

# Psychosocial issues in cancer

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**There are many dimensions to psychosocial issues in cancer; two of which are focused here and relate to (i) the question of whether psychological factors play any role in cancer prognosis, and (ii) the quality of triage for serious psychological morbidity. These two may be inter-linked. If seriously depressed patients have a poorer outlook in relation to their length of survival then it is important to know whether depression gets diagnosed and treated. The view that psychological responses, such as depression, may be linked to disease course in cancer has always been controversial and never more so, than at the present time when medicine strives to be evidence based. That psyche or the 'mind' can influence somatic disorders such as cancer is perceived sometimes as a step back into the past when 'healers' or quacks practiced treatments that called upon the strengths of the 'mind' to effect a cure. So, what evidence is there that psychological variables impact upon cancer? What evidence is there that serious depression is accurately diagnosed? What is the best way to treat diagnosed depression in people with cancer? The evidence will be summarily reviewed.**

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## Does psychological response influence survival and if so, how?

A few studies have examined the influence of psychiatric symptoms or coping style on disease outcome in cancer patients. The presence of psychiatric symptoms was significantly related to good outcome in one study<sup>1</sup> and to poor outcome in three studies<sup>2-4</sup>. In terms of coping style or personality only a few studies have examined these using scientifically sound methods. One highly influential study suggested that breast cancer patients with a fighting spirit had improved survival at five and ten years follow-up and those showing a helpless or hopeless response did less well in terms of overall survival<sup>5</sup>. However, this study was under-powered, including less than 60 patients. The results were also confounded by disease stage. Of the breast cancer patients included, those with stage I and II disease were combined; information on lymph node status was unavailable at the time of study inception. The evidence on the impact of psychological response has remained equivocal. More recently we have studied the impact of coping style and depression on disease outcome

in a large cohort of breast cancer patients<sup>6</sup>. After controlling for disease stage and other known prognostic variables, we were able to ascertain that helplessness/hopelessness and serious depression had an adverse impact on survival at five years follow-up. The coping response of helplessness and hopelessness can be considered a focal symptom of serious depression and thus these data provide some sound evidence that more serious depression can impact on cancer prognosis. These results require replication by other research groups.

It is often assumed that the mechanism linking psychological response to poorer disease outcome involves direct biological connections. The psycho-biological model for these effects argues that it changes in stress hormones and their interaction with the immune system that impacts on the course of cancer to bring about changes in disease prognosis. Up or down regulation of the immune system has been suggested as the mechanism for any differences in disease prognosis. The evidence to support this model remains sparse and finding good methods for assessing the effect of the immune system on cancer remains a challenge. A pragmatic explanation might relate to the way in which symptoms of helplessness and depression affect behaviour. Cancer patients with serious depression are more likely to be non-compliant with cancer therapy, more likely to have cancer treatments delayed or reduced, will eat and sleep less well, have poorer self-care, be less vigilant about disease symptoms and less able to use proactively those resources that might bring health improvements. However, our evidence for an adverse impact of helplessness and depression on disease outcome in breast cancer suggests that improving triage and treatment of depression may improve quantity as well as quality of life.

## Triage and treatment of serious psychological problems in routine practice: How good is it?

Psychological care of cancer patients should be an integral part of their medical care and available at all stages of their treatment. However, it is not clear what might be the best model of care, whether one model suits all circumstances, and how psychosocial care services can be delivered most effectively when resources are extremely limited. It is likely that any recommendations for integrating psychological care into routine oncology practice will have training and resource implications. Any change in service development, therefore needs to be strongly

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evidence-based. The aim here is to make a brief review of evidence on;

- known *level* of psychological morbidity;
- *detection/diagnosis* (i.e. triage) of psychological morbidity, and
- future *priorities* based on the literature.

### *Level of psychological morbidity*

Evidence on level of psychological morbidity among cancer patients is variable depending on methodological factors such as type and timing of assessment. One frequently cited study<sup>7</sup> placed the level of psychological morbidity at 47% of patients surveyed. However, this level of distress also varies depending on type of diagnosis, disease stage and gender. Adjustment disorder with anxiety and depression is the most frequently reported psychiatric diagnosis but problems can be wide-ranging including major depression, organic mental syndromes (e.g. dementia), relationship difficulties, sexual dysfunction, body image disturbance, familial, vocational and occupational disruption, and phobias.

A recent meta-analysis indicated that the level of serious psychiatric problems in cancer patients does not differ from the general population with the exception of depression, and this remains higher<sup>8</sup>. In a review by Sellick and Crooks<sup>9</sup> they conclude that serious depression is found in 6–15% of the cancer patient population as a whole across the various studies reviewed. These prevalence rates for depression will also include those cancer patients who were present with either pre-existing depressive disorders or previously undetected depressive illness not necessarily caused by having cancer.

