Cancer Pain—A Provoker of Emotional, Social and Existential Distress

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Although methods for controlling most cases of severe cancer pain exist, probably about 50% of patients still suffer from unnecessary, poorly controlled pain. Cancer pain has a substantial negative effect on mood, resulting in anxiety, depressive feelings and even suicidal thoughts and cognitive functions are disturbed. As cancer pain often originates from skeletal metastases, movements and daily activities (ADL) functions are restricted. Cancer pain is associated by the public with progressive disease and dying and is therefore a trigger of existential fears, for both patients and the public. Pain treatment and education are therefore high-priority matters with effects far beyond the physical suffering.

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Although it is possible to offer adequate pain control to more than 90% of cancer patients (1), the reality is very different because of lack of knowledge, skills and wrong attitudes. In a recent study of a hospice program, McMillan concluded that pain was still a problem and that only 42% of patients reported a pain intensity of 5 or less on VAS (Visual Analogue Scale from 0 to 10) (2). In a survey of 2074 deaths Addington-Hall et al. found that 47% of patients who received their care from GPs reported only partial pain control and the corresponding figure for hospitals was 35% (3).

IASP (International Association for the Study of Pain) has stressed that pain always has an emotional component. Still, the considerable psychosocial and existential consequences are often overlooked. Although the hospice concept of 'total pain', i.e. physical, emotional, social and existential/spiritual pain, has been of value in understanding and stressing different types of suffering, it may have confused the conception of pain versus suffering. For example, emotional pain might denote that the emotional stress in the late stages of palliative care is a 'painful' experience, but the 'total pain' concept should be distinguished from 'ordinary physical pain' and its emotional, social and existential consequences, with a profound effect on quality of life (see Table 1).

CANCER PAIN AND MOOD

Many clinicians have observed the correlation between pain and mood, especially concerning acute pain and anxiety, and the relationship between long periods of unrelieved pain and depressive feelings. Sometimes the primary motivator is questionable, i.e. does pain induce mood changes or is the opposite more true? For example, in chronic pain of non-malignant origin, the mood disturbance may precede the pain.

For cancer pain the relation is rather obvious that there is a clear relationship between the degree of unrelieved pain and negative effects on mood. Therefore, behavioral techniques may be most beneficial in chronic non-malignant pain, whereas direct pain treatment focused on the physical pain is needed in most cases of cancer pain.

Unrelieved pain is strongly associated with anxiety and depressive feelings and successful treatment of pain can reduce these problems (4–11). The magnitude of the problem is great. In a study by Cleeland depression was reported in one-third of the patients (assessments made by the staff) (12). On direct questioning, the figures are higher. Dorrepaal et al. (4) reported that pain influenced the mood in two-thirds of the patients and Strang et al. (5) found similar figures: 56% of patients reported significant (26%) or pronounced (30%) anxiety and the corresponding figures for depressive feelings were 71% (35% + 36%) (4–6 or 7–9 on a 9-point scale).

In cancer studies either VAS or numerical point scales are used but not DSM criteria. The reasons are that cancer patients are not a psychiatric clientele, but persons with adequate reactions to a life-threatening disease. Another

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advantage is that using VAS, the assessment can focus on the impact of pain on mood. DSM criteria are useful for identifying depression, but they cannot distinguish between a depression caused by the cancer diagnosis itself and other factors such as pain.

The relationship between pain and anxiety is significant even when the possible mediating effects of the variables of illness severity and age are removed (10). In the study by Lancee et al., pain was, in fact, the strongest independent explanatory variable (13). Concerning depression, it is more likely that cancer pain induces depression, than that depression induces pain (14).

The emotional component is also dependent on the possibility of hope. Even if pain cannot constantly be controlled, pain-free periods may be of great value and are significantly correlated with a lower degree of mood disturbances (5). This is probably related to the fact that a pain-free period is strong proof of the existence of effective treatment. A contributory effect is probably that pain-free periods allow the patient to rest, which gives new strength for coping.

