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Distress in palliative care patients: Developing patient-centred approaches to clinical management

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ABSTRACT

It is widely recognised by clinicians that depression is a difficult symptom to identify amongst patients with advanced illness. Many of the symptoms of depression are difficult to elicit in patients who are approaching the end of life. Additionally, many believe that a 'degree' of depression is almost normal as patients approach life's end. More recently the concept of demoralization as a separate entity to depression has been described which can be briefly described as a disorder of meaning and hope. In this paper, we review these diagnoses together with the latest screening tools which can help clinicians to recognise better such pathologies in their patients and discuss interventions that can be utilised to help patients with depression or demoralization to have a better quality of life.

1. Introduction

Life threatening illness such as cancer provokes profound emotions,[1] never more so if you are given a terminal diagnosis

> 'But yes you do get depressed – you feel black. You feel why me? And you can't do things…It was dark days for a while…My wife says I was suicidal…You do feel rejected.'
>
> (45 year old man terminal lung cancer, unpublished data)

This paper looks at how clinicians can and should respond to such distress in palliative care patients. Drawing on a case study from a recent research project (Reeve Understanding distress in people with cancer: the role of the General Practitioner. Liverpool University PhD thesis, 2006), we discuss two current approaches to understanding and managing clinical care in this patient group and highlight the need for future practice-centred research.

2. A case study: Joan

Imagine that an additional patient has been slotted on Friday afternoon into your oncology clinic by the Breast Cancer Nurse. 'Joan' is a 55-year-old woman with metastatic disease who completed treatment for her primary cancer 10 years previously. Her diagnosis of recurrence came as a shock, but she had adjusted to the news and been managing well. However, she recently presented to clinic with some leg weakness; spinal cord compression was confirmed and she commenced a course of radiotherapy. During this time, her sister died sud-

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denly. Joan is now crying all the time and unable to leave the house and the nurse specialist is concerned by Joan's levels of distress. Joan describes her own story in Box 1.

Box 1 Joan's story (unpublished dataReeve 2006)

> 'They thought I had compression of the spinal cord, [and] I was treated like someone with a broken back. Which was scary… And [then] I came home to find my sister dead in bed. It was awful. Such a shock. And then I had to start my radium the next day. And go on like automatic pilot whilst all the funeral was going on...I had really bad effects after the radium…I couldn't eat, couldn't drink. And I was in constant pain for 6 weeks… …It was like a thousand million chili peppers going off in your mouth…I had no energy. No one prepared me for how bad it was going to be… I'd had no time to grieve over my sister because I'd just been in agony… So between the pain and sickness, oh I just felt like, just dying… I felt so ill and I didn't know what was the matter with me. And I was panicking and fighting this tiredness … And I ended up in floods of tears.'
>
> (55 year old woman with breast cancer, 'Joan' is a pseudonym)

Perhaps it is of no surprise that Joan was distressed when facing a terminal diagnosis, the loss of her sister and the physical impacts of her illness and treatment. Yet we know that emotional distress can worsen the impact of physical illness[2,3]; threaten physical health, and interfere with providing medical treatment.[3–7] Distress has considerable consequences and impact for patients and their carers, but also for health services.[8–12] Distress is an important health need, but one that is often unmet, reflecting difficulties in both the conceptualisation and effective management of distress.[8,13,14]

When presented with health needs, physicians rely on diagnostic processes to offer insights into prognosis, and the risks/benefits of interventions. Modern biomedical accounts of illness are underpinned by a scientific model of disease, whereby symptoms are viewed as the result of an underlying pathological process.[15] Interpretation of patient symptoms leads to diagnosis of the underlying pathology and, hence, access to treatment and prognostic information. Joan's story suggests both a physical or organic cause for her distress related to her cancer and treatment effects and a psychopathological cause such as depression. Current palliative care guidance emphasises the importance of a holistic assessment of need and, hence, the need to address the full range of needs, including spiritual or existential distress related to the loss of her sister and her own impending death.[16] What is not clear within current guidance is how, in practice, a clinician might do this.

