INTEGRATED CARE

Mental health needs in cancer – a call for change

Authors: Asanga Fernando,[A] Marisa Tokell,[B] Yostina Ishak,[C] Jenna Love[D] Matthias Klammer[E] and Mickey Koh[F]

ABSTRACT

There is continued under-recognition and underinvestment in the psychological and mental health aspects of care for cancer patients, despite the fact that increased patient survival rates in cancer mean that patients are living longer after diagnosis. In this article, we advocate for better integration and joint working between clinicians across all areas, including education and research, impacting positively on the outcomes and care of cancer patients.

KEYWORDS: cancer, oncology, haematology, mental health, integrated services, psychiatry, psychology, commissioning, medical education, simulation

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Introduction

The complex and dynamic landscape of oncological treatment is ever-changing, with recent advances across oncological, haemato-oncological, surgical and radio-therapeutic techniques improving patient survival rates across tumour types. Yet it is clear that efforts have primarily been dedicated to furthering treatment within the biomedical sphere, at a time when patients are living longer with and beyond cancer, with continued under-recognition and underinvestment in the psychological and mental health aspects of care for cancer patients. It is obviously important to highlight that the COVID-19 pandemic has added to the burden on patients' mental health, enforcing isolation during the often-prolonged inpatient admissions associated with oncology. Furthermore, pandemic-related delays in diagnosis have had a huge impact on the frequency as well as the severity of cancer-related psychiatric problems.

This article has brought together authors working in oncology and psychiatry to advocate for better clinical integration and to explore joint working that goes beyond this to education and research, impacting positively on the outcomes and care of cancer patients.

The epidemiology of psychiatric morbidity in cancer patients

Data show that the prevalence of depression and anxiety among cancer patients is up to 20% and 10% respectively, regardless of the treatment phase or point in the disease trajectory.[1] Moreover, 35–40% of cancer patients have a diagnosable psychiatric disorder according to ICD-10 criteria,[2] which undoubtedly has a deleterious impact on their quality of life while also increasing healthcare costs.[2,3] A recent comprehensive analysis of 183 studies over the past 20 years also offers a concerning global picture: the prevalence of depression among cancer patients was estimated to be 27%.[4] This marked increase from earlier reports[5] along with an escalating trend over the years[6] prompts an urgent call for comprehensive and integrated care that encompasses both oncology and mental health.

The origins of mental health issues among cancer patients are multifactorial and wide-ranging. While the burden of depression and anxiety in cancer patients is considerable and well-documented,[1,4–6] cancer patients also face a wider array of psychiatric disorders. These include stress-related, neurocognitive, adjustment and somatic symptom disorders,[2] as well as neuropsychiatric manifestations including psychosis caused by neuroplastic lesions,[7] psychiatric changes associated with paraneoplastic syndromes,[8,9] and drug-related psychiatric symptoms. Each of these conditions poses significant risk to overall cancer treatment engagement and, in turn, both mental and physical health outcomes.

This potential risk becomes apparent in studies indicating that the prevalence of suicide in cancer patients is 20% higher than those without cancer, particularly during the crucial 6 months following diagnosis.[10–12] A cancer diagnosis – regardless of tumour type – often involves an intense treatment regime and times where prognosis and associated quality of life remain filled with uncertainty. This inherently amplifies patients' susceptibility to psychological distress and mental health crisis. This estimation of risk is, however, variable; it reflects that different tumour types have different profiles with regards to the prevalence of associated mental illness and may be influenced by factors, including pain and ability to perform vital functions such as eating and breathing[11] (Table 1).