PAIN, AND DAILY ACTIVITIES (ADL)

Unrelieved pain has a great impact on ADL functions. Dorrepaal (4) found that one-third of patients with pain problems were seriously limited in ADL functions. An interesting finding by Portenoy et al. (15) is that there is also a significantly impaired performance score in patients with pain in cases such as ovarian cancer, where skeletal metastases are rare.

PAIN AND SLEEP

The first aim for cancer pain treatment, according to WHO, is freedom from pain during sleep. This is an important goal, as pain problems are often accompanied by lack of sleep, which intensifies the pain experience and impedes effective coping.

There is a relationship between sleeping patterns, pain and mood, although the indications are not clear-cut. In a study of cancer pain 58% of the patients woke up during the night because of pain. These patients expressed more anxiety ($p < 0.001$) and depressive feelings ($p < 0.05$) than those who slept through the night (5). There are two possibilities: either patients with pain and mood disturbances have more sleeping problems, or those patients who wake up because of pain sleep less and, consequently, the lack of sleep makes them exhausted and creates anxiety.

Table 1

Unrelieved cancer pain has negative effects on most aspects of quality of life

Mood
Social activities
ADL functions
Sleep
Cognitive functions
Existential dimension

PAIN AND COGNITIVE FUNCTIONS

Preserved cognitive functions are an important part of the patients' autonomy. Unrelieved pain has a negative influence on concentration and makes it difficult to watch the TV, read or perform other tasks that require intellectual effort. About half of the patients report a negative impact of pain, and social activities such as visits and conversations decrease significantly with increasing pain ($p < 0.0001$) (5).

In addition, suboptimal pain treatment in itself may affect cognitive functions directly. The dose required for analgesia in an opioid-sensitive pain seldom impairs cognitive functions in any significant proportion. However, if pain treatment is preceded by an inadequate analysis, there is a risk that strong opioids will be used in partly or highly opioid-resistant cases, which leads to increasing doses and a picture that is dominated by side effects and still with poor pain control. This problem underlines the importance of thorough pain analysis and the need for various treatment options for different situations.

PAIN AND SOCIAL ASPECTS

In a study of 93 patients Strang concluded that 17–37% of the patients were significantly hampered in different social activities, including hobbies and contacts with friends, and that as many as 48–85% of the patients experienced some or a profound negative influence on the eight different issues (6). Some of the impairment was related to other aspects of the illness, but the correlation to pain intensity was significant (p 0.05 to < 0.001).

Cancer itself implies several losses: loss of health, loss of friends, loss of energy, and so on. The experience of pain aggravates these losses. The obvious association is the reduction of ADL functions, restricted ability in movement and walking. Other social losses are more subtle, but still important. Pain changes the roles in the family. The strong husband becomes a weak fragile person in need of help, even with simple tasks. A wife may perceive her inability to perform household tasks as burdensome. Although it is possible to preserve autonomy and dignity under optimal condition even in the later stages of the disease, the risk of losing both is still a reality, especially if pain is not controlled.

When life becomes restrained in physical, emotional and social aspects, this may affect the sense of coherence,

which is of utmost importance for quality of life (QOL). What is left of a person's standing after several important losses? Support from family and friends may empower the sense of coherence, but for patients with an insufficient network, illness itself will challenge it and unrelieved pain will definitely threaten it.

EXISTENTIAL ASPECTS AND AUTONOMY

Pain might be considered as a metaphor for dying and death (16) and as such is greatly feared by the public (17). Unrelieved pain provokes anxiety, existential fears and fear of losing autonomy (18). In a study of semistructured interviews with 78 cancer patients, pain intensity was significantly correlated with fear of the dying process and fear of the future. For a proportion of patients who had accepted their illness and the fact that they were facing death, fear of pain progression and distress during the dying process was more frightening than the diagnosis in itself or the knowledge of an impending death. Pain also triggered thoughts about injustice: 'How could there possibly be a God when I am put through suffering like this'?

To what extent pain provokes existential pondering is partly related to the ascribed meaning of pain (19). Pain may be perceived as a warning signal, but it may also be experienced as a threat, a punishment or a trial. It may be associated with religious concepts and, thus, the relation between pain and existential distress may vary.

