Psychosocial care for cancer patients in primary care? Recognition of opportunities for cancer care

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The paper outlines psychosocial problems experienced by cancer patients and the current barriers to service delivery. New models of psychosocial service provision are put forward, emphasizing information, communication and technology aids in an attempt to improve co-ordination of care. The management of cancer patients has evolved greatly over the past decades, and patients are well placed to benefit from the experiences of primary care professionals in the delivery of chronic illness disease management strategies.

\textbf{Keywords.} Cancer, primary care, psychology, secondary care, service delivery.

Introduction

Psychosocial problems are common in patients throughout the cancer journey. The Department of Health has emphasized the need for psychosocial problems to be addressed,\textsuperscript{1} and in the USA guidelines have already been brought out.\textsuperscript{2} At present, psychosocial problems are encountered at all levels of care. However, management of systems already in place remains a problem. Our experience and the experience of others\textsuperscript{3} suggests that primary care professionals can be well equipped to undertake such work, decreasing stigma associated with psychiatric disorders and utilizing skills used to treat other chronic diseases. In this paper, we will review the relevant literature regarding the detection and treatment of psychosocial issues in primary care. The aim of the paper is to outline psychosocial needs of cancer patients and determine how these needs either are, or could be, met within primary care, in addition to the secondary care setting. The three main objectives are to describe the current systems for delivering psychosocial care to cancer patients, to consider how psychosocial care is delivered in primary care in other chronic diseases and describe the role primary care could develop as part of a more integrated system for providing psychosocial care for cancer patients. Improved outcomes are a primary focus for all professionals involved in cancer care.

“‘Psycho-oncology’ is concerned with relationships between cancer and the mind. ‘Psycho-social oncology’ is a similar term with broader implications that cancer concerns not just individual patients but their families, friends and colleagues, and the society in which they live.” (p. 6)\textsuperscript{4}

Physical, psychological and social problems in cancer

The diagnosis and treatment of cancer is associated with substantial physical, psychological and social morbidity for a significant minority of patients.\textsuperscript{1,5–9} Physical side effects of both disease and treatment include fatigue, hair loss, oral inflammation, immunosuppression, anorexia, nausea, vomiting, pain, weakness and disfigurement, and are a significant burden for many patients.\textsuperscript{10–12} Side effects may be acute and short term (e.g. hair loss), chronic (e.g. weakness) or variable in their course.\textsuperscript{13} Up to a third of patients will develop a major depressive disorder, generalized anxiety disorder or adjustment disorder after a cancer diagnosis, representing an increased relative risk of three times the prevalence in the general population.\textsuperscript{1} At the less severe end of the morbidity spectrum, all cancer patients experience some distress.\textsuperscript{14} Distress can be seen as “an unpleasant experience of an emotional, psychological, social, or spiritual nature that interferes with the ability
to cope with cancer treatment. It extends along a continuum, from common normal feelings of vulnerability, sadness and fears, to problems that are disabling, such as true depression, anxiety, panic, and feeling isolated or in spiritual crisis” (p. 115). In addition, cancer patients must contend with changes to their domestic and working lives, with some patients experiencing problems with daily living, finances and employment.

Studies of psychological morbidity among cancer patients in secondary care suggest that only a small number of distressed patients are identified and treated. The model for treatment used in some cancer centres (Table 1) identifies need and projected numbers of distressed patient requiring treatment.

A critical review assessing psychosocial interventions (education, behavioural training, individual psychotherapy and group interventions) for cancer patients identified that “a structured, psychiatric intervention consisting of health education, stress management and behavioural training, . . . including problem-solving techniques, and psychosocial group support offers the greatest potential benefit.” A lack of systematic psychological screening and under-treatment are due to a combination of factors including under-reporting of symptoms, a lack of awareness or understanding of psychological services and under-recognition of psychological morbidity by health professionals. There is some evidence which suggests that psychosocial needs change over time. Lev et al. suggest that cancer patients’ quality of life and self-efficacy decrease over time. Post-operatively, the majority of breast cancer patients experience high levels of psychosocial dysfunction; however, these problems resolve within 1 year. After the first year, psychosocial problems experienced by breast cancer patients appear to plateau, and remain unchanged when assessed at 2 and 3 year intervals.

