Improving the recognition of concerns and affective disorders in cancer patients

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Prevalence of affective disorders

Up to one third of patients with cancer will develop an affective disorder (generalised anxiety disorder, major depressive illness or an adjustment disorder) [1–5] regardless of disease stage [6, 7].

Key psychological factors include the following: difficulties patients have in coming to terms with the inherent uncertainty of their prognosis; a lack of practical or psychological support from relatives, friends and health professionals; the stigma associated with a cancer diagnosis and failure to find an adequate explanation for the development of the illness [8].

Treatment related factors include the development of body image problems, sexual difficulties and adverse effects of chemotherapy. Female gender and a past history of affective disorder are key vulnerability factors.

The influence of patients’ concerns

The number and severity of patients’ concerns in the first few weeks after a diagnosis of cancer predicts the onset of affective disorders. In a prospective study of 673 newly diagnosed patients with cancer, Parle et al. [9] found a strong association between the number and severity of patients’ concerns and the later development of clinical anxiety and/or depression. Patients reported a median of two major concerns with a range from 0 to 11. The most frequently reported concerns were ‘the illness itself and inability to do things’. Patients who reported they were worried by ‘feeling upset or distressed’, ‘feeling different from others’, ‘physical symptoms’, ‘masculinity and femininity’ were likely to have an affective disorder at the initial assessment. Only one concern independently predicted a subsequent affective disorder and this was lack of support as perceived by the patient. A similar association between the number of concerns experienced and the level of psychological distress was also found in a sample of 87 terminally ill patients [10].

Given the prevalence of affective disorders and influence of patients’ concerns, it is important to know how successful doctors and nurses are at eliciting them.

Detection of psychological problems

Craig and Aberloff [11] used the Symptom Checklist 90 to assess the prevalence of psychiatric morbidity in 30 patients consecutively admitted to an oncology unit. A quarter of patients had levels of psychiatric symptomatology similar to those found in patients referred to a psychiatric emergency service. Yet, it had gone undetected.

Derogatis et al. [12] sought to determine the nature and degree of discrepancies between cancer patients and their primary treatment physicians in their perceptions of manifest psychological symptoms. Twenty-three patients admitted to an oncology service were asked to complete the Symptom Checklist 90 within a week of admission. Within 3 days of that administration the treating physician was asked to use a 100 millimetre linear analogue scale to rate patients on key psychological symptoms. There was a clear tendency for depression to be underrated and anxiety overrated. Physicians were affected in their judgements by patients’ reports of personal inadequacy, self-depreciation and anxiety.

Hardman et al. [13] used the structured psychiatric interview to assess psychiatric morbidity in 126 patients consecutively admitted to a medical oncology unit. Those doctors and nurses who knew the patient best were asked to state whether they thought patients were suffering from clinical anxiety and/or depression. Of those patients found to have an anxiety state, 79% had been diagnosed correctly, but at the cost of labelling as morbidly anxious 40% of those patients who had a normal mood state as judged by the psychiatrist. The nursing staff recognised only 49% of those who had a depressive illness while the medical staff detected 40%. Even a specialist chemotherapy nurse, who saw the patients regularly, performed no better than her nursing colleagues.

Fallowfield et al. [14] assessed the ability of 143 doctors to establish the psychological status of 2297 patients during outpatient consultations in 34 cancer centres and hospitals in the UK. Prior to seeing the doctor, consenting patients completed a short self-report questionnaire [General Health Questionnaire (GHQ) 12] designed for the psychological screening of a large population. At the end of the consultation doctors completed visual analogue scales to rate patient distress. Of the 2297 patients, 837 (36.4%) had GHQ scores suggesting
depression and/or anxiety. The doctors’ sensitivity (true positive rate) was 28.87% [standard deviation (SD) 25.29], specificity (true negative rate) was 84.79% (SD 17.44). Their misclassification rate was 34.7% (SD 13.79) meaning that for 797 patients the wrong assessment was probably made.

**Failure to pick up patients’ concerns**

This failure to detect anxiety and depression is paralleled by health professionals’ inability to elicit patients’ concerns. In general, only 40% of newly diagnosed cancer patients’ concerns will have been disclosed in the follow-up year [9]. Similar rates of disclosure were found in patients being treated within hospices [10]. This failure to recognise anxiety and depression and elicit key concerns represents a major barrier to providing effective psychological care to patients with cancer.

The reasons for it need, therefore, to be understood. Both health professionals and patients contribute to the problem.

**Patient-led**

Patients consecutively admitted for the treatment of breast cancer [15] and patients with lymphoma [2] who had developed affective disorders but had not disclosed them were asked why they had failed to do so. Most patients were loath to disclose their problems because they believed that anxiety and depression was an inevitable consequence of having cancer and being treated for it. Anxiety and depression were viewed as understandable reactions. So there was no point in mentioning them, especially as they believed that nothing could be done. They worried that if they disclosed they were feeling anxious or depressed they would be viewed as ‘ungrateful’, ‘pathetic’ and ‘neurotic’ by the doctors and nurses caring for them. They correctly perceived that their carers were busy and did not wish to burden them further, especially when they had come to respect and like them.

