Psychological distress in patients with advanced cancer

Fiona Cathcart MA MSc AFBPsS, Consultant Clinical Psychologist, *St Columba's Hospice, Edinburgh*

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Psychological distress may be understandable in the face of the many losses and uncertainties at the end of life but it is not inevitable as not all patients are psychologically distressed. Some are passively resigned to their death, while other patients are able to confront the challenge actively and find more personal meaning in life such as increased intimacy in their relationships. This latter situation is unlikely to occur unless the suffering caused by uncontrolled pain and symptoms or by family friction and damaged personal relationships is alleviated.[1] This article discusses the psychological distress which may be experienced by patients and the non-pharmacological interventions which may be used to manage it. Discussion about psychiatric disorder in palliative care is beyond the remit of this article and can be found elsewhere.[2]

Psychological distress may be undetected and untreated in patients with advanced cancer. There is also growing awareness of the unalleviated distress caused by non-malignant diseases such as end-stage cardiac failure and chronic obstructive pulmonary disease (COPD). Data obtained on 209 patients with COPD in the year before death found that low mood was reported in 77% but relieved in fewer than 8%.[3]

Anxiety

Anxiety presents in different ways and may exist as:

- a general response to the situation, a low to moderate level of anxiety most of the time
- a specific phobia related to an aspect of the disease or treatment, or
- panic attacks.

Patients may want to discontinue treatment because of anxiety levels they cannot tolerate. The anticipatory nausea and vomiting associated with chemotherapy can be reduced using behavioural strategies based on desensitisation. This intervention can be taught to oncology health professionals to enable it to be delivered more rapidly to patients than would usually be the case if referral to another department were required.[4] Patients can find it difficult to articulate concerns about the end of life even when clinicians invite questions. An opportunity to rehearse questions with another person may be necessary before the patient is able to voice specific fears.[5]

A cognitive approach can help patients identify the thoughts that cause them distress and find ways of challenging them before the anxiety escalates. For example, patients who experience breathlessness and feel anxious can be helped to manage the psychological component of this symptom. It is important to stress to them that the psychological intervention is part of the treatment and neither means that their symptoms are 'in the mind' nor replaces other interventions.

Addressing all the components of the presenting symptoms enables more effective support to be given.[6] For example, it should be acknowledged that an exacerbation of breathlessness is frightening and it be explained that how patients think about being breathless can help stop an episode sooner or prolong it. Patients can be encouraged to find a strategy such as:

> *I can stop myself from adding more to being breathless if I use what I was taught (distraction/imagery/breathing out); this will help me get through it sooner. I had this yesterday morning and it passed. The rest of the day wasn't so bad. It didn't last then and it won't last now.*

If asked what will happen if it proves to be the final episode, an explanation can be given about what others can continue to do to keep the patient as comfortable as possible, exploring any possible fears there may be of suddenly choking or suffocating.

Sexual abuse

A few patients reveal that their fear of the dying process is linked to childhood sexual abuse. These memories may have become more intrusive again if they have lost body hair because of chemotherapy. They are afraid of others handling their bodies and providing intimate care at a time they envisage lying helpless, disoriented and unable to speak. They may not want this information disclosed to other team members but it can help to reassure them by offering to write a list of explicit requests which can be incorporated into a nursing care plan if needed: for example, staff identifying themselves by name before touching, repeating this frequently during care. This is good practice with any drowsy or confused patient but becomes essential with such vulnerable patients at the end of life.

Depression and the desire to die

A systematic review of depression in palliative care estimated a 15-30% prevalence depending on the definition used.[7] Assessment of depression is problematic in advanced cancer because many of the usual signs of depression such as loss of appetite and a disturbed sleep pattern may reflect the disease process. Similarly, thoughts of death may be realistic and a basis for appropriate planning rather than morbid. Endicott suggests substituting some symptoms for others which are more useful in this situation (Table 1).[8]

Table 1. Suggested substitute symptoms for depression in the palliative care setting.[8]

Symptom	Suggested substitute
Weight loss or gain	Looks depressed
Disordered sleep pattern	Socially withdrawn
Loss of energy	Pessimism
Poor cognition	Lack of reactivity

Key Points

Identify and address concerns of patient and carer

Use assessment measures and resources designed for the patient group

Find realistic and more helpful ways of thinking

Rehearse difficult situations by discussion

Help problem-solving and support prior adaptive coping strategies

KEY WORDS: breathlessness, cognitive behaviour therapy, depression, desire to die, learning disabilities, sexual abuse, suicide