It remains important to know at what point in the cancer journey psychosocial issues arise.

### Current provision of psychosocial services

In the past, the availability of services to meet patient needs has grown out of consumer- and professional-led initiatives, e.g. the Tak Tent service which offers support and information, founded by Sir Kenneth Calman. Currently, cancer patients can receive structured psychosocial support from secondary care health professionals with backgrounds in social work, psychiatry and mental health, in addition to services provided by community-based organizations. Services in the community include support groups, information and counselling services, and financial assistance. However, the number of patients using these services and how effective they are in addressing psychosocial needs is difficult to establish. One study suggests that one in four distressed patients had accessed psychological services, and although distressed patients reported a strong desire to access other support services, fewer than one in 10 did so.

Ideally, an overall management system for the detection and treatment of psychological and psychosocial problems, integrating community- and primary care-based services, may improve service delivery. Psychosocial care can be properly delivered in secondary care, where highly intensive treatment is carried out; however, as treatments of cancer become more mobile (e.g. ambulatory chemotherapy administration units), we can begin to think about seamless care across the service continuum. Until recently, psychosocial standards for oncology care have not been

<table>
<thead>
<tr>
<th>Time since diagnosis</th>
<th>Need</th>
<th>Percentage of patients and relatives with this need</th>
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<tbody>
<tr>
<td>Diagnosis</td>
<td>General emotional support and information (accurately and sensitively delivered) to cope with distress</td>
<td>100</td>
</tr>
<tr>
<td>Diagnosis</td>
<td>Short-term interventions and crisis management to deal with levels of anxiety and depression severe enough to affect quality of life</td>
<td>50</td>
</tr>
<tr>
<td>Six months after diagnosis</td>
<td>Management to deal with levels of anxiety and depression severe enough to affect quality of life</td>
<td>25</td>
</tr>
<tr>
<td>One year after diagnosis</td>
<td>Management of specialist psychological and/or psychiatric intervention to deal with high level symptoms</td>
<td>10</td>
</tr>
<tr>
<td>Recurrence</td>
<td>Management to deal with levels of anxiety and depression severe enough to affect quality of life</td>
<td>50</td>
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Based on figures from Guidance on Cancer Services—Improving Supportive and Palliative Care for Adults with Cancer Manual and personal correspondence with Dr Peter Harvey.
present. However, American standards now call for: repeated screening of cancer patients for distress; clinical practice guidelines for treatment of psychosocial problems; a multidisciplinary approach; and the inclusion of distress as a quality assurance measure. There remains a dearth of published articles regarding changes in patient management in secondary and tertiary care despite the fact that research has demonstrated increased levels of psychosocial distress. Barriers may include the poor identification of psychosocial problems by health care staff, and reluctance on the part of patients to initiate discussion of psychosocial issues (e.g. patients prefer the opening to come from the oncology doctor). In one recent paper, one in three patients who indicated need for service had support, 9% of patients were not offered support and only 22% of patients who were offered support accepted.

The role of primary care in cancer care

The Calman–Hine Report, NHS Cancer Plan and the Commission for Health Improvement recognize the centrality and importance of primary care in cancer care. They acknowledge the vital role of primary care in cancer management, and detail initiatives to improve links between primary and secondary care, establish cancer leads for each Primary Care Trust (PCT), and develop PCT-based clinical data sets. However, at present, the main roles of primary care in cancer care are in the recognition of symptoms and symptom clusters suspicious of cancer, effective investigation and referral, and in the management of palliative and terminal care. Other roles include the organization of routine screening, prevention and health promotion, and management of risk behaviours (e.g. smoking cessation), genetic counselling and the recognition and management of side effects of treatment or of progressive disease.