Patients reported that their reluctance to disclose their mood disturbance was reinforced by the behaviour of health professionals they encountered. Few doctors and nurses asked them the kinds of questions that made them feel it was legitimate to disclose any psychological problems. They said they were not usually asked how they had been affected psychologically by diagnosis or treatment or what the perceptions were about their overall predicament. If they had undergone surgery, which involved the loss of important body parts or functions, they reported that it was rare for them to be asked how they had reacted to the surgeon and how surgery had affected their daily lives, mood state and personal relationships. In the absence of active enquiry, they believe, albeit wrongly, that health care professionals were not interested in these aspects of their experience.

Despite this lack of active enquiry by health professionals, some patients claimed they tried to give cues to the doctor; for example, by mentioning they were upset or worried. However, doctors and nurses seem reluctant to acknowledge and explore their cues further. Instead they attended selectively to physical aspects.

**Professional-led reasons**

Direct observations of interactions between doctors and nurses and patients with cancer during individual training in communication skills and of real consultations has confirmed that the patients’ claims were valid [16]. Listening to audio-tape recordings of their consultations during feedback sessions indicated that open directive questions like ‘how have you felt about losing the breast?’ were rarely asked. Questions about the patient’s perception of their predicament, for example, ‘how do you see things working out in the future?’ were asked by only one in 20 of the health care professionals involved. Only a third to one half of patients’ verbal cues about psychological aspects were explored. Instead they used interviewing strategies designed to avoid disclosure of emotion.

Butow et al. [17] studied how nine oncologists responded to verbal cues given by 298 cancer patients by analysing audio tapes of their consultation. They showed a marked selective attention, responding to 72% of informational cues but only 28% of emotional cues given by the patients.

**Blocking strategies**

The most common blocking strategies used by doctors are offering advice and reassurance as soon as the patient appears worried or distressed (‘There is no need to worry. Your cancer is localised. Let me tell you what we can do’). This reassurance is premature because the patient’s concerns about a breast cancer diagnosis have not been elicited.

Another common strategy is to normalise distress (‘I can see you are upset. Everybody is at this stage. Let me tell you what’s going to happen next’).

Switching the topic from an emotional to a medical issue is a particularly interesting strategy since sometimes it seems to happen without the doctor being conscious of it (doctor: ‘How are you feeling today?’; patient: ‘Am I dying?’; doctor: ‘How has your breathing been?’).

The common use of these strategies educates patients that the doctor does not want to elicit their feelings and the underlying concerns. It might be hoped that nurses would be less likely to block disclosure of emotions and concerns. Objective scrutiny of 54 cancer nurses each assessing a newly diagnosed patient, a patient with recurrence and a patient with terminal illness found that >50% of the nurses’ utterances were designed to block disclosure [18]. Consequently their coverage of patients’ psychosocial concerns was extremely limited or absent.

The reasons why doctors and nurses dedicated to cancer care block disclosure need to be understood if doctors and nurses are to be helped to relinquish them and respond constructively to cues about distress and concerns.
Reasons for blocking

Fears

Interviews with doctors and nurses [16, 19, 20] have established consistent reasons. Probing patients’ emotional reactions will unleash strong emotions. They will not be able to contain the distress, anger or despair and this will damage the patient psychologically.

Showing such interest in the patient as a person will encourage them to ask difficult questions like ‘why hasn’t chemotherapy worked?’ Exploring feelings and concerns will take up too much time and bring the doctor or nurse too close, emotionally, to the patients’ predicament. All these factors could threaten their own emotional survival.

This latter fear is supported by the findings of Ramirez et al. [21] in a study of 882 senior cancer doctors in the UK. Over 25% had high burnout scores as assessed by the Maslach Inventory. They were feeling exhausted emotionally, depersonalised and detached, and believed they were accomplishing little. Twenty-seven per cent were judged to have anxiety and/or depression on the basis of their responses to GHQ 12.

Burnout was more prevalent in consultants who felt inadequately trained on communication and management skills.

Inadequate training

An increasing number of doctors and nurses in cancer care acknowledge their lack of training in key communication skills [22, 23]. They have not learned how to quickly elicit patients’ concerns, and the associated feelings, and respond appropriately. Nor have they acquired strategies for helping patients who become very distressed or angry, ask difficult questions, find it difficult to cope with uncertainty or deny their diagnosis. So it is safer for them to attend selectively to medical matters and use blocking strategies in response to patients’ cues about concerns and feelings.

Support

The use of blocking strategies is greater when doctors and nurses feel undervalued as persons by the institution in which they work [18, 19] and worry they will not be offered practical help and advice if they encounter difficulties.

