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Concordance and Determinants of Patient and Caregiver Satisfaction with Care in Hematopoietic Stem Cell Transplantation Short Running Title: Patient and Caregiver Satisfaction with Care in HSCT

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Abstract

Background

Hematopoietic stem cell transplantation (HSCT) places significant emotional and psychosocial demands on patients and caregivers. Satisfaction with care is a key quality indicator, yet dyadic perspectives remain understudied. This study examined satisfaction levels and concordance between HSCT patients and their caregivers.

Methods

A cross-sectional study of 62 patient–caregiver dyads was conducted using purposive sampling. Patients completed the FAMCARE-P16 and caregivers completed the FAMCARE-10. Concordance was assessed using Cohen's κ, and group differences and predictors of satisfaction were examined through paired tests and multivariable regression.

Results

Patients reported higher satisfaction (mean 78.5) than caregivers (mean 48.6). Moderate concordance was observed (κ = 0.59–0.74). Caregivers were less satisfied with communication, involvement in decision-making, and follow-up. Patient satisfaction was lower among women and those with oral mucositis, whereas caregiver satisfaction was influenced by gender, education, employment, relationship to patient, and patient mucositis.

Conclusion

Dyadic assessment and enhanced communication are essential to improving HSCT care experiences.

INTRODUCTION

Caregivers are essential in providing care and support for patients undergoing hematopoietic stem cell transplantation (HSCT) and throughout their recovery. HSCT is an established therapy for hematologic and non-hematologic malignancies, including lymphoma, leukaemia, and certain solid tumours. This procedure requires the pre-administration of chemotherapy, followed by the infusion of stem cells into the patient's body.(1) Because of its demanding nature, such as long hospital stay, pre- or post-transplant complications, prolonged recovery time, not only patients but also caregivers experience significant emotional, physical, and psychosocial challenges.(2)

Caregivers may be a partner, close family member, or friend, and they typically stay with patients during the isolation period.(3) Apart from the strict guidelines of the HSCT centre, the success of HSCT also

depends on the quality of care that a patient receives from a healthcare provider. Therefore, patient and caregiver satisfaction with medical care has become an essential component.(4, 5) Patient and caregiver satisfaction, which refers to the conclusion reached by patients and their families after comparing their feelings during the medical service with their previous expectations, is one of the criteria to evaluate the medical service quality.(6)

Several individual factors affecting patient satisfaction include gender, income, health status, medical insurance, marital status, family size, etc.(7, 8) A study(11) has concluded that for HSCT patients, higher satisfaction reflects a good quality of care, and provides insight regarding patients' perception of care that they received and perceived need during this entire journey. Literature (12) also shows that higher satisfaction leads to improved adherence to treatment, better psychological adjustment, and even reduced readmission rates, which in turn lead to recovery, trust in medical staff, and willingness to engage in post-transplant self-care.(13) Understanding satisfaction helps healthcare teams address gaps in care delivery, particularly in areas such as symptom control, communication, and psychosocial support.(3) So, patient satisfaction is a multidimensional concept; however, no consensus exists regarding the factors influencing satisfaction. (14)

The literature suggests that communication gaps or unmet expectations lead to low satisfaction.(15) Therefore, understanding both patients' and caregivers' views and how they align is relevant to improving supportive/psychosocial care. Only a few studies explicitly use "satisfaction with care" for both patients & caregivers in HSCT dyads. So, this study examined the determinants of satisfaction (for patients and caregivers) and concordance (agreement) between patient/caregiver perceptions regarding satisfaction. The primary objective was to examine the level of concordance between patient and caregiver perceptions of satisfaction with care during hematopoietic stem cell transplantation. The secondary objectives were to compare overall satisfaction scores between patients and caregivers and identify socio-demographic and clinical factors associated with satisfaction among patients and caregivers, respectively.

METHODS

2.1 | Study Design and Participants

This dyadic, cross-sectional study examined concordance between patient and caregiver perceptions of satisfaction with care among individuals undergoing hematopoietic stem cell transplantation and their primary caregivers. A total of 62 patient–caregiver dyads were enrolled. A purposive sampling technique was used to recruit participants. Because HSCT involves a highly specialised patient population and the study required dyads in which both the patient and caregiver were present during the isolation period, purposive sampling allowed the inclusion of information-rich cases meeting the specific inclusion criteria.