Authors: [A]consultant cancer liaison psychiatrist and clinical director, St George's University Hospitals NHS Foundation Trust, London, UK, and honorary senior lecturer, St George's, University of London, London, UK; [B]medical student, Newcastle University, Newcastle, UK; [C]senior clinical pharmacist, St George's University Hospitals NHS Foundation Trust, London, UK, and clinical pharmacology tutor, St George's, University of London, London, UK; [D]clinical psychologist, St George's University Hospitals NHS Foundation Trust, London, UK; [E]consultant haemato-oncologist, St George's University Hospitals NHS Foundation Trust, London, UK and honorary senior lecturer, St George's, University of London, London, UK; [F]professor of clinical haematology, St George's University Hospitals NHS Foundation Trust, London, UK, and St George's, University of London, London, UK

Table 1. Estimated increases in suicide rate compared with the general population according to tumour type

Tumour type	Risk of suicide (SMR)[10]
Mesothelioma	4.51
Pancreatic	3.89
Oesophageal	2.65
Stomach	2.20
Cancer of unknown primary	1.86
Colorectal	1.30

SMR = standardised mortality ratio

Various factors, including demographic information such as location and sex, also influence the two- to three-fold increased risk of psychiatric disorders compared to the general population.[13,14] For instance, some studies have found that female cancer patients may be more susceptible to anxiety and depression[15,16] during their cancer journey and that individuals residing in rural settings may experience poorer mental health than to those living in urban areas.[17,18] There is a clear need for physicians, psychiatrists, health economists and policy analysts to advocate together with patients and carers for more research on the demographic factors implicated in cancer care and more broadly across healthcare.

The psychiatric impact of cancer-related treatments is often poorly understood, leading to significantly deleterious impacts on the quality of life of patients as well as carers. As oncological treatments continue to evolve rapidly, it is important that there is due focus on how these treatments impact the quality of life of cancer patients, of which a key component is mental health. This applies to existing oncological therapies as well as to novel and emerging therapies, such as immunotherapies, with their associated neurotoxicity, and CAR-T cell therapies. For example, high-dose steroids have significant adverse impacts on patients' mental health, including manic, psychotic, or hypomanic symptoms which are likely dose-related in nature and significantly increase the risk of patient harm.[19,20]

The case for better clinical integration within cancer care

This need for investment in providing clinical services for those with cancer-related mental health sequalae is evident not only in this observed knowledge gap, but also in NICE guidance[21] and regional commissioning guidance,[22] which indicates that approximately 25% of cancer patients will require formal psychological or mental health support in the first year following a cancer diagnosis. While formal NICE guidance in this area seems to stop abruptly at diagnosis, it is evident that the need for mental health input increases through a patient's cancer journey, with 9% of patients expressing suicidal ideation at their first outpatient appointment, escalating to approximately 36% in end-of-life stages.[23,24]

The under-recognition and associated undertreatment of depression in cancer patients remains perhaps the most pressing and urgent issue of relevance to cancer patients and their families; studies demonstrate that 73% of cancer patients with a diagnosis of depression are not receiving potentially beneficial care for their depression.[25] A recent study[19] also reaffirms that cancer patients with comorbid mental health concerns are reluctant to seek professional mental health support, with a range of contributory factors underlying this; effective strategies to address this will need to be coproduced by clinicians and patients.

Patients with haematological cancers are no different to patients with solid tumour pathology, and experience strong challenges to their mental health resulting from drug-induced neurotoxicity and from the duration and intensity of the chemotherapy regimens often required, particularly in acute leukaemias, aggressive lymphomata and multiple myeloma. A recent study elucidated that higher levels of psychological distress and poor mental health are associated with a low level of quality of life in a cohort of mostly older patients with chronic haematological disorders.[26]

Prolonged and intensive chemo-immunotherapeutic therapies for younger patients with aggressive haematological malignancies often incorporate autologous or allogeneic stem cell transplantation. Associated risks to the patient's mental health include long inpatient stays and a step-up in dose intensity of therapeutic agents used. A prospective 3-year inpatient single-institution study[27] in patients admitted for haematopoietic stem cell transplantation determined that overall prevalence of psychiatric disorder was high at 44.1%, with an adjustment disorder in 22.7%, a mood disorder in 14.1%, anxiety disorder in 8.2% and delirium in 7.3%.