In this review, we focus on two possible diagnoses – a pathological account of depression, and one of existential despair or demoralisation – as frameworks that practitioners may use to understand and inform management of distress. We discuss the strengths and weaknesses of each in supporting clinical practice, focusing on the practical difficulties for clinicians in using, and combining, multiple concepts in the clinical care of their individual patients.

3. Depression

Joan described low mood, loss of energy, change in appetite, recurrent thoughts of death and poor concentration – all symptoms that may be indicative of depression. Depression in people facing devastating loss may seem inevitable; recent prevalence studies have estimated that between 1% and 69% of patients with terminal cancer suffer from clinical depression.[7,17–21] Whilst higher than the average rates in UK populations (7.8%, 95% confidence of interval (CI) 3.3–17.5%), studies suggest that depression is not an inevitable part of dying.[22] Clinical depression can be differentiated from the expected 'normal sadness' when faced with terminal illness.[7,17–24]

Consideration of known risk factors for depression suggests why it may be more common in terminally ill cancer patients. Key elements over and above those seen in the general population focus on physical health problems and psychosocial factors.[7,19,20,24] The former include poorly controlled pain, metabolic abnormalities, drug therapy and specific effects of some tumours (e.g. pancreatic and brain). Social factors include loss of independence with advancing disease and inadequate social support.

Untreated depression in the terminally ill is associated with reduced quality of life for patients and their carers[25,26]; increased difficulty in palliation of physical symptoms such as pain, longer in-patient episodes and elevated health care costs and increased mortality.[18,27,28] Yet, depression is reported to be a treatable condition.[7,29–31] Antidepressant medication can improve symptoms of depression,[7,29–31] even in the final days and weeks or life.[32] Amphetamines or neuroleptics can be used in patients with a very limited survival time.[7] The clinical model of depression offers utility in dealing with these patients through predicting clinical course and outcomes from interventions.[33] Clinical guidance recommends proactive screening and treatment of depression.[7]

Much of our work has sought to contribute to this care by validating a screening tool for depression for use in terminally ill patients.[34–36] Many of the physical symptoms used within standard diagnostic tools for depression are also symptoms of underlying malignancy, e.g. tiredness, weight loss, appetite change.[19–21] Behaviour that may indicate depression in a physically well individual may be appropriate in someone facing death; for example, disengagement from previous areas of interest is a common experience.[19] Standard screening tools may, therefore, be inappropriate. Given the frailty of palliative patients, tools need also to be brief and easy to understand and complete. Our work has demonstrated that the Edinburgh Depression Scale (EDS), first devised for use with mothers in the postnatal period, is a suitable screening tool for depression in this population.[34] It is short, consisting of 10 questions; and does not ask about the presence of physical symptoms which may contribute to a diagnosis of depression but are also common in patients with cancer. Having been validated against a gold-standard of the PHQ-9, a score of 13 or above is considered to indicate high risk of depression with a reported sensitivity of 81% and specificity of 79%.[34] More recently, we have developed a shortened version of the EDS – the Brief Edinburgh Depression Scale. This tool has six items with a sensitivity of 72% and specificity of 83%.[37] It is now widely used within palliative care settings in the UK and USA and is being translated into other languages.

However, the pathological basis and, hence, validity of a diagnosis of depression remains uncertain.[33] In applying a diagnosis of depression, a clinician creates a hypothesis that a shared underlying disorder accounts for the patient's symptoms, rather than making a certain statement about the underlying pathology.[38,39] There are currently two diagnostic definitions of depression described within DSM-IV[40] and ICD-10, but with only 83% concordance between the two.[41,42] The utility of the diagnosis is said to account for its continuation within clinical settings, but can this be questioned? Returning to our case study, Joan was diagnosed with depression and started on antidepressants. She reported that

> 'And that night, I took [an antidepressant] and I slept. And then I took them second day and I thought, I'm starting to feel a little bit more energetic. Like I've got a bit more energy. And by the 3rd day, I was feeling a lot better and I thought, it must have been. The depression. Because I'd gone through so much.'

Pathopharmacology cannot explain the rapid effect of treatment on Joan's symptoms. The diagnosis seems to have contributed to positive change; but events also contradict the theoretical account of depression, raising doubt about the diagnosis. Perhaps, we need an alternative explanation to account for her distress and subsequent response to therapy.