The current role of primary care in the delivery of psychosocial care in cancer

The identification and treatment of psychosocial issues occur in primary care but are not formally recognized or integrated into existing structures. The relationship between secondary care and primary care at the different treatment stages is a starting point. For many primary care health professionals, the experience of cancer management ends after referral and only recommences after intensive treatments have been completed or when palliative and terminal care is needed. In some instances, especially during the acute phases of cancer treatments, patients are advised to contact secondary care directly in the event of problems or concerns. The specialist nature of cancer treatment means primary care is often bypassed during treatment. Few studies have examined cancer patients’ use of primary care after diagnosis. MacLeod found breast cancer patients made more contacts with their GP within the first year after diagnosis compared with pre-diagnosis. Allgar et al., in an analysis of Health Survey for England data, found that a third of respondents with cancer had contacted their GP in the last 2 weeks, more than other illness groups. Gulliford found that of breast cancer patients consulting their GP post-diagnosis, only 7.5% of consultations were for cancer-related problems. However, none of these studies explored whether consultations were for psychosocial problems, and no other data exist concerning the prevalence of psychosocial issues in cancer patients in primary care.

Barriers in primary care

Effective integrated care may be diminished by poor communication between primary and secondary care. In a study of communication between GPs and specialists, only one in five GPs had received a report from the specialist by the time their patient had initiated a consultation. Almost half of GPs surveyed described the communication process as too slow, with a quarter describing the information provided as insufficient and a similar proportion stating that the role of each care provider was poorly defined. Patient perceptions of GPs lacking specialist knowledge, and GPs being too busy to deal with information requests regarding their diagnosis and treatment may also be perceived barriers to the effective use of primary care. When some patients access primary care, for example district nurses, it appears to be for services unrelated to cancer information provision.

Compared with other chronic diseases, cancer remains a relatively rare diagnosis in primary care. With only 7–8 new cases a year per GP, the number of cancer patients (let alone the number of specific site cancers, each with its own aetiology, course and outcome) primary care professionals have, and therefore gain experience and knowledge through, is small. This may compound beliefs that cancer care, in all of its manifestations, is specialist, to which primary care contributes little. The lack of data concerning the management of psychosocial issues in primary care is also an issue. Work is needed to determine the ways in which cancer patients are managed and supported in primary care.

The case for greater involvement of primary care in the delivery of psychosocial care

The psychosocial needs of patients with chronic diseases other than cancer are detected (if somewhat poorly) and
managed predominantly in primary care. For example, other chronic diseases (e.g. diabetes) have well organized services focusing on disease management using programmes involving multidisciplinary teams, regular monitoring and patient education, and underpinned by National Service Frameworks. The impact of a diagnosis of heart disease, diabetes or arthritis is well understood by GPs and practice nurses, who have the expertise and access to resources to deal with the long-term effects of chronic conditions and treatments on psychosocial issues. These services also allow patients to take more control of the treatment provided for their illness.

In many ways, chronic illness management is the ‘bread and butter’ of primary care and uses the considerable skills, attributes and expertise that primary care professionals retain. These include the skills and qualities that GPs have regarding trust and compliance with treatment regimes in general, and in turn on improved treatment outcomes and survival. The ongoing, long-term relationship with primary care ensures a patient’s cancer experience is understood within a social and family context. GPs and other primary care professionals are able to provide emotional support and reassurance, and have the capacity to co-ordinate care effectively within a practice. In addition, detailed knowledge of the patient raises health professionals’ awareness of patients’ coping skills and areas of functional deficit. GPs have a good understanding of the need to refer on to more specialized services where appropriate. These services include district and practice-based nurses, patient information advisors, counselling (both genetic and psychological), and a range of housing and financial services. Primary care professionals are uniquely placed to fulfil a central role in the trajectory of the cancer journey from diagnosis and through to treatment and recovery or palliative care. Lastly, patients may feel more comfortable, and almost certainly will have greater access to a local health centre than a large secondary-based treatment facility for follow-up or information regarding ongoing issues.

