is apparent to the family or medical staff, yet the patient him/herself may be unwilling to consciously admit to increasing levels of pain, fearing that this is indicative of advancing disease. Experienced hospice staff may be able to recognize and respond to the patient's denial of pain, but sometimes further interventions by a multidisciplinary team can identify issues that other staff members may be unwilling or unable to deal with (de Rond et al., 2000).

In our hospice, several staff members with considerable experience, knowledge, and good working practices in this area recognized that a multidisciplinary focus on these areas would enhance their methods of working and lead to improvements in patient care. This way of thinking changed the emphasis from patient barriers affecting adequate pain relief to, instead, trying to understand how multiple factors may interact in a complex manner to limit the effect of pharmaceutical measures resulting in less than optimal pain relief. Consequently, the multidisciplinary Pain Management Group was formed in 2002 to holistically assess patients presenting with complex pain and to draw upon the expertise of a number of different professionals for decision making and treatment.

Referrals to the hospice come from a number of sources such as hospital palliative care services or general practitioners. It has become apparent that the hospice receives a large number of referrals of patients with mesothelioma from a nearby specialist cardiothoracic center. The number of patients with mesothelioma seen at the hospice is larger than the numbers generally seen at other hospices in the United Kingdom. On the basis of this, our experience with mesothelioma patients is likely to be more extensive than that of others.

Patients present at different stages in their disease continuum; some attend day therapy for a variety of therapeutic interventions and others are terminal and die in the hospice. The pain management group, however, worked with patients who presented particularly complex cases at any stages of their disease where a number of factors were interacting to create a complex pain syndrome and for whom application of the WHO analgesic ladder was insufficient to resolve pain.

Although good practice and conventional treatment continued to be followed, the altered perspective on complex pain also led to the development of a Pain and Mood Questionnaire (PMQ). The PMQ is a brief scale designed not only to produce quantifiable data that can be used to monitor the effects of different interventions, but more importantly, may facilitate a patient/staff discussion about pain, anxiety and depression, control, frustration, dignity, and other issues of importance to person with cancer.* If the PMQ is administered a number of times, changes in these areas can also be documented.

The remainder of this article outlines the rationale for the formation of the Multidisciplinary Pain Management Group, its composition, and its strengths. We then propose and illustrate how a multidisciplinary approach might work in different ways with different patient groups with correspondingly differing needs. If we view the work of the group in the context of the representations of cancer pain outlined above, we see that the domination of one or another of the representations is depen-

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*The introduction of the PMQ has provided enhanced information on the psychological state and needs of the patient but has also highlighted the need for further education for staff to enable communication around difficult emotions. This will be the subject of a forthcoming paper.

dent on the extent to which the patient's pain can be relieved by pharmaceutical measures, which, in turn, is dependent on whether the patient's psychological or existential suffering is resolved. The group's view that sometimes psychological work must be done prior to, or in combination with, pharmaceutical measures runs counter to much of the prevailing thought in this area.

Rationale for Formation of the Group

In 2001, a group of staff members working in both palliative care and chronic pain arenas recognized the need to improve pain management through both education and clinical assessment and intervention. They planned to focus initially on the inpatient unit at a regional adult hospice, then to extend this to incorporate all aspects of the specialist palliative care services. The group that was formed was a multidisciplinary group of experienced professionals coming together to provide the holistic assessment and treatment of the patient in pain, incorporating a family perspective and consideration of health care providers. It was also expected to be a forum to plan, discuss, and supervise the management of complex individual cases. There was scope within the group's remit for planning and creative thinking of future development of services. An important aim was to see patients whose pain was difficult to analyze and to improve coordination of care.

The Composition of the Group

The core/strategic group consists of a consultant physician, consultant anaesthetist, a senior psychiatrically trained psychotherapist, a psychological therapist, a senior nurse, and a research psychologist. The core group draws in additional specialist staff such as physiotherapists, nursing staff, or occupational therapists at an early stage in the patient's time at the hospice. All members of staff working in the hospice have been encouraged to be involved with the group on an ad hoc basis, to refer difficult cases to the group, and to attend the meetings. The principle endorsed by the pain management group has been the use of all modalities of treatment in order to best relieve pain and to minimize the requirement of pharmacological therapies by drawing upon the expertise of a number of different professionals. The group worked to ensure that staff throughout the hospice would feel involvement with the group, would receive prompt feedback from a referral to the group, and would not consider their role in patient care was being usurped.