PAIN TREATMENT OR EUTHANASIA?

There are three great fears that patients facing death report:

1. The fear of pain (and other troublesome symptoms).
2. The fear of being abandoned when facing death.
3. The fear of losing autonomy.

For most patients the fear of pain is the most frightening nightmare. On those occasions when patients have discussed suicide or when I have been asked by patients about euthanasia, the underlying reason has always been unrelieved pain and fear.

Case 1

A male of about 65 years, suffering form prostatic cancer that was generalized to most parts of the skeleton. Intense incidental pain despite high doses of methadone combined with paracetamol, whereas the pain in absolute rest was acceptably controlled. He had suffered from unrelieved pain for many weeks and was exhausted. He had thought it all over and expressed his plans for suicide. He was calm but decisive.

During the discussion it was obvious that pain was the reason for concrete suicidal plans. His pain was analyzed. There was a significant component of inflammatory pain that had not been treated. After a change in the prescription he became totally pain free within three days and the suicidal thoughts disappeared. Now he values highly the time he has left.

Table 2

Alternative methods for effective cancer pain treatment, depending on underlying cause and type of pain

Opioids
NSAIDs
Corticosteroids
Other co-analgesics
Palliative radiotherapy
Orthopedic surgery
Bisphosphonates
Hormonal treatment
Palliative chemotherapy

Case 2

A female about 75 years old with generalized breast cancer. She expressed a direct wish for active euthanasia and explained it without emotion. She had previously been a nurse, so she 'knew' how the end would be. She had been in pain for four days and had not been able to sleep. She felt nauseated and could not eat.

We talked about it and made a plan for improved symptom control. After three days, she was pain free and her appetite returned. She had slept two whole nights and commented: 'I know that I will die soon, and that does not scare me. But now, when I am free of symptoms and have rested, I realize that my life is as good as it can be. I have my husband and my children with me, they are here all the time and that is the important thing for me. Now I can socialize with them and with my friends again and, yes, now I have a good quality of life'.

BARRIERS TO EFFECTIVE PAIN TREATMENT

Lack of knowledge and skills are still the principal barriers to effective pain control. Successful treatment is based on a pain analysis in order to identify subtypes of pain and to be able to choose appropriate treatment modalities. There are many treatment options and they should be selected depending on underlying cause and type of pain (see Table 2).

Although strong opioids have a central role, other methods are also needed. As the metastatic process gives rise to inflammation and release of substances such as prostaglandins, the use of NSAIDs or corticosteroids (20) constitute a causal, rather than a symptomatic treatment. Alternative routes (spinal) or delivery systems (infusers) should be used when needed to optimize the effects. Palliative radiotherapy has a remarkable effect on bony metastases (21) and painful metastases in soft tissues and viscera (22). Orthopedic surgery in spinal fractures may have an impressive effect on both nociceptive and neurogenic pain,

but also on other neurological deficits (23). Bisphosphonates given appropriately can have an analgesic effect (24) as can hormonal treatment (25) and chemotherapy (26), which many doctors are not aware of.

One of the problems is that although these methods exist, the deep knowledge about them and skills to use them are often lacking.

Other barriers are fear of addiction, but also inability or reluctance to report pain (27, 28). Patients do not always know how to describe pain and may therefore risk being undertreated for that reason.

The other reason is reluctance. According to Wilkie & Keefe (29), as many as 42% of patients did not want other people to know that they are suffering pain. For these people denial constitutes a primitive but functioning form of coping. By denying the pain, the tumor progression is also denied.

Another neglected area is patient education. Much of the care is performed on an outpatient basis and patients are prescribed several analgesics and co-analgesics. However, without proper patient education they cannot use their drugs optimally. Patient education is beneficial for optimizing the results (30).

CONCLUSION

Pain has a profoundly negative effect on physical, emotional, cognitive, social and existential dimensions of life. It can even have a negative effect on the mood of the caregivers, creating tensions and depression (31). Effective pain control should therefore be a high-priority matter in order to enhance the overall quality of life for patients and their families.

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