Original Article

Medical Oncology Patients: Are They Offered Help and Does It Provide Relief?

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Abstract

Context. Identifying modifiable gaps in the symptom management pathway, as perceived by patients, is the first step to relieving patient suffering.

Objectives. The objective is to describe the proportion of patients experiencing treatable cancer-related symptoms who reported 1) a health care provider at the treatment center offered assistance for their symptom, 2) they accepted the assistance offered, and 3) the assistance relieved suffering. Variation in symptom management among treatment centers also was examined.

Methods. A survey was done with 528 medical oncology outpatients recruited from six treatment centers. Eight items explored management of prevalent, burdensome, and treatable cancer-related symptoms: pain, fatigue, other physical side effects, and emotional distress. Participants were asked about symptom management provided at the clinic from where they were recruited. Questions referred to the last occasion the patient experienced the symptom.

Results. Fewer patients were offered help to relieve fatigue (44%) and emotional distress (57%), than pain (90%) and other physical side effects (84%). In most cases, help was not offered as clinic staff were not aware of the patient's symptom. Although the vast majority of patients accepted the help that was offered, more patients accepted help for physical symptoms (pain, 97%; fatigue, 95%; and other side effects, 98%) than emotional symptoms (87%). When care was provided, most patients experienced at least a little relief from pain (99%), fatigue (94%), and emotional distress (96%). Symptom management did not vary significantly by treatment center ($P = 0.073$).

Conclusion. Quality improvement initiatives must focus primarily on improving providers' awareness of their patients' symptoms and ensuring that patients are subsequently offered help. J Pain Symptom Manage 2015;50:436–444.

Key Words
Cancer, pain, fatigue, distress, quality of care, medical oncology

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Introduction

Most cancer patients will experience one or more side effects as a result of their cancer and treatments, including fatigue (up to 91%),[1] pain (up to 59%),[2,3] distress or anxiety (up to 45%),[4,5] or depression (up to 49%).[6] Appropriate symptom management is a fundamental component of quality cancer care[7] and is essential for optimizing quality of life.[8]

Deficits in the Symptom Management Pathway

Despite the availability of guideline recommendations regarding symptom management,[9–12] physical and emotional symptoms are often under-recognized[13–15] and undertreated.[16–18] The reasons for the evidence-practice gap are threefold. Less than optimal symptom management may be a consequence of 1) patients not being offered help, 2)

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patients not accepting the help that is offered, or 3) the help offered is of little benefit. First, concordance studies indicate that providers may not accurately detect or may underestimate the severity of common physical symptoms, such as pain or fatigue,[13,14] or emotional distress.[15,19] Second, awareness of cancer-related symptoms by clinic staff may not necessarily lead to appropriate or sufficient treatment.[16,20] Less than half of patients receive any advice or support for fatigue,[17,21] and psychosocial needs remain unmet in up to 25% of all patients.[18,22] Third, when patients are referred to treatment, patient uptake of services and adherence to treatment is often suboptimal.[23–25]

Does the Current Literature Identify Gaps in the Symptom Management Pathway?

Little empirical data are available quantifying patients' perceptions of where in the symptom management pathway gaps occur. This may, in part, be the result of a lack of appropriate tools to identify these evidence-practice gaps. Existing symptom assessment tools[26] quantify symptom severity but do not assess the adequacy of clinical actions taken to address such symptoms. Although several tools have been developed to assess patient-reported barriers to symptom management, these items primarily focus on patient-related barriers, for example, patient's fear of addiction to pain medication.[25] Other studies exploring patients' symptom experience have examined medical records[3,27–29] and/or assessed quality of life and unmet needs via a patient-report survey.[2] Although these approaches have helped to quantify evidence-practice gaps, they have limitations. First, documentation of the presence of symptoms and their treatment in administrative records may be incomplete or inaccurate.[27] Issues identified in quality of life and unmet needs surveys are not solely attributable to the quality of symptom care received, as factors including stage of disease and type of cancer are known to contribute to the outcome.[22]

Is There Variation in Symptom Management Across Treatment Centers?

It is increasingly recognized that to improve the quality of patient care, changes to the health care system are required.[7] Although a number of studies have focused on patient and cancer-related predictors of symptom experience,[30,31] fewer have explored how the organization of care within the treatment center may impact on patients' symptom experience.[32–36] There is evidence to suggest that organizations with superior symptom management may have lower staff to patient ratios, use policies and procedures for symptom management, or have greater clinician-patient continuity of care.[32–35] However, to our knowledge, no previous studies have explored organizational variation in symptom assessment, treatment, and outcome from the patient's perspective. Understanding whether patient experiences of symptom management vary across cancer treatment centers may help to pinpoint potential system-level factors that can promote or obstruct quality symptom management. Identification of treatment center characteristics associated with better care could be used by health services to improve care delivery.

Aims and Rationale

To improve our understanding of the delivery of care at modifiable points in the symptom management pathway, it is important to explore the provision of symptom management care from the patient's perspective. Therefore, this study aims to describe the proportion of medical oncology outpatients experiencing cancer-related symptoms (pain, fatigue, other general physical side effects, or emotional distress) who reported that they: 1) were offered assistance for their symptoms by a health care provider at the treatment center; 2) accepted the assistance that was offered to them; and 3) experienced a degree of symptom relief from the accepted treatment; and to explore variation in symptom management between treatment centers.

Methods

Sample

Six large publicly funded medical oncology clinics, representing five of seven Australian states and territories, participated. All clinics provided treatment to at least 400 new medical oncology patients per year. Four clinics were situated in major cities and two in inner regional areas, approximately reflecting the distribution of clinics across the participating Australian states (23% located in regional areas).

Eligible patients had a confirmed cancer diagnosis of any tumor type, were attending the outpatient medical oncology clinic for their second or subsequent appointment, were aged 18 years or older, able to read and understand English, and judged by clinic staff to be able to give informed consent and complete the survey.

Procedures

Eligible patients were approached by research staff while waiting for their clinic appointment and invited to participate in the study. Age and gender of nonconsenters were collected. Consenting patients completed a baseline survey assessing patient and clinical characteristics. A second survey assessing symptom management was mailed to consenting patients four weeks