Palliative Care in Hematologic Oncology: A Needs Assessment

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Background: As patients with hematologic malignancies further enter the scope of practice for palliative medicine physicians, it is important to have an accurate view of their needs. Historically, there is a paucity of research examining symptom burden in this cohort. Even fewer studies explore the experience and perceptions of frontline hematology providers. As our Geriatric and Palliative Medicine team at North Shore University Hospital (NSUH) embarked upon a collaborative Supportive Care model on our hospital’s dedicated Leukemia and Bone Marrow units, it was necessary to gain insight from providers about this population to maximize this endeavor.

Objective: Identify issues seen by hematology providers with a heightened prevalence greater than 65 percent.

Methods: To better characterize these patients’ needs, we conducted a supportive care needs assessment survey of the staff (faculty, fellows, nurse practitioners, nurses, social workers, and case management) from the Leukemia and Bone Marrow units. The survey encompassed eighteen domains and attempted to assess their prevalence in patients according to the Hematology team. It included symptom burden, social and functional complexities, advance care planning, and goals of care. Free text responses were used to capture staff input about challenges in caring for this population, personalized staff input about challenges in caring for this population, patients’ expectations, and opportunities for us to assist.

Results: We received a response rate of 30% (30/101) with respondents primarily being nurses. It revealed the most commonly seen domains. Those selected as “frequently” or “almost always” were fatigue (97%), nutritional issues (96%), gastrointestinal issues (93%), anxiety (80%), goals of care (69%), and advance directives (69%). We learned that symptom management was a challenge for the staff. Managing patients’ expectations about chemotherapy was a key concern. Lastly, clear communication with patients throughout treatment and caregiver support were consistent themes.

Conclusion: Determining the four most prominent symptoms encountered by hematology staff were fatigue, nutritional issues, gastrointestinal issues, and anxiety can help refine patient assessment. Additionally, communication and decision making concerns were important to staff. These results underscore the necessity of frontline provider perspectives while treating those with hematologic malignancies to guide future educational and clinical initiatives at the institutional, community, and national level.

What is the biggest challenge in managing patients’ symptoms?
- Pain management consults are needed upon admission and during in-patient stays
- Patient symptoms are long lasting, a minimum of 2 weeks
- Pain may be part of disease process and therefore unresponsive to pain medication
- Psychosocial effects of chronic pain
- They are complex

What is the biggest challenge in managing patients’ expectations?
- Patients want answers to questions that are often unknown
- Effects of chemotherapy and providing quality chemo teaching
- Patient understanding of disease process and continuous education reinforcement
- Constant change of patient acuity from day to day
- Patient gets overwhelmed of the unknown
- Being realistic with the patients

What would be most helpful to you?
- Finding a way to support people through transplant with language that describes possible symptoms without terrifying them
- Having a goals of care conversation with each patient
- Palliative and oncology social work collaboration
- Caregiver support

Respondent Demographics

Domains of Care

References:
2) LeBlanc Thomas W., “In the sandbox: palliative care and hematologic malignancies” The Journal of Community and Supportive Oncology. 01 Feb 2014, 12(2):44-45

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