Anhedonia

Loss of interest (anhedonia) remains relevant. Asking two patients with a common hobby such as golf the same question about a forthcoming event may elicit two opposite replies. One may hope that unexpected visitors will not arrive as the TV coverage of the tournament starts, while the other may have interest in neither the game nor visitors, stating that everything seems pointless. Short assessment measures which screen for depression, designed to be used in a population with physical illness, are available, for example, the Hospital Anxiety and Depression Scale. The Edinburgh Postnatal Depression Scale has been recommended as a screening tool for depression in a palliative care population because of its specificity and sensitivity.[9] Chochinov[10] argued that asking the short question 'Are you depressed?' was as useful as longer questionnaires but Lloyd-Williams *et al*[9] found this simple question was less accurate in predicting depression in a UK palliative care population.

Suicide

The incidence of suicide in patients with advanced cancer increases with disease progression. A Swedish study of suicide in the over-65s reported serious physical illness as an independent risk factor for men.[11] Thoughts of suicide are related to uncontrolled pain and lack of social support.[2] Factors indicating patients most at risk are listed in Table 2.

Desire for death

Some patients express a desire to die and may request assistance to achieve this. A Canadian study of 200 palliative care patients surveyed the desire for death defined by a criterion cut-off point on a scale developed by the authors.[12] There was a median interval of 43 days between initial interview and death. The desire to die was common (44.5%) but transient for most patients. An attempt was made two weeks later to reassess the 17 patients (8.5%) described as unequivocal in their wish to die, but all but six had either died, deteriorated beyond interview or been discharged home. Only two of the remaining six had maintained their desire for death (Table 3). The desire for death was correlated significantly with depression and also correlated with pain and low family support.

Psychological interventions

Much of the literature on psychological interventions is based on studies with seriously ill patients not imminently approaching the end of life. A range of interventions in palliative care has been described, but controlled studies of psychological interventions in patients with far advanced cancer are difficult because of patients attrition.[13,14]

Cognitive behaviour therapy

Encouragement to identify and achieve small goals can help lift mood and reduce the sense of helplessness. Cognitive behaviour therapy is effective for the psychological problems of patients with cancer[15] and can also benefit staff by offering a structured way to maintain support when both patient and staff feel helpless.[16]

Body image problems can be helped by rehearsing the feared situations in fantasy and developing strategies to handle insensitive questions or symptoms which could cause embarrassment, such as vomiting in a public place. Rather than reassuring the patient that these things will not happen it can be more rewarding to acknowledge their fears and explore what they could say or do to cope with the situation.

Personality disorders

Some patients may have had long-standing difficulties in coping with the problems of daily life and the disease presents them with yet another crisis. Patients with borderline personality disorders may use large amounts of clinicians' time because of their behaviour rather than because of complex physical symptoms. Such patients may risk further deterioration to their health because of non-adherence to treatment or may cause disruption within the clinical team

Table 2. Risk factors for suicide.

- Previous suicide attempts
- Current thoughts of suicide
- Substance abuse, alcohol or drugs
- Elderly male
- Low social support
- Impulsivity and disinhibition
- Uncontrolled pain
- Advanced disease
- Depression

Table 3. Desire for death among 17 palliative care patients: two week follow-up.[12]

Patient situation	No
Deceased	4
Too ill to participate	4
Discharged or unavailable	3
No longer reached cut-off score	4
Maintained score above cut-off score	2
Total	*17*

because of disagreements about management. Some can acknowledge their emotional distress but others will angrily reject any suggestion of a psychological component. The role of the psychologist may be in supporting team cohesion in the face of this psychological assault.[17] Challenging patients obtain attention by making demands and staff become reluctant to interact with them at other times. It is important to remain engaged and to encourage more adaptive behaviour when possible. The patient may have limited capacity to change but a working contract needs to be established – even if its basis needs to be revisited frequently! If there is a history of substance abuse, analgesia may be withheld by staff because of fears of addiction. The patient will become more anxious and angry, and problems escalate. Advice should be sought from the appropriate local service such as liaison psychiatry, in combination with a palliative medicine specialist.[18]

Cognitive impairment

Cognitive impairment can be part of the disease process but its aetiology may be distinct and predate the cancer, for example in people with dementia or learning disabilities. The latter are under-represented in screening programmes and may present late in their illness. Morbidity and mortality patterns are different for some cancers from those in the general population, with a higher incidence of leukaemia and testicular cancer.[19] More accessible resources have become available to help patients with cognitive impairment make informed choices, but under current legislation another adult cannot give consent for treatment. Assessment of pain and symptoms often relies on interview or visual scales which may be inappropriate. If there are communication difficulties, misunderstandings will result in poor care. Systematic observation measures using non-verbal behaviour are being developed and can document the characteristic ways in which an individual expresses distress, for example by becoming withdrawn or unusually vocal.[20] These can help the clinician interpret a confusing and contradictory presentation.