A recent large, population based dataset[28] using the US Surveillance, Epidemiology and End Results (SEER) Program, linked to Medicare claim data, assembled a cohort of 13,244 patients aged 67 and above with lymphoma and focused on anxiety and depression. The authors found that a high proportion (one in six) of patients had been diagnosed with either condition in the 2 years preceding their lymphoma diagnosis and that this was associated with inferior overall survival and lymphoma-specific survival. As possible reasons for this, the authors propose barriers to access, delayed cancer treatments and reductions in adherence. The study supports the growing awareness that clinicians should undertake comprehensive psychosocial assessments at diagnosis.

Patients undergoing haematopoietic stem cell transplantation (HSCT) have a well-documented series of psychological sequlae stretching across the entire multi-episode transplant process from donor selection to long-term follow up. Patients assigned to receive an allogeneic HSCT experience the anxiety associated with identifying a matched donor, who may be a sibling, and with uncertainties over their willingness to donate. This is often followed by an isolating hospital admission for the transplant followed by the uncertainty of waiting for the donated stem cells to successfully engraft. Following initial engraftment, the uncertainty of secondary graft failure remains even up to 3 months post-transplant. This is in addition to the restricted lifestyle imposed for up to a year following the transplant while waiting for the immune system to sufficiently recover, during which time there remain restrictions relating to food, activity and social interaction; this is all unique to the long timelines of HSCT. In addition, there are early and late HSCT-specific complications, some potentially life-threatening and which can extend for years post-transplant, exacting a considerable psychological strain on the patient. Some of these serious complications, like chronic graft-versus-host disease (GvHD), which can manifest 1–2 years post-transplant as extensive sclerotic skin changes, can result in joint movement restrictions and body image issues. Chronic GvHD is also an immune-mediated multi-system disease which can affect nearly every organ in the body. Treatment related to HSCT often involves the need for immune suppression like high dose steroids which can also result in considerable psychological side effects in patients. The need for lifelong follow-up and monitoring post-HSCT adds to the ongoing psychological impact of the disease and the treatment on the patient. Depending on the age at transplant, there are also potential issues related to growth, puberty, onset of menopause and even blood group changes, which can exert considerable psychological stress on the patient. As such, there is a high prevalence of psychological distress and diagnosable psychiatric illness, including depression symptoms (~35%), delirium (~35%), and PTSD symptoms (~20%), is reported by these patients and observed by their clinicians.[29] Psychological distress in HSCT patients is associated with worse health outcomes including increased mortality and higher risk of GVHD.[30]

Increasingly, due to the diverse range of psychological challenges that have been observed at different stages of the transplant process, it is recognised that formal psychological assessment of a patient intending to proceed to a transplant should be strongly encouraged and possibly mandated as part of the pre-transplant workup for eligibility and suitability. Early identification of patient vulnerabilities to psychiatric comorbidities can also facilitate timely diagnostic assessment and treatment. Post-transplant follow-up care is often multidisciplinary and continued access to such formal psychological support is also proving to critical to comprehensive patient care.

The cumulative burden of the unmet care gap

Overall, a significant proportion of cancer patients report a disconnect between the attention given to their physical needs versus their mental health requirements. Studies indicate that 58% of cancer patients feel their emotional needs are less acknowledged than their physical needs.[22] Moreover, the psychological shadow of cancer treatment continues to loom over survivors; even a decade later, up to 54% of cancer survivors (over one million individuals alive in the UK today) still grapple with at least one psychological issue.[22]

Furthermore, the most recent cancer experience survey reports that only 27% of patients felt they could receive adequate emotional support at home from community or voluntary services after their treatment.[31] Beyond the individual impact, cancer also profoundly affects carers and families, finances, employment, sexual functioning and relationships.[32] Therefore, the critical role of mental health in enhancing patient experiences, quality of life, overall functioning, and ultimately survival outcomes necessitates the recognition and remediation of this gap in cancer care.

