Original Article

The Symptom Burden of Patients with Hematological Malignancy: A Cross-Sectional Observational Study

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Abstract

Context. Current literature suggests that contact with specialist palliative care for patients diagnosed with hematological malignancy is infrequent. As part of an investigation into patterns of care, the symptom profile of this patient group required elucidation.

Objectives. The purpose of this study was to determine the patterns of symptoms and level of distress in patients diagnosed with a hematological malignancy.

Methods. One hundred eighty patients diagnosed with a hematological malignancy attending a tertiary referral hospital completed the Memorial Symptom Assessment Scale-Short Form. Comparisons were made to published symptom prevalence studies of those with nonhematological malignancies.

Results. Patients with hematological malignancy had a considerable physical and psychological symptom burden, with an overall mean of 8.8 (±5.9) symptoms. The mean number of symptoms was significantly greater in those on treatment ($P < 0.05$), those with poorer performance status ($P < 0.001$), inpatients ($P < 0.01$), and those with a more advanced disease stage ($P < 0.001$) than their respective counterparts. Symptom prevalence ranged from 69% for fatigue to 9% for vomiting. Global, physical, and psychological distress scores were high and varied significantly according to disease stage, Eastern Cooperative Oncology Group status, and patient location. The mean number of symptoms and level of distress were comparable to those patients with metastatic nonhematological malignancy.

Conclusion. Patients with hematological malignancy are likely to have symptom control needs similar to those with metastatic cancer. Because such symptom burden appears to affect those at all phases of illness, comprehensive symptom assessment is suggested throughout. The introduction of palliative care services during times of increased symptom burden may assist hematologists and other carers in the management of their patients' distress and quality of life. J Pain Symptom Manage

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Hematological malignancy, symptom burden, palliative care, symptom distress, physical symptoms, psychological symptoms, MSAS-SF

Introduction

In recent years, there has been an increased recognition that the principles of palliative care should be made available earlier in the course of any chronic terminal illness, and that these principles can be delivered alongside therapies intended to prolong life.[1] Despite this, the available evidence suggests that patients with hematological cancers are less likely to access palliative care services, and those who do are more likely to do so at a later stage in their illness than patients with other malignancies.[2–4] In a study by Maddocks et al.,[2] only 27% of acute leukemia patients had contact with palliative care services in their final month of life, compared with 75% of colorectal cancer patients. A retrospective study in a comprehensive cancer center confirmed this finding, with hematological patients accessing palliative care less frequently (11% vs. 89%) and at a later stage (0.6 months vs. two months) than those with solid tumors.[3] In addition, Fadul et al.[5] revealed that the diagnosis of hematological malignancy was an independent major predictor of a low rate of access to palliative care services compared with patients with solid tumors (18% vs. 44%, respectively). Epidemiological studies suggest that hemato-oncological patients more commonly die in acute hospitals (often with escalating interventions), than those who die of solid tumors.[2,4,6]

It is likely that there are multiple factors influencing the current patterns of care. These include, but are not limited to, factors such as symptom burden, or the presence of various diagnostic groups with different disease patterns, prognoses, and times to relapse. The variable and unpredictable responses to treatment, the option of multiple and novel therapies even in the advanced stages, the unpredictable nature and potentially high mortality of treatment complications, unclear goals of care, and knowledge of palliative care services by medical teams and patients add to this difficulty of determining the “right” time to refer to specialist palliative care services.[7]

The burden of symptoms in patients with hematological malignancies has not been well documented in the literature. A study comparing symptom burden in 250 patients with hematological malignancy and solid tumors at first palliative care consultation found that hemato-oncological patients had a similar symptom score for pain and drowsiness but higher scores for delirium than patients with solid tumors (41% vs. 16%).[8] The symptom burden of those patients not referred to palliative care services has not been systematically described. The purpose of this study was to document the symptoms and levels of distress in patients diagnosed with a hematological malignancy. We hypothesized that such patients have a low symptom burden.[9] If this is supported, then the need for specialist palliative care input earlier may be limited and current patterns of care appropriate. If not, we hoped to identify key opportunities throughout the illness where palliative care input may assist to improve symptom distress and quality of life for these patients.

Methods

Consecutive patients with an established diagnosis of hematological malignancy attending the hematology outpatient clinic, the day-treatment unit, or admitted as an inpatient at a nonallograft adult tertiary referral center between May 2009 and September 2009 were approached to participate in the study. Patients were eligible if they were older than 18 years and had been diagnosed with a hematological malignancy irrespective of the stage of their disease. Participants completed the Memorial Symptom Assessment Scale-Short Form (MSAS-SF), a multidimensional symptom assessment tool validated in cancer and