Conclusions

Psychological distress is common in advanced disease, resulting in poor quality of life for the patient and giving both the relatives and professional carers a sense of frustration and failure. Finding ways to alleviate this distress allows the patient to die peacefully, helps relatives in their bereavement and enables the clinician to continue to provide sensitive care at the end of life.

References

1. Cherny N. The treatment of suffering in advanced cancer. In: Chochinov HM, Breitbart W (eds). *The handbook of psychiatry in palliative medicine*. Oxford: Oxford University Press, 2000.
2. Breitbart W, Chochinov HM, Passik SD. Psychiatric symptoms in palliative medicine. In: Doyle D, Hanks G, Cherny N, Calman K (eds). *The Oxford textbook of palliative medicine*, 3rd edn. Oxford: Oxford University Press, 2004:746–71.
3. Elkington H, White P, Addington-Hall J, Higgs R, Edmonds P. The healthcare needs of chronic obstructive pulmonary disease patients in the last year of life. *Palliat Med* 2005;**19**:485–91.
4. Morrow G, Roscoe JA, Hickok JT. Nausea and vomiting. In: Holland JC, Breitbart W, Jacobsen PB (eds). *Psycho-oncology*. New York: Oxford University Press, 1998:476–84.
5. Santos MJH, Greer S. Adjuvant psychological therapy with a terminally ill cancer patient. *Behavioural Psychotherapy* 1991;**19**: 277–80.
6. Bredin M, Corner J, Krishnasamy M, Plant H *et al*. Multicentre randomised controlled trial of nursing intervention for breathlessness in patients with lung cancer. *BMJ* 1999;**318**:901–4.
7. Ly KL, Chidgey J, Addington-Hall J, Hotopf M. Depression in palliative care: a systematic review. Part 2. Treatment. *Palliat Med* 2002;**16**:279–84.
8. Endicott J. Measurement of depression in patients with cancer. *Cancer* 1984;**53** (10 Suppl):2243–9.
9. Lloyd-Williams M, Spiller J, Ward J. Which depression screening tools should be used in palliative care? Review. *Palliat Med* 2003; **17**:40–3.
10. Chochinov HM, Wilson KG, Enns M, Lander S. 'Are you depressed?' Screening for depression in the terminally ill. *Am J Psychiatry* 1997;**154**:674–6.
11. Waern M, Rubenowitz E, Runeson B, Skoog I *et al*. Burden of illness and suicide in elderly people: case-control study. *BMJ* 2002;**324**:1355.
12. Chochinov HM, Wilson KG, Enns M, Mowchun N *et al*. Desire for death in the terminally ill. *Am J Psychiatry* 1995;**152**: 1185–91.
13. Cathcart F. The contribution of clinical psychology to palliative medicine. In: Doyle D, Hanks G, Cherny N, Calman K (eds). *The Oxford textbook of palliative medicine*, 3rd edn. Oxford: Oxford University Press, 2004:1073–8.
14. Llewelyn S, Murray AK, Johnston M, Johnston DW *et al*. Group therapy for metastatic cancer patients; report of an intervention. *Psychology, Health and Medicine* 1999;**4**: 229–40.
15. Moorey S, Greer S. *Cognitive behaviour therapy for people with cancer*. Oxford: Oxford University Press, 2002.
16. Jones K, Johnston M, Speck P. Despair felt by the patient and professional carer; a case-study of the use of cognitive-behaviour methods. *Palliat Med* 1989;**3**:39–46.
17. Passik S, Hay J. Symptom control in patients with severe character pathology. In: Portenoy RK, Bruera E (eds). *Topics in palliative care*, vol 3. Oxford: Oxford University Press, 1998:213–27.
18. Welch S. Management of substance misuse problems in the general hospital. Review. *Clin Med* 2002;**2**:513–5.
19. Tuffrey-Wijne I. The palliative care needs of people with learning disabilities: a literature review. *Palliat Med* 2003;**17**:55–62.
20. Regnard C, Mathews D, Gibson L, Clarke C. Difficulties in identifying distress and its causes in people with severe communication problems. *Int J Palliat Nurs* 2003;**9**: 173–6.