Levels of depression tend to be higher among cancer patients than those found in the general population at all points. The prevalence of depression in the general population lies between approximately 3–19% depending on whether it is one year or lifetime prevalence rate which is being reported and the specific diagnostic criteria (e.g. DSM, SCID) being applied. Medical illness has also been associated with a 41% higher prevalence rate of psychological morbidity relative to those with no medical disorder<sup>10</sup>. Not treating moderate depression has long-term implications as it has been estimated that 80% of those with less severe symptoms of depression (i.e. Dysthymic Disorder) will go on to develop major depression if left untreated<sup>11</sup>. Massie and Holland<sup>12</sup> indicated that depression in cancer patients was persistently under-diagnosed and under-treated. More recent evidence confirms this persistent under-diagnosis of depression<sup>13</sup>. Symptoms of depression not only have an impact on quality of life but also on the patients' ability to self-care and to tolerate cancer treatments. Untreated psychological morbidity has also been linked with more frequent out-patient attendance, longer in-patient stays and increased visits to the

community doctor, suggesting that effective detection and treatment of psychological problems is likely to be more cost-effective than allowing them to go undetected and untreated<sup>14</sup>. The cost to families is also great not only in terms of the mental health of family members but the additional stress, both emotional and financial, placed on families who must cope with a depressed relative with cancer.

Distress is common among recently diagnosed patients and this has been highlighted as a period of special need for emotional support<sup>15</sup>. However, some of this distress is transient and may remit without any additional intervention. Therefore, it is important to distinguish between transient and normal levels of low mood and abnormal levels of depression or anxiety.

Very few studies have broadened the assessment of psychological morbidity so that it includes information on the type of problem causing the distress observed, although it is often implicit that it is the burden of cancer that is the primary contributor. It is likely that the more seriously depressed patients carry a heavy burden in the form of other life stresses of which cancer may be only one. In order to develop an effective psychosocial treatment plan and facilitate decision-making in terms of type of support needed, it is also necessary to understand more about the presenting problems contributing to the accompanying symptoms of anxiety or depression. There is no doubt that high levels of anxiety or depression are symptomatic of existing problems but knowing the specific underlying causes will be more informative when it comes to management decisions. Therefore, a short checklist of problems could be integrated into routine case history taking only for those patients where there is evidence of significant distress.

It is also important to bear in mind that not all patients with distress want, or can pay for, professional help. Service users' preferences and financial resources need to be taken into account. Greer and colleagues<sup>16</sup> using the Hospital Anxiety and Depression Scale as a brief screening tool in a cohort of recently diagnosed cancer patients, detected a 22% combined rate of anxiety and depression, however, when patients were approached a few days later and offered entry to a randomized trial of psychological therapy, as many as one third of those showing a high level of distress declined. Some gave practical difficulties limiting their ability to attend the hospital for the purpose of the therapy sessions but many simply indicated that they did not want any professional help. Stigmatization from using mental health services, misconceptions about the nature of the service, and the availability of other resources, may be some of the factors that contribute to this non-uptake as well as the inability to pay where the service cannot be offered free of charge.

*High risk periods:* The time around the diagnosis of cancer is acknowledged as a period of increased distress

for the majority of patients. A number of studies also draw attention to the high levels of distress beyond the period of initial diagnosis. Goldberg *et al.*<sup>17</sup> found high levels of anxiety and depression in approximately 25% of breast cancer patients at 12 months following initial diagnosis. There is evidence that this level can persist for up to two years or more after diagnosis<sup>18-19</sup>. Levels of depression and anxiety can also be higher in those patients with advanced disease<sup>20</sup>, with pain being an important contributory factor. Pain and depression are likely to interact and management of one without the other is unlikely to produce satisfactory results. In the palliative care setting psychological care is now increasingly recognized as a priority and integral to good patient management. The majority of cancers still remain incurable, emphasizing the important role for psychological care that aims to improve quality of life, especially in those who are terminally ill.

Taking the evidence altogether it is now possible to conclude that brief routine screening of cancer patients for depression and anxiety should be implemented within standard clinical practice. This screening should preferably be undertaken at the time of diagnosis, end of primary treatment, or time of relapse where this occurs, and should be *routinely* established in the terminally ill. *Depression in the terminally ill should be treated as vigorously as for those patients with a better cancer prognosis. All staff should have basic skills to determine if there is any suicidal risk so patients may be managed appropriately.* A few basic questions for determining if the patient intends suicide have been described by Burton and Watson<sup>21</sup>;

- does the patient have a plan for suicide?
- how lethal is that plan?
- under what circumstances might they carry it out?
- how likely does the patient think it is that they will act on the plan?