4. Demoralisation

Joan revealed that a diagnosis of depression made sense of her experiences, bringing meaning and explanation for her distress. The importance and the impact of the loss of meaning on health outcomes are described within Kissane and colleagues' work on demoralisation.

Demoralisation describes a disorder of meaning and hope. In the last few years, psychiatry has focused on disorders of mood or affect, but in so-doing has neglected the role of meaning in understanding illness experience. Although demoralisation may be a harbinger of DSM-IV major depression[40] or ICD-10 depressive episode, or co-exist with these, empirical studies have shown it to be conceptually different to depression.[41] The central feature of depression within psychiatry is pervasive anhedonia, the loss of consummatory pleasure in the present. However, the demoralised may retain the capacity to smile and enjoy the present moment; but for them, the future is perceived to be without value, a loss of anticipatory pleasure. Recent studies of coping have highlighted the seminal role of discovering meaning as a fundamental pathway of adaptation.[43,44] Meaning-based approaches to coping bring an enriched understanding to the process of adjustment.[45]

A rich literature describes the construct of demoralisation, including Engel's account of a 'giving up–given up' complex in the medically ill, Frank's work on hope in the restoration of morale and Frankl's descriptions of the importance of meaning in transcending suffering.[46–48] Morale can vary across a spectrum of mental attitudes, ranging from disheartenment (a mild loss of confidence) to despondency (starting to give up) and despair (losing hope), before eventually reaching the state of demoralisation (having given up). Whilst the left-hand side of this spectrum is a comprehensible response to adversity, the right hand side is pathological through its maladaptiveness, the extent of personal distress and its potential to generate greater harm through further deterioration and suicidal behaviour. Conceptualising demoralisation in this way as an illness, Kissane and colleagues proposed the diagnostic criteria outlined in Table 1.[49]

The importance of demoralisation as a clinical concept is clear.[50] Cluster analysis of structured psychiatric interviews of medically ill patients differentiates demoralisation, anhedonia and grief as distinct syndromes of distress.[50] Hopelessness is more contributory than depression to the development of suicidality and Owen et al first demonstrated this empirical association in the cancer setting.[51,52] Breitbart demonstrated the contribution of hopelessness to suicidality amongst AIDS patients and Chochinov in palliative care.[53,54] Demoralisation accounts for significant distress, but may also affect clinical care through an impact on patients' capacity to consent to treatment.[55] Demoralisation is also a contagious emotional state, readily transmitted to family members, doctors, nurses and health care teams, necessitating attention to any such countertransference feelings, lest patient care suffer as a result.[56]

The utility of the concept was aided by the development of a tool to measure demoralisation, the Demoralisation Scale (DS).[57] In a cohort of patients with advanced cancer, the scale demonstrated good reliability, strong concurrent validity with a range of measures of the quality of life, hope, hopelessness and depression, as well as predictive validity in developing a desire for death with severity of demoralisation. The dimensions of the phenomenology of demoralisation are captured in its subscales: dysphoria, disheartenment, loss of meaning, helplessness and sense of failure. Divergent validity is found in its ability to differentiate demoralisation and depression.[57] When allowance is made for demoralisation to be co-morbidly present with depression, prevalence rates between 20% and 30% for demoralisation are seen across studies, with higher rates in advanced than early cancer states.[58–60]

Management includes psychotherapy and narrative therapy. Reconstruction of a robust sense of purpose despite illness is fundamental to overcoming meaninglessness. Where vulnerability comes from the loss of control, establishing a sense of agency promotes mastery. Similarly, isolation is

Table 1 – Proposed diagnostic criteria for demoralisation syndrome
Complaints of life's meaninglessness, pointlessness or loss of purpose
Sense of pessimism, helplessness and stuckness in the predicament
Loss of hope for improvement or recovery
Associated isolation, alienation or lack of support
Potential to develop suicidal thoughts and plans
Phenomena persisting over more than two weeks

overcome through the development of a sense of communion with others, confusion through coherence, despair with hope, resentment with gratitude and cowardice with courage.[61–63] Empathic dialogue that normalises any sense of adversity and unfairness can be fostered through approaches that make use of the life narrative.[64,65] In this manner, suffering is acknowledged, dignity affirmed and hope generated, whilst highlighting, wherever possible, the patient's strengths and resilience to stress.[66] An existential focus on what is authentic, purposeful and achievable through living in the present moment has merit.[67] Bedside psychotherapy with the medically ill has been used to address demoralisation through the recognition of each core existential theme and related pathways in order to optimise coping.[68]