Development of effective training methods

If doctors and nurses involved in cancer care are to be more able to elicit concerns and recognise mood disturbance they need to learn strategies which will allow them to overcome patient barriers to disclosure and also develop more confidence in their ability to elicit patients’ concerns and distress and deal with difficult communication situations they encounter when delivering care.

Early work with General Practitioners [24] established that doctors able to distinguish patients with anxiety or depression were characterised by making good eye contact at the outset of the consultation, clarifying patients’ complaints, responding and exploring available cues suggestive of emotional distress, asking questions about patients’ feelings, enquiring about the situation at home, making supportive comments, handling interruptions well and maintaining eye contact at a reasonable level.

In a subsequent study [25] the value of directive questions inviting the patient to talk about specific areas, responding to non-verbal cues, being empathic, and the use of open to closed cones were also found to be important in distinguishing patients who had anxiety and depression from those who did not. Davenport et al. [26] found that verbal rather than non-verbal cues given by patients were the most indicative of psychological distress.

Work within child adolescent psychiatry found that parents were much more likely to give an accurate history concerning their children’s behavioural or psychiatric problems if they were asked open directive questions (‘How is he getting on at school?’), specified the topics they wanted to talk about rather than left it to the parents, requested detailed and exact information about any behavioural problems (‘What exactly happens when he has a tantrum?’) and repeated summarising and checking what patients have said [27].

Subsequent work showed that these communication skills were just as relevant to the cancer situation as to general practice and child and adolescent psychiatry. A validation study involving 206 health professionals attending 12 workshops on communication skills in cancer care confirmed that exactly the same behaviours promoted patient disclosure of concerns and cues about distress and mood disturbance [22]. Moreover it confirmed that inhibition of disclosure of concerns and distress was associated with the use of leading questions, closed questions, multiple questions, spending time clarifying physical aspects before any psychological questions are asked, asking questions with a physical focus only and giving advice and reassurance before the patients’ concerns have been elicited.

Training methods

There is a substantial literature in training medical students in interviewing skills [28] which confirms that if communication behaviour is to change health care professionals need an explicit model of the behaviours they have to learn, a demonstration of these behaviours in action, an opportunity to practice under safe conditions and receive explicit constructive feedback about their performance. They then require an opportunity for further practice and feedback.

The use of multi-disciplinary three-day workshops [29] has been found to help participants acquire most of the desired skills and relinquish most of the undesired behaviours. However, they are even more effective when attention is paid not only to the acquisition of skills, but also to the reasons underlying any blocking behaviours used by the doctors and
nurses when they practice key communication tasks in role-play [30]. Fallowfield et al. [31] considered that training would be more effective when carried out in a small group of four or five doctors or nurses. They also believe that it is important to pay attention to the feelings and concerns of the participants. In a recent study, 160 oncologists were randomly allocated to written feedback followed by a workshop, workshop alone, written feedback alone or a control group. They found that their intensive three-day training courses produced significant subjective and objective changes in key communication skills. However, as with the methods used by Maguire et al. [29] and those subsequently described by Parle et al. [30] there is still considerable room for improvement in their communication skills after training, suggesting that transfer of learning from the workshops was not as great as it might be.

Recent research by Heaven [32] studied the effect of workshop training of nurses as a single discipline followed by four sessions of clinical supervision in the workplace. This was compared with specialist cancer nurses given workshop training alone. There was little if any transfer from the group trained only in a workshop, whereas those given clinical supervision as well showed much more transfer, particularly in the area of acknowledging and exploring patients’ cues.

Razavi et al. (Razavi D, Delvaux M, Bredart A, Farvacques C, Sclachmuylder J-L, personal communication) carried out an ongoing and intensive course for nurses and looked at the extent to which they transferred their learning from these extended courses to the workplace. The nurses had practised with simulated patients. They found there was relatively little transfer to the workplace. It is likely that the most effective method of training doctors and nurses to elicit concerns and recognise mood disturbance would be intensive 3-day workshops followed by feedback in the workplace of actual performance.

It is also evident from current data that in addition to acquiring the positive skills to elicit patient concerns and relinquishing the inhibitory behaviours, doctors and nurses need to be taught specific probes about key symptoms of anxiety and depression. They also will have to be helped to overcome their inhibitions about asking these more personal questions, particularly those which seek to elicit if there is any risk of suicide (‘have you ever felt so low you have wanted to harm yourself?’, ‘have you ever got close to do anything?’, if yes, ‘what exactly have you tried?’).

Many attempts have been made to develop questionnaires that would replace the need for personal assessment by clinicians of their patient’s mood and concerns. However, none of them have been sufficiently accurate to be trusted in the clinical situation. At best, patients who score above the suggested thresholds on scales like the Hospital Anxiety and Depression Scale [4] will still need a separate clinical assessment because only two out of every five patients who score above the threshold will turn out to be true cases. So, there is no substitute for health professionals in cancer care being trained to elicit patients’ key concerns and to determine whether or not patients have developed an affective disorder.

References