It is also important to highlight that many symptoms suffered by cancer patients, such as fatigue, have psychiatric and psychological components that better integration will allow better recognition of, as well as likely improved knowledge in terms of management.[33]

In summary, while there have been monumental leaps within the biomedical sphere of oncology, there remains a stark disparity when it comes to the provision of integrated mental health care for cancer patients. The empirical evidence revealing the high prevalence of mental health issues, including depression, anxiety, severe mental illnesses and neuropsychiatric disorders among cancer patients, warrants an urgent call for a more holistic approach. As demonstrable evidence for integrated psycho-oncology services emerges,[2,34]

Box 1. Case vignette: The role of cancer psychiatry in the assessment and management of comorbid serious mental illness impacting on cancer care

Background

RB is a 61-year-old man with a diagnosis of non-small cell lung cancer – specifically adenocarcinoma with brain metastases. He has not attended his last two clinic reviews and has disengaged with his lung cancer clinical nurse specialist.

Additional psychosocial information

RB has been stable with regards to his schizophrenia over the past few years, and compliant on oral antipsychotic treatment prescribed by the GP. He has not been under the care of a community mental health team for several years due to his recent stability in mental state. He lives at home alone, having separated from his wife, who lives with their son approximately 20 minutes away. He does not smoke and until recently has maintained functioning and is able to carry out activities of daily living independently.

What cancer psychiatry can add

RB has pre-existing schizophrenia which had been well controlled. However, it is possible that the impact of cancer has resulted in a reduction in functioning and has contributed to reduced compliance with his antipsychotic medication, which in turn has led to a psychotic relapse. A psychiatrist can liaise accordingly with the patient and their GP, assessing mental state and potentially involving community mental health services if warranted on the grounds of severity of relapse and associated risk to themselves or others.

Furthermore, a psychiatrist who is embedded in cancer care will have an enhanced understanding of the cancer-related factors that may be exacerbating his mental state; for example, they may be aware that he has recently been started on a higher dose of steroids on account of his brain metastases, and that this has triggered a probable steroid-related mood disorder/psychosis. This in turn needs addressing in terms of monitoring mental state for both positive and negative psychotic symptoms and paranoia, considering a possible reduction in steroids in conjunction with oncology and deciding whether antipsychotic medication is required.

In addition, a psychiatrist embedded within oncology is more likely to be able to work closely with the clinical nurse specialist and other members of the team with whom the patient has rapport, such as support workers. Once there has been appropriate stabilisation and monitoring of mental state, the psychiatrist can draw on their understanding of how schizophrenia affects patients' cognition to help these colleagues improve the patient's engagement with cancer services. Practical measures that could be facilitated could text message reminders, or a support worker accompanying the patient for the visits to phlebotomy/pharmacy that are integral to his cancer care.

Furthermore, an embedded cancer psychiatrist can also respond in real time to changes in clinical presentation, as well as referring if needed to other services (such as financial support, nutrition etc), facilitating the provision of holistic care.

Box 2. Case vignette: the role of embedded cancer psychology, working together with cancer psychiatry and haematology in risk management

Background

TN is a 56-year-old Black British woman who has been diagnosed with IgA multiple myeloma and has been treated with CVD chemotherapy to a stringent complete response and then consolidated with an autologous stem cell transplant. During the admission for the stem cell transplant, she described feeling very low in mood and overwhelmed about her condition and expressed some intermittent suicidal ideation. She was experiencing widespread pain, which was partially controlled with analgesia, and also nausea and vomiting related to the chemotherapy, and was struggling with being isolated in the ward and away from friends and family. The consultant on the ward, who knew the patient well, spoke to the patient and completed a risk assessment, as well as reviewing management of the pain and nausea. On the basis of the risk assessment, the medical team felt she had no specific plans to harm herself at that time, but was feeling very overwhelmed and anxious. A referral was made to the cancer psychological support service comprising both specialist cancer psychiatry and cancer psychology.

What integrated cancer psychological support can add

Upon being referred to the cancer psychological support team, an assessment identified a number of social and psychological factors that were exacerbating the patient's distress, including a longstanding tendency towards anxiety and a lack of social support.