Function of the Group

Different health care professionals' expertise and experience are brought together and used to assess and manage patients who report uncontrolled pain. The group also discuss patients where discrepancy is seen between the expected physical manifestations of advanced disease and the expression of that pain. Following a discussion in the group and a physical and psychological assessment, if appropriate, a treatment plan is drawn up in negotiation with the patient and implemented. Feedback to the staff caring for the patient on the ward, in day therapy, or in the community has been identified as a priority so that care is coordinated and no professional feels deskilled or excluded. Notes of the discussions are kept and these are drawn upon in this article.

Improved outcomes, either psychological or physical, have not always been easy to record due to the ever-changing nature of disease, but a key outcome that is often seen following intervention by the group is the streamlining of patients' medication regimen. Where successful, the group also has an impact on patient quality of life and longevity. The specific interventions might involve any or all of the team's expertise, incorporate extended contact with the patient's family, and would certainly involve a more holistic, psychologically oriented way of considering the patient and his or her total pain experience. This is made possible by having a number of different disciplines present in the group so that the all aspects of the patient's pain—biological, psychological, social, and spiritual—are addressed concurrently. A coherent approach to all these elements at once can often lead to a reduction in the amount of opioid medication given, allowing patients to experience improved cognitive function, yet with their pain controlled, thus opening the door for the psychological suffering they are often feeling to be acknowledged, addressed, and perhaps dissipated. At other times it is necessary for psychological interventions to occur in order for the pain to begin to be controlled because the pain is not just physical pain but psychological anguish and suffering.

The group's impact can also be measured in terms of wider benefits for the National Health Service through enhanced use of general practitioners' time, decreased medications, less use of hospital resources, and sometimes a return to the family home. The group's remit also extends to the patients' wider family (partner, parents, children) if necessary through supportive interactions/interventions offered throughout the patient's illness. Thus, there is a role for the group in preventing psychological morbidity in carers and family postbereavement.

PATIENTS WITH COMPLEX PAIN ARE NOT ALL THE SAME

This article describes different groups of patients categorized by the presence of a number of different factors that lead to adequate or less satisfactory pain management. The psychological and physical factors current and past result in a number of barriers to optimal pain control such as difficulty in talking, fear of advancing cancer, anger, misunderstandings of pain, and symptom control. We found that we could support and care for patients better if we understood the interaction of these different factors and accounted for them in our treatment regimens and in accordance with the time that remained in their lives.

Where there are a number of factors involved or specific disease or psychological characteristics present, interventions may meet with greater or lesser success. This then leads to different experiences of pain for patients at the end of their life and in turn to different representations of cancer pain either as intractable or as something that is successfully managed by professionals by progressing patients up the WHO pain ladder. From discussions in the Pain Management Group meetings and numerous consultations with at least 30 patients and their families, we are moving toward recognizing a range of different factors.

Risk Factors for Unresolved Pain

Time

One factor is time (or lack of time). At one end of the spectrum we see relatively "uncomplicated" patients where the impact of a number of complicating factors can be reduced and pain control usually achieved. Such patients may have had a long disease trajectory, having been offered a number of different interventions (surgery, radiotherapy, a number of courses of chemotherapy). Their cancers might also have been slower to spread in the first instance, allowing treatments to be carried out; this time span allows them to adjust to their disease and impending death. This also means that a number of psychological issues can be worked through during day therapy visits to the hospice or as a natural result of time. These patients are likely to be older men and women (perhaps in the their 70s and 80s), often having grown-up families who have also become accepting of the eventual outcome over the time period.

Patient Age

We have observed a second set of factors unrelated to pathological elements of disease progression per se that interact to impact on the total pain experience. These factors are frequently related to patient age (reproductive status, dependent children left behind, their own relative youth) and where the patient is situated in his or her life continuum. For example, sometimes a person dying nearer retirement age may find the loss of the good years of retirement particularly difficult to bear. A number of other factors may be related to the patient's age, such as role in the family and financial burdens.

Previous History

A further set of issues may be present in some patients such as previous pain experiences (chronic pain unrelated to cancer) or the sequelae of cancer treatment (lymphodema) or a combination of both. Others have a longer history of cancer that was "cured" but which the patient now fears is returning. A number of further related issues can arise from this such as intimacy, sex, and body image problems. Due to the complexity of their pain history, the patients may have been accessing a number of different specialists and be taking a number of different, perhaps inappropriate or conflicting, pain medications.