Narrative therapies build up a coherent account of the person's accomplishments, fostering celebration and a sense of fulfillment, whilst highlighting roles, relationships and the apparent purpose of the patient's life.[69] A shared consensus is sought about all that has been accomplished, whilst unfinished business can be identified and pursued in the time remaining. Interpersonal psychotherapy has utility in examining roles and transitions.[70] One adaptation of the narrative approach in the palliative care setting has been Chochinov's model of dignity-conserving therapy.[71] Through this approach, the clinician helps create a legacy document, which celebrates the patient's life, affirms their worth and promotes respect. Breitbart's research team has been testing an eight session group psycho-educational model of exploring meaning, focusing on the sense of personal responsibility, attitudes, creative and experiential values and the meaning they bring to life.[72,73]

Demoralisation describes a model of care which emphasises the importance of meaning in the maintenance of well-being. Preliminary work drawing on narrative and psychotherapy principles describes potential therapeutic interventions. However, this is a relatively new concept with limited evidence of the nature and effectiveness of this approach, especially within the routine clinical assessment and management of patients. Elements of the described narrative approaches are enshrined within existing models of good primary care and palliative care.[74,75] There is much research yet to be done looking at how this new framework can be applied in the clinical setting.

Joan's narrative revealed a loss of meaning; the depression diagnosis helped restore understanding and hope, bringing relief from her symptoms. Possibly demoralisation was a more appropriate diagnosis given her symptom complex. Yet, it remains unclear whether the narrative diagnostic and therapeutic process within a demoralisation framework would have offered equivalent positive effects. Her story highlights the importance of the patient's perception of their illness experience and what they might see as legitimate approaches to management, when seeking to understand and manage distress.

5. Discussion

We have described two frameworks which could be used to understand Joan's expressions of distress and hence guide treatment. Returning to our scenario of a late afternoon clinic visit, how can these concepts be applied in the clinical setting to support Joan?

Joan may have been experiencing both a psychopathological change in mood linked to neurotransmitter imbalance (pathological depression), and also a profound loss of meaning: both diagnoses would be correct. How is the clinician to manage this scenario – which diagnosis takes precedence? Within the hierarchy of knowledge described in evidence-based practice, the depression diagnosis comes first as management is supported by randomised controlled trial evidence. Interventions for managing a pathological depression are also more fully described and are arguably better suited to current models of clinical care.[76] Awareness of the contextual issues in which illness occurs is fundamental to good clinical practice, but the primary focus would be on identifying and managing a pathological illness of depression before considering alternatives such as demoralisation.[77] Yet, this assumes that there is no risk in adopting a biological, or pathological, approach to assess need in the first instance. There is a growing body of knowledge suggesting such focusing solely on pathological diagnosis when assessing patient needs can create problems.[78–80]

Gallo proposed that we need a new system for classifying mental distress, since current pathological models of depression cannot explain the range of self-identified need.[81] Such an approach would draw on alternative explanations of distress than those described in a pathological account, and thus better support the needs of practitioners currently seeking to meet patient needs that sometimes fall outside of the knowledge base that practitioners gain from the pathological framework described within evidence-based medicine approaches.

We (MLW/JR) are currently conducting a study looking at the relative impact of depression and demoralisation on patient outcomes over time in a cohort of palliative care patients. This may offer further insight into the integration of different diagnostic approaches and thus to supporting the reality of daily clinical practice.

Current population level studies of risk are, therefore, constrained in their understanding of individual patient need. Future research is still needed to refine the individual concepts of depression and demoralisation including developing interventions. However, we also need a research stream focused on the application of these concepts in clinical practice. How in reality do clinicians use/apply the concepts developed in research; how do they integrate sometimes conflicting concepts; and what are the impacts for patients in terms of needs assessment and outcomes? And most important of all, how can we do it better?

Conflict of interest statement

None declared.

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