Patients at increased risk of suicide may have a previous history of suicide attempts, have suffered a recent loss such as bereavement, are often socially isolated and may have other chronic problems such as housing or financial difficulties.

Where resources allow, screening should continue at routine follow-up. Where possible, patients showing high levels of anxiety or depression should be assessed further to determine the specific underlying problem. This accumulating, and now substantial evidence on levels of psychological morbidity and usefulness of screening tools, contributed to the recent release in the United States of a consensus statement with recommendations for national guidelines on psychosocial care in cancer<sup>9</sup>. Some of these recommendations are:

- the introduction of psychosocial screening for all new patients;

- additional screening for patients at high risk of psychological morbidity;
- training professionals so that they can understand cues for distress.

#### *Detection of psychological morbidity and methods of screening*

If cancer services are to include routine methods for the detection of distress it will be necessary to ensure that evidence-based practices are developed. In this respect it is important to determine what conclusions can be drawn from the existing literature on the efficacy of psychological screening in detecting distress.

The majority of studies have focused on establishing the most effective method of detecting serious levels of anxiety and depression and there now exists a substantial literature on this topic. Generally methods of screening fall into two categories; (a) use of a brief semi-structured interview or (b) use of a psychometrically sound standardized questionnaire. The use of these methods has produced variable results but there are trends in the data. One of the earliest studies<sup>22</sup> indicated that doctors detection rate of psychological morbidity was low (22%) when compared with that of a nurse with specific training in use of a mental status examination (89%). Sensky<sup>23</sup> while claiming good rates of detection based this on patient-doctor correlations of 0.21–0.33. On the other hand, Slevin<sup>24</sup> reported a poor detection rate based on patient-doctor correlations of 0.31–0.50, suggesting differences in interpretation of 'effective' detection. Differences in detection rates also vary depending on whether it is sensitivity or specificity which is being reported (sensitivity is the ability to detect the presence of distress and specificity, the ability to detect the absence of distress). Evidence shows that staff consistently over-estimate, or show a high detection rate, for anxiety but a poor detection rate for depression<sup>25-29</sup>. Passik<sup>13</sup> noted a marked tendency by cancer doctors to under-estimate the level of symptoms in the more seriously depressed and explained this in terms of their use of indicators of depression. Depression ratings were influenced by crying, depressed mood and medical factors rather than by more reliable indicators such as anhedonia, suicidal thinking and hopelessness. Furthermore, while oncology staff may be good at identifying anxiety they are poor at identifying frequency and importance of problems.

Standardized questionnaires have been used in a number of studies although many of these measures may have inflated the true rates of psychological morbidity because they failed to take account of the physical symptoms assessed which can be explained by both depression and anxiety or cancer disease and treatment side-effects. More recently this problems has been recognized and there has been a move toward using measures of depression and anxiety which exclude biasing items measuring somatic

symptoms. Payne<sup>30</sup> evaluated breast cancer patients using three brief screening methods; a visual analogue scale, the Hospital Anxiety and Depression Scale (HADS) and the Brief Symptom Inventory and found that all three were equally effective. Razavi<sup>31</sup> found the full-scale score of the HADS to be effective in detecting serious morbidity. Moorey *et al.*<sup>32</sup>, examining the structure of the HADS in a large sample of cancer patients, concluded that it is best used in the format originally recommended by the test authors with separate scoring for depression and anxiety rather than combining these scores. Although there has been disagreement about the sensitivity and specificity of the standard cut-offs for serious psychological morbidity, which varies depending on disease stage, the HADS performs well overall and remains the screening method of first choice in oncology.

Recognising any shortcomings of the HADS is not a basis for rejecting it as a screening tool. Rather it means that we are better able to take these factors into account in our interpretation of scores. It is unlikely that other brief questionnaire-based screening tools perform significantly better and the study of Payne *et al.*<sup>30</sup> confirms this view.

In the review by Sellick and Crooks<sup>9</sup> it is concluded that good practice guidelines should include screening of 'every new cancer patient for symptoms of depression using a valid instrument such as the HADS, or Beck Depression Inventory . . . the General Health Questionnaire may be of use to identify general psychosocial distress'.

