Question 1: What are the most common unmet needs of caregivers of adult stem cell transplant patients that are identified through a validated survey?

Objective: To identify the unmet needs of caregivers of adult stem cell transplant patients through a validated survey prior to hospital admission.

Background: Stem cell transplant patients are required to have a primary caregiver prior to the beginning of their chemotherapy and throughout the transplant process (can last up to/but not limited to 100 days for allogeneic patients and up to/but not limited to 30 days for autologous patients). The caregiver is required to transport the patient to and from clinic appointments, administer all medications, perform central line care, and notify the team of any changes in the patient’s condition. Assessment of a caregiver’s competency is assessed by the oncology social worker prior to transplant. This assessment consists of approximately ten “yes or no” questions, along with education provided to the patient by the transplant coordinator. Transplant patients are required to undergo a psychological evaluation prior to admission to the hospital. Inclusion of the caregiver into this requirement would allow for an additional outlet for the caregiver, and an opportunity to identify any needs that were missed during the social work interview.

Currently, there are numerous discrepancies between MUSC’s current transplant policies and how caregivers are chosen. Patients have arrived to clinic without their medications, central line care teaching, and/or adequate transportation. When patients and their family members arrive to the outpatient area they are faced with an onslaught of new information. It would be prudent to properly assess a patient’s caregiver and his/her needs prior to transplant to ensure they are capable of taking care of the patient.
SEARCH FOR EVIDENCE

**Search strategies** included articles published in English, publications within past 20 years, and research-based articles

**Databases** included PubMed, Cochrane, CINHAL, and Scopus

**Key words/terms** included caregivers, guardians, assessment, survey, unmet need(s), bone marrow transplant, and stem cell transplant

CRITICALLY ANALYZE THE EVIDENCE

<table>
<thead>
<tr>
<th>PICO Question:</th>
<th>Which assessment tool best identifies the needs of caregivers of adult stem cell transplant patients prior to hospital admission?</th>
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</thead>
<tbody>
<tr>
<td><strong>Author/Date /Journal</strong></td>
<td>Armoogum, Richardson, and Armes 2013 Supportive Care in Cancer: Official Journal of the Multinational Association of Supportive Care in Cancer</td>
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<tr>
<td><strong>Purpose of Study</strong></td>
<td>Aims to describe the supportive care needs of informal caregivers (ICGs) of adult bone marrow transplant patients; To explore relationships between levels of unmet need, psychological morbidity, and patient and informal caregiver characteristics</td>
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<td><strong>Study Design</strong></td>
<td>Quantitative, cross-sectional survey</td>
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<td><strong>Sample &amp; Setting</strong></td>
<td>139 informal caregivers of patients within 24 months of BMT (or the patients, themselves) completed and returned questionnaires</td>
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<td><strong>Outcomes</strong></td>
<td>Associations were found between number of ICG unmet needs and whether ICG considered the patient to have resumed their usual activities (n=98, p=0.018), if ICG perceived their relative (the patient) to have anxiety and depression (n=98, p=0.005), and finally ICG perceived their relative (the patient) to have sexual dysfunction (n=98, p=0.004). Associations were tested but were not found between the number of ICG unmet needs and type of BMT, time since BMT, patient suffering gut problems or infections. <em>Managing concerns about...</em></td>
</tr>
<tr>
<td><strong>Design Limitations</strong></td>
<td>Lower Quality Rating if: ☐ Studies inconsistent (When there are differences in the direction of the effect, populations, interventions or outcomes between studies) ☐ Studies are indirect (Your PICO question is quite different from the available evidence in regard to population, intervention, comparison, or outcome) ☐ Studies are imprecise (When studies include few patients and few events and thus have wide confidence intervals and the results are uncertain)</td>
</tr>
<tr>
<td>Study</td>
<td>Objective</td>
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<tr>
<td>----------------------------------------------------------------------</td>
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<tr>
<td>Aslan, Kav, Meral, Tekin, Yesil, Ozturk, Bulut, Anaboifo, Dover, and Yazar 2006 Cancer Nursing</td>
<td>To identify the needs of caregivers of BMT patients throughout the BMT trajectory</td>
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<tr>
<td>Girgis, Lambert, and Lecathelinais 2011 Psycho-Oncology</td>
<td>To begin to test the psychometric properties of a measure designed to capture the multi-dimensional supportive care</td>
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<td>Date: 5/15/14</td>
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<tr>
<td><strong>Grimm, Zawacki, Mock, Krumm, and Frink</strong> 2000 Cancer Practice</td>
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<tr>
<td><strong>To compare the emotional responses and needs of the caregivers of patients who undergo bone marrow transplantation (BMT) for hematologic malignancies, as observed in an inpatient/outpatient (IPOP) setting with those in an inpatient setting.</strong></td>
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<td>Longitudinal descriptive study</td>
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<td>43 caregivers of BMT patients from the inpatient unit and the IPOP ambulatory-care setting; study was conducted at a National Cancer Institute-designated comprehensive cancer center in the mid-Atlantic region of the United States</td>
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<td>Total mood disturbance, subscale measures of anger, anxiety, confusion, and fatigue were significantly less in IPOP caregivers than in inpatient caregivers at pre-BMT, at day 21, and at discharge. IPOP caregivers were significantly more satisfied with the meeting of their psychological needs than were inpatient caregivers at day 21. The inpatient caregiver group exhibited significant negative correlations between total mood disturbance and satisfaction of needs, meaning that as mood disturbance increased, the satisfaction of needs being met decreased. At baseline, total mood disturbance was negatively correlated with the satisfaction of both psychological needs (p=0.016) and patient care needs (p=0.044). At discharge, total mood disturbance was negatively correlated with the satisfaction of needs (p&lt;0.01). Concerns about recurrence ranked as the most important moderate-high need (18.6%).</td>
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**Non-Experimental/Observational Studies**
(case-control, cohort, cross sectional, longitudinal, descriptive, epidemiologic, case study/series, QI, survey)