New models of psychosocial provision incorporating primary care

There is good justification for providing psychosocial care from primary care. Cancer care could be developed where management of psychosocial issues is undertaken routinely, with confidence, and to a high standard by primary care professionals. Such a service could be developed as part of a shared and integrated service spanning health service sectors. Patients with differing needs and preferences may access services in different settings, varying from patients who exclusively prefer secondary care to those who exclusively prefer primary care at different times. This may have the outcome of ensuring more patients have psychosocial issues managed, and managed better. This could be achieved through the use of specialist GPs, health or clinical psychologists.

The way forward

Given that all cancer patients experience some distress, and need emotional care and support, an integrated care system for the detection and management of cancer is required. Primary care needs the organizational skills to identify cancer patients as a population, take advantage of the confidence existing skills in chronic disease management provide and access existing resources (community and secondary) to delivery a better service for cancer patients. The method for integrating cancer care and ensuring quality management of patients will require emphasis on information systems, communication and technology.

Information

In many practices, it is impossible to know accurately who these patients are, and the structure of both paper and electronic records means registry data are not always readily available, even when the patient consults. Clinical data sets (as outlined in the NHS Cancer Plan) will provide registers of cancer patients to enable opportunistic or targeted identification and treatment of at-risk individuals. An update on a patient’s current treatment would also follow on.

There is also a requirement to determine current practice and barriers in relation to psychosocial issues in cancer. Identifying the scope of psychosocial issues addressed in primary care, consultation rates and accuracy of PCT-based registries will provide the evidence on which to base policy and affect patient outcomes.

Due to the increasing survivorship and treatment successes of the last two decades, other services are also important. Primary care can provide reports for employment agencies and welfare support for patients moving towards integration into the workforce or maintaining standards of living. In the palliative and terminal stages of illness, where psychosocial issues again become important, an increased role for multidisciplinary teams (especially psychological and spiritual services) is an identified need and is provided in primary care. Additional training, used successfully in secondary care, can also support this service.

Communication

Better communication will equate to greater involvement of primary care during acute treatment, and improved co-ordination. Currently, many patients are not receiving continuous care, GPs are not always informed about the progress of their patients, especially
around discharge, and there often exists an absence of an overall co-ordinator of care or guide for the cancer journey. A greater role for primary care during the acute phase of cancer treatments would act to increase both knowledge and confidence in managing issues. It would also act to begin to put GPs back into a central co-ordination role. Without co-ordinated care for the treatment journey, cancer patients may be left unsupported at critical times in their illness and requiring more intensive support at a later stage. The co-ordination of services will clarify responsibilities for professionals involved in the care of the cancer patient and will result in improved communication throughout the health care system. A co-ordination role may represent little more at present than improved communication, but would act to fill the current ‘void’ many GPs feel between referral for suspicious symptoms and the end of active treatment. Community and secondary care resources would also be used at this time.

**Technology**

Technological innovation in secondary and tertiary care has seen major advances, with the use of touch screen technology and automated collection of quality of life data. At present, however, GPs can experience long delays in obtaining test results from secondary care, can receive inadequate information regarding diagnosis and treatment, and can have patients not monitored upon discharge.

The use of electronic records can provide shared information between primary and secondary care incorporating psychosocial assessment. Patient-held records may include patients in this sharing of information, placing greater responsibility on the patient and leading to greater patient-centred care. In some localities, GPs with special interests in cancer may develop and provide a practice-wide, or PCT-wide role in the development and co-ordination of cancer services encompassing psychosocial issues.

**Conclusions**

- Psychosocial issues in primary care are likely to remain a low priority in primary care until the role in primary care is more firmly established and recognized
- The formal management of psychosocial problems in cancer is currently almost exclusively undertaken in secondary care
- Good precedents exist to suggest primary care could have a significant role in psychosocial care
- Strategies have been suggested as to how primary care could begin to deliver such care; an integrated service across health service sectors is needed. PCT cancer leads are central to this process.

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