THE MULTIDISCIPLINARY APPROACH TO PAIN MANAGEMENT

Medication and Interventional Techniques

As illness progresses, medication needs will change, sometimes on a daily basis, and perhaps increase, but a key role for the pain management group is rationalizing a patient's medication regimen, ensuring adequate pain relief yet minimizing the impact on a patient's cognitive functioning and allowing the potential for effective communication that can otherwise so often lead to ineffective treatment. Effective pain relief may be accomplished by conventional pharmacological medicines or by the use of interventional techniques (in the hospice or nearby hospital). Pain blocks also allow reduction in systemic medication and polypharmacy, and even if the impact is short-lived, important insights into the complexity of pain are often gained, further clarifying which other physical or psychological interventions may be helpful.

The Pain and Mood Questionnaire

Patients who have had an earlier diagnosis of cancer or who have cancers that have been slower to spread do have an extended time span that might allow them to adjust to their disease and their impending death. To facilitate this, the pain management group has advocated the use of the PMQ, which can be utilized a number of times, opening discussions about pain and suffering, allowing the existential element of the pain to be better managed. Using this presents an opportunity for patients and staff to see how frequently both the mind and the body are involved in the pain experience. Discussions in the group drawing on what the patient might say when completing the PMQ has allowed us to recognize when a patient's pain is more about suffering and existential pain than pain from a diseased body; however, even with a length of time between diagnosis and death, the agony of dying from cancer may not always be relieved.

Specialist Psychological/Psychiatric Support

The Pain Group has successfully supported patients with specific problems such as obsessional behavior or exaggerated fear of medical procedures. Further input from the group psychiatrist can be sought and patients can have a number of sessions, perhaps using techniques such as systematic desensitization or focused psychotherapeutic interventions to help them overcome fears. This psychiatric input may then improve pain management by allowing them to have a diagnostic procedure that paves the way for further treatment. General psychological therapy for them or their families is also available.

Holistic Approach

The number of different factors involved, and the number of psychological, physical, and social issues involved, necessitates that a number of different interventions be implemented, coordinated, and monitored. For example, in one patient, we may see complex medication issues relating not only to the current cancer, but also to recurrent pain from a back injury. We might find that although psychosocial support had been offered and received this might have been largely crisis driven and inconsistent. The same patient may worry about leaving young children and have had invasive treatment affecting body image and sexuality.

The key role for the Pain Management Group here has been to focus on the patient's pain holistically, rationalizing the medications and coordinating the care of the patient to one center only. If this is not possible, the group tries to ensure that at least all the practitioners are aware of the others' involvement. Using all the resources of the medical professionals represented in the group has allowed us to examine the patient's pain from both a chronic and a palliative pain perspective. The members of the team work in a nonhierarchical fashion so input from each discipline is valued and different approaches often combined. The different members of the group have also learned from each other through the sharing of their unique disciplinary perspectives. Each member of the group has found it possible to do more in their own area of expertise because of the other activities being carried out by other members of the team. As no member is working in isolation, the benefits to patients are increased.

DISCUSSION

This article uses the experience of a multidisciplinary pain management group to illustrate the different factors that may lead to less satisfactory pain management. We found that we could support and care for patients better if we understood the interaction of these different factors and accounted for them in our treatment regimens and in accordance with the time that remained in their lives.

The hope is that patients attending a hospice may end their lives with existential pain issues largely resolved and physical pain under control, and in the majority of cases, this is the case. We noted that where barriers to adequate pain relief could be removed, the representation of cancer pain as unbearable broke down, and patients could end their lives calmly, with their pain and suffering held in check, and openly communicating their needs to staff, who could then deal with them. However, either because of late referral to the hospice or to the Pain Management Group or because of the sheer number and weight of different potential factors involved, it was not always possible to completely settle all the difficulties. For such patients the representation of cancer pain as being intractable is the appropriate one and it is likely that relatives may afterward talk of the death as difficult.