- Insufficient sample size
- Sample not representative of patients in the population as a whole
- Sample not defined at common point in course of disease/condition
- Variables (confounders, exposures, predictors) were not described
- Outcome criteria not objective or were not applied in blind fashion
- Insufficient follow-up, if applicable
- For diagnostic study, gold standard not applied to all patients
- For diagnostic study, no independent, blind comparison between index test and gold standard

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<thead>
<tr>
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<th>Design</th>
<th>Sample</th>
<th>Findings</th>
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<td>Siston, List, Daugherty, Banik, Menke, Cornetta, and Larson</td>
<td>To assess performance status and psychosocial adjustment to illness, mood, and stress response of patients and caregivers prior to admission for allogeneic BMT</td>
<td>Cross-sectional survey</td>
<td>40 individuals who would receive allogeneic BMT and their primary caregivers ** 33 eligible participants at the University of Chicago Medical Center, and 7 eligible participants at Indiana University Hospital between January 1996 and March 1998**</td>
<td>25% of BMT patients had psychosocial adjustment scores indicating clinical levels of psychosocial maladjustment and moderate to severe stress response systems. Caregivers reported more disturbances in extended family relationships and health care orientation. Patients, however, reported greater impairments in their vocational environments indicating difficulty performing their work, increased absenteeism, or changes in work goals due to illness.</td>
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<tr>
<td>Turner, Adams, Boulton, Harrison, Khan, Rose, Ward, and Watson</td>
<td>To describe health status, levels of anxiety and depression, unmet supportive care needs and positive outcomes in the partners/family</td>
<td>Quantitative survey</td>
<td>659 partners and close family members of adults with a diagnosis of breast, colorectal, or prostate</td>
<td>127 (49.4%) respondents reported at least one unmet supportive care need, with an average of 2.7 unmet needs per respondent (SD = 5.2). Respondents that expressed at least one unmet need listed an average of 5.5 needs (SD</td>
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Practice Recommendation: Strong Recommendation, Low Quality Evidence

A practice recommendation would include revising the current standard operating procedure regarding the care of the outpatient hematopoietic progenitor cell transplant patient, suggesting a psychological evaluation of the caregiver prior to the patient’s admission, and therefore utilizing these results to improve caregiver support and prioritize current healthcare resources.

Six studies were found evaluating the needs of cancer patients’ caregivers throughout various stages of the patient’s disease process. The results of the studies were mixed.