While there was some ongoing dynamic risk that cancer psychiatry would monitor, it is important in a scenario like this to recognise the interplay of psychological factors contributing to her dynamic risk. The patient had been working prior to the diagnosis of myeloma, but had to stop work due to the treatment and onset of widespread pain and had a number of financial concerns. With the patient's consent, relevant information was shared with the team to support them in caring for her, and she received a referral to support with benefits. It became apparent that the patient found it difficult to understand all the information provided during discussions with her medical team and had a number of worries that she hadn't raised with the medical team, and this was adding to her distress. A multiprofessional meeting was arranged, including the patient, the haemato-oncology team, the cancer psychologist and the cancer psychiatrist, where the medical information was discussed again and the patient was supported in assimilating this information. The clinical psychologist, being integrated in the haematology team, had a good knowledge of stem cell transplantation and the psychological consequences that could arise, and could provide outpatient psychological input post-discharge to support with management of longer-term effects, including fatigue and ongoing anxiety and depression, providing continuity of care and ongoing integration with the psychiatry and medical teams.

oncological services must undergo a paradigm shift towards an era of comprehensive cancer care era recognises, prioritises and addresses mental health concerns. Box 1 and Box 2 outline clinical vignettes that illustrate how this could work in practice.

Integration beyond the clinical

While the case for clinical integration between cancer care and mental health services has been set out by patients, policy and the evidence base, there is a compelling argument that medical leaders should aim for integration that goes beyond the clinical, into the spheres of research, quality improvement and educational opportunities. It is clear that oncologists may not receive adequate training in dealing with behaviour that challenges in oncology patients,[19] despite the benefits of educational training in the management of mental illness, including training using the modality of innovative, experiential high-fidelity simulation, having been well documented across professions and contexts.[35–37] This is an important and overlooked area, with effective, evidence-based guidance and training available.

Heeding this call, the authors have developed pioneering interprofessional simulation programmes across oncology, palliative care and mental health that have proven beneficial both locally, and in terms of influencing practice nationally, improving the confidence and knowledge of medical and nursing personnel including oncologists and oncologists-in-training in the assessment and management of cancer-related mental health sequalae, which will undoubtedly have positive impacts on the assessment and management of comorbid mental illness in cancer patients.[38]

Indeed, behaviour that challenges often impacts upon patient cancer engagement, and all too often falls to psychiatry teams to manage, sometimes inappropriately. Verbal de-escalation as well as honest and clear communication are clearly the responsibility of all clinicians and while it is important to seek guidance for specific rapid tranquilisation and pharmacological management of agitation, oncologists should attempt to verbally de-escalate agitation in a manner that maintains and promotes trust and autonomy.

Furthermore, it is important to highlight that the aforementioned educational interventions have not only succeeded in improving knowledge and confidence levels in attendees but have also brought together a faculty of cross-disciplinary community of clinicians who have sought to maximise the integration that they have established educationally, and develop further multiprofessional training opportunities together, such as during the COVID-19 pandemic.[39] Finally, the case for integration going beyond the clinical is made clear by the fact that communities of practice, brought together by educating and teaching together, can be powerful advocates for further research, audit and quality improvement within their own clinical practice, helping to drive change and constant service improvement.[40]

Conclusions

This article makes the case for more effective clinical integration of services that addresses the clinical need for counselling, specialist psychology and specialist psychiatry care for cancer patients.[32] We urge medical professionals, policy makers and relevant stakeholders to acknowledge the growing body of evidence surrounding the prevalence and impact of psychiatric comorbidity among cancer patients. As our understanding of the biomedical complexities of cancer advances, so should our approach to comprehensive care. The commitment to improving quality of life for cancer patients demands not only the availability of integrative oncology services, but also a shift in medical education that bridges this gap in care, and as such, clinical integration is not simply enough. Integration that goes beyond the clinical, into education, research and quality improvement, which is genuinely multiprofessional and co-produced with patients, will be pivotal in cultivating a new cohort of healthcare providers well-equipped to address both the physical and mental health challenges in oncology. This task is crucial in ensuring that the physical and psychological health needs of cancer patients are simultaneously met with the most effective, compassionate, and informed care possible. ■

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Address for correspondence: Dr A Fernando, St George's University Hospitals NHS Foundation Trust, Blackshaw Road, Tooting, London, SW17 0QT.
Email: afernand@sgul.ac.uk