There have been a number of methodological problems with studies evaluating detection rates. For some, the patient samples are too small to draw confident conclusions and in many the number of staff raters has been too low. Often a convenience sample is used without attention to the timing of assessment. Where one or two staff are rating many patients this may introduce a biasing effect. This is clearly illustrated by the study of Ford<sup>33</sup> where the detection rate was based on a doctor-patient correlation of 0.48-0.85 for one study doctor and -0.24-0.16 for the other study doctor, thereby highlighting the need to take into account any significant rater differences. Ratings of many patients by one staff person also fail to reflect what happens in clinical practice where patients may be seen by many different staff. The impact of raters' gender and their level of knowledge of the patient are often either overlooked or poorly controlled for in these studies. Yet these factors will influence the detection rates for psychological morbidity. Differences between staff raters is under-investigated, as too is the possible contribution of professional role. Comparisons of group mean scores for detection rates is also less helpful than comparisons based on doctor-patient dyads.

### Research priorities

An important priority is to improve the rates of detection of psychological morbidity in cancer patients and the

detection of depression in particular. Rates of depression are known to be higher in cancer patients than in the normal population. There is a failure to detect and treat depression in cancer patients which is likely to impact not only on patient quality of life but on the effective implementation and delivery of cancer treatments. Holland and Rowland<sup>34</sup> pointed out some time ago that much of the responsibility for provision of psychological care will fall on the oncology staff and, indeed, all oncology staff need to be able to provide some level of psychological care for their patients. Although much of this psychological care is within the scope of routine oncology practice, criteria and guidelines for referral on to specialist mental health services are required for patients with difficult psychological problems. The majority of cancer units are likely to be failing to meet even minimum standards in this respect at present but centralization and rationalization of cancer services provide an opportunity to develop and test best models of service to remedy this gap in provision.

*Impact of screening on resources:* The introduction of psychological screening is often approached with apprehension as many oncology professionals consider that they do not have the resources to meet the increased service needs created. Don't look for a problem that you can't solve is a common belief. However, there are two points worth considering; firstly, better use of already existing resources is possible if properly targeted and utilized. Secondly, although evidence shows that level of moderate psychological distress may be high at some points, more serious psychological morbidity affects only a minority of patients. Brewin *et al.*<sup>35</sup> found approximately 4% of cancer patients screened in their survey met DSM IV diagnostic criteria for major depression and Grassi and Rosti<sup>36</sup>, taking both major depression and dysthymia together, found a prevalence rate of 15%. This more serious psychological morbidity requires effective provision, and access to existing liaison mental health services is helpful. Knowing who needs this specialist level of care is an essential aspect of good practice in oncology.

### How do you treat serious depression in cancer patients?

Some of this depression can be treated effectively through use of anti-depressants. Such treatment is within the scope of routine oncology practice. Training aimed at improving the cancer doctor's confidence in using anti-depressants, alongside cancer therapies, is likely to be an extremely cost-effective intervention.

There is now very clear evidence that brief problem-focused psychological intervention can bring an improvement in quality of life and help reduce symptoms of depression and anxiety<sup>37</sup>. There is also evidence that these

treatments can be provided by the medical and nursing staff under the supervision of the clinical psychology or liaison psychiatry staff<sup>38</sup>. Only the most serious and complex cases will need the input of specialist mental health professionals.

Given the multidisciplinary nature of cancer treatment and the tendency for patients not to be seen by the same doctor or nurse throughout the whole cancer treatment programme, the importance of using reliable and valid screening methods is underlined. These should be robust enough to be applied with confidence by different professionals in different contexts.

Screening should involve two steps. *Step one*: aims to determine those who need more detailed assessment in order to conserve the time and resources needed to make a full assessment of problems; *Step two*: aims to determine the specific nature and level of distress so that decisions can be made regarding when, how and where this can be managed within routine cancer care and when referral on to specialist services is required.

The aim would be to use a brief screening method as triage following which a checklist would be used to determine action needed. Some of these issues on detection and diagnosis have been covered in detail by Burton and Watson<sup>21</sup>.

## Conclusions

It is likely in the future that cancer doctors and nurses will need to improve their skills in the detection of psychological morbidity and especially serious depression. Although screening questionnaires may be useful; an alternative would be to integrate screening questions into routine history taking by medical or nursing staff so that they become confident in asking a few key questions which will allow them to determine if there are serious mental health problems in their patients. They may feel better able to make decisions as to whether these problems can be managed within local resources or require referral on to other agencies. It is also important to clarify training needs and service user preferences.

Serious depression may impact on cancer prognosis. Accurate detection and treatment of depression may improve survival in cancer patients and is likely to improve quality of life; it is a laudable aim that all cancer doctors and nurses should not only be able to communicate effectively with their patients but know how to diagnose serious depression. The financial costs of providing training for these skills will be offset by the savings that occur through improved patient compliance with cancer treatments, reduced hospital and clinic visits and improvements in the patient's and their family's ability to

provide care from within their own resources in their community.

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