One quantitative cross-sectional survey examined the supportive care needs of informal caregivers (ICGs) of adult bone marrow transplant patients. It also explored the relationships between levels of unmet need, psychological morbidity, and patient and informal caregiver characteristics. Associations were found between the number of ICG unmet needs and whether ICG considered the patient to have resumed their usual activities, if ICG perceived their relative (the patient) to have anxiety and depression, and finally ICG perceived their relative (the patient) to have sexual dysfunction. “Managing concerns about cancer coming back” was reported at the number one most frequently endorsed unmet need. The 139 caregivers who were surveyed were not defined at a common point in the course of the patient’s condition, and variables (confounders, exposures, predictors) that could have affected their needs were not described (Armoogum, Richardson, and Armes, 2013).

Another quantitative survey tested the psychometric properties of a measure designed to capture the multi-dimensional supportive care needs of cancer caregivers: the Supportive Care Needs Survey- Partners and Caregivers (SCNS- P&C). This survey serves as the most appropriate validated tool to assess caregiver needs. Across all domains significantly more participants with baseline/clinical
anxiety or depression identified experiencing at least one unmet moderate or high need than non-anxious or non-depressed participants (p<0.01). Concerns about recurrence ranked as the most important moderate-high need (18.6%). Caregivers of patient with various solid tumor diagnoses were selected during different stages of the disease process, and variables that could have affected the outcomes were not defined (Aslan, et al. 2006).

A third quantitative study described the health status, levels of anxiety and depression, unmet supportive care needs and positive outcomes in the partners/family members of breast, prostate, and colorectal cancer survivors. Nearly half of the respondents identified at least one unmet need with caregivers with a history of anxiety identifying more unmet needs. The study population only included survivors of solid tumor malignancies, and did not identify confounding variables. Caregivers of these survivors were not identified at a common point; they were assessed from 5-16 years post-diagnosis (Girgis, Lambert, and Lecathelinais, 2011).

A longitudinal survey was conducted to identify the needs of caregivers of BMT patients throughout the BMT trajectory. Fear ranked as the highest psychological need/problem of lay caregivers (n=58, mean= 3.66, SD= 1.95). Leisure activity deficit was highest on social needs/problems (n=58, mean= 4.42, SD= 2.78). The most significant correlation existed between leisure activity deficit and social isolation. The sample size of 58 caregivers was neither sufficient nor was it representative of patients in the population as a whole. Caregivers were surveyed during different stages of the transplant process, which may have also altered the results (Grimm, Zawacki, Mock, Krumm, and Frink, 2000).

An additional longitudinal descriptive study sought to compare the emotional responses and needs of the caregivers of patients who undergo bone marrow transplantation (BMT) for hematologic malignancies, as observed in an inpatient/outpatient (IPOP) setting with those in an inpatient setting. Although this survey was more of a comparison of IPOP outcomes versus inpatient outcomes, it was still able to identify the relationship between total mood disturbances/psychological needs of caregivers and satisfaction of needs being met. Like many of the previous studies, this study lacked sufficient sample size, and identification of the variables that could have affected results (Siston, et al. 2001).

Lastly, a cross-sectional survey assessed performance status and psychosocial adjustment to illness, mood, and stress response of patients and caregivers prior to admission for allogeneic stem cell transplant. This study identified patients at a common point prior to transplant, although it did not identify unmet needs in particular. Caregivers reported disturbances in extended family relationships and health care orientation during this survey. This study did not include caregivers of patients receiving an autologous stem cell transplant and therefore was not representative of the patient population as a whole (Turner, et al. 2011).
There was inconsistency between all six studies regarding sample selection, type of needs identified, and survey tool used to identify the needs of the caregivers. Overall, there are several types of needs of caregivers of oncology patients, but stem cell transplant patients were only the focus of a few of these studies.

**APPLY THE EVIDENCE**

- There are several types of needs of caregivers of stem cell transplant patients that can be identified using the Supportive Care Needs Survey- Partners and Caregivers (SCNS-P&C).

**EVALUATE THE EVIDENCE**

Outcome & Process Measures:
- Number of supportive caregiver needs identified prior to hospital admission

Implementation Plan:
- Revise Standard Operating Procedure BMT 047.01 Care of the Outpatient Hematopoietic Progenitor Cell Transplant (HSCT)-Adults to include a revised version of the Supportive Care Needs Survey- Partners and Caregivers
- Require psychological evaluation of caregiver prior to patient’s admission
- Utilize results to improve caregiver support and prioritize healthcare resources
- Present evidence to key stakeholders
- Present recommendation to Quality Management (Oncology service line)
REFERENCES