Mesothelioma Patients

Arising from our experience, we have observed a group of patients that exemplify not only the specific factors that may lead to unresolved pain, but also the interaction of such factors. The pain experience of patients with mesothelioma is often an extreme example of complex pain. The time between diagnosis and death is relatively short (often less than a year) and potentially curative treatments are rarely offered. Patients often leave behind a young family and partner. We have identified a number of specific psychological factors that may arise with this group of patients, notably reluctance to take any responsibility for their pain management and unwillingness to engage with coping strategies for pain. They are often very angry because the disease has been caused by factors outside their own control. In some cases, litigation may be ongoing. These patients often displayed rigid thinking and an inability to admit to and discuss their advancing disease, which became a barrier to pain relief. Furthermore, these patients frequently expressed a strong desire to be unaware of their surroundings and to be heavily sedated, which further precluded engaging with the ongoing issues.

There are also specific patho-physiological manifestations with this disease that affect the nature of the pain and the complexity of the treatment, for example, the widespread growth of the cancer in the pleural cavity. The cancer is often the result of exposure to asbestos in early years and we do not have such effective cancer therapies, resulting in much anger and shock being felt by them and their families. We have observed that these patients are often withdrawn and display signs of being in considerable pain (curling up in bed) and yet are reluctant to engage with coping strategies or psychological therapy of any kind that might bring about an acceptance and understanding of their situation. These patients frequently feel that it is the medical staff's responsibility to remove the pain.

We frequently found with this group that psychological interventions *and* pharmacological interventions needed to be carried out together. It was not appropriate to wait until the pain was controlled before instigating psychological support, because with these patients, the pain may have such an element of existential suffering to it, that the physical symptoms cannot be relieved until both psychological and physical aspects of the pain are addressed.

Early interventions with psychological support/therapy could sometimes help with these patients and their families but frequently there was insufficient time for the intensive interventional work to be done before the patient died. Patients need to have sufficient physical and psychological capacity to do this work, so it cannot be done at the very end of life. They also need to have the will to do it. We felt that given more time, it might have been possible to engage with these patients and to support and guide them through the intense work that has to be done, but their late referral, sometimes due to late diagnosis, often precluded this.

The number of patients that we have seen in the Pain Management Group with mesothelioma is considerable in contrast to other hospices. Our experience with this group of patients may be unique and we intend to try and formalize our initial impressions of these patients by carrying out a prospective study of their psychological characteristics.

Research in palliative care presents a number of difficulties, such as finding homogenous patient groups and patient attrition. We feel that conducting research on a homogenous sample of mesothelioma patients will give rise to stronger results. As the numbers of patients presenting with mesotheliomas (due to exposure to asbestos in their earlier working lives) is likely to increase over the next few years (Treasure et al., 2003), pain teams might need to be alert to the need to intervene with the patient and family as early as possible to engage with the difficult issues involved. Patients with pancreatic cancer share a number of similarities with this group and also might need early psychological interventions and extended support.

Toward the end of life, medication needs will increase, but sometimes pain that has not responded to somatic therapies is attributed to psychological factors when, in fact, medical factors might not have been adequately appreciated (Breitbart & Payne, 2004). The hospice is able to take advantage of input from an anaesthesiology consultant with considerable experience in chronic pain who is able to identify issues that can be missed by physicians who focus on cancer pain to the exclusion of chronic pain. The representation of anaesthesiology as a discipline in the multidisciplinary group is in accordance with National Institute for Clinical Excellence (2004, p. 132) guidelines.

We realize that there are overlaps in the factors that affect the psychological and physiological response to pain and pain medications; however, for the purposes of optimally treating and supporting patients and their families, the realization that not only do these factors exist, but they can multiply in their effects is an important observation. Furthermore, if staff can recognize the importance of psychological and somatic influences interacting from the earliest stages of patients' histories, there is a greater chance of engaging with them and supporting them through the last stages of their life with pain under control.

CONCLUSIONS

The multidisciplinary approach to complex pain in the palliative care setting follows many of the principles established in management of chronic pain (e.g., Foster et al., 2003; Patrick et al., 2004). We consider that the perspective of a pain management group is much better placed to make a difference toward the end of a patient's life by thinking of patients' unrelieved pain through a number of different perspectives, rather than by following either a psychological *or* a medical approach. Although cancer pain is always treated in an individualized way and physicians respond to the changing circumstances and advancing disease as the need arises, we consider it important to point out that where some factors are constant, it may be appropriate to treat the patients following a coherent pattern that has previously met with some success. Thus with mesothelioma patients it may well be appropriate to try and take an opportunity for early psychological interventions if possible.

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