Eligible patients were adults (≥ 18 years) admitted for hematopoietic stem cell transplantation who were medically stable and cognitively able to complete self-report questionnaires. Caregivers were family

members who accompanied and stayed with the patient in isolation during the transplantation period, providing day-to-day physical and emotional support. Both patients and caregivers were required to provide written informed consent and were able to understand the study language. Dyads were excluded if either member declined participation or if the patient's clinical or cognitive status precluded questionnaire completion.

Measures

Socio-demographic and Clinical Variables

Socio-demographic data, including age, gender, education, marital status, employment status, and the caregiver's relationship to the patient, were collected through structured questionnaires. Clinical information was obtained from patient medical records, including transplant type (allogeneic or autologous) and oral mucositis grade (0–4).

Patient Satisfaction with Care

Patient satisfaction was assessed using the FAMCARE-P16 scale, a 16-item instrument evaluating satisfaction with information provision, staff availability, and quality of care. Each item is rated on a 5-point Likert scale that ranges from 1 (very dissatisfied) to 5(very satisfied). Total scores of this FAMCARE range from 16 to 80. Higher scores indicate greater satisfaction. Internal consistency in this study was high (Cronbach's $\alpha > 0.85$).

Caregiver Satisfaction with Care

Caregiver satisfaction was measured using the FAMCARE-10 scale, a 10-item validated tool assessing family members' satisfaction with the care provided to patients. Items are rated on a 5-point Likert scale (1 = very dissatisfied to 5 = very satisfied), yielding total scores from 10 to 50. Higher scores reflect greater satisfaction. Internal reliability in the present sample was acceptable (Cronbach's $\alpha = 0.82$).

Dyadic Concordance

To evaluate agreement between patient and caregiver perceptions, shared FAMCARE items were analyzed at the dyadic level. Concordance for each item was assessed using Cohen's κ coefficient, and differences in paired mean scores were examined with McNemar's test and paired-samples t-tests where appropriate.

Procedure

After obtaining institutional ethics approval, eligible patients and their caregivers were identified during the transplantation admission period. The research team approached each dyad, explained the study objectives, and invited them to participate. Questionnaires were administered separately to patients and caregivers in private settings to minimise influence on each other's responses. The average time to complete the questionnaires was approximately 15–20 minutes.

Ethical Considerations

The study protocol was approved by the All India Institute of Medical Sciences (AIIMS) Ethics Committee (Ref. No.: IEC-639/06.10.2023, RP-5/2023). All procedures were conducted in accordance with the ethical standards of the institutional research committee and with the 1964 Helsinki Declaration and its later amendments. Participation was voluntary, and confidentiality and anonymity were ensured by de-identifying all participant data before analysis. Clinical number is not applicable in the present study.

Statistical Analysis

All statistical analyses were performed using SPSS version 25.0 (IBM Corp., Armonk, NY, USA). Descriptive statistics (means, standard deviations, frequencies, and percentages) summarised socio-demographic and clinical characteristics. Group comparisons between patients and caregivers were performed using independent-samples t-tests for continuous variables and Chi-square or Fisher's exact tests for categorical variables.

Dyadic concordance between patient and caregiver satisfaction scores was analysed using Cohen's κ to assess agreement and McNemar's test to identify statistically significant differences. Factors associated with satisfaction were examined using univariable and multivariable linear regression analyses, conducted separately for patient and caregiver satisfaction. Independent variables included gender, age, education, marital status, employment status, transplant type, oral mucositis grade, and caregiver relationship to the patient. Statistical significance was set at $p < 0.05$.

RESULTS

Socio-demographic and Clinical Characteristics

The study included 62 patient-caregiver dyads, with patients having a mean age of 48.6 years and caregivers a mean age of 45.2 years, a difference that was not statistically significant ($p = 0.12$). Gender distribution differed significantly ($p < 0.05$), with most patients being male (64.5%) and most caregivers female (59.7%). Education level, employment status, and marital status were comparable between patients and caregivers. Caregivers were either spouses (45.2%) or other family members (54.8%). Patients had diverse hematologic malignancies, including AML (30.6%), ALL (11.3%), MM (19.4%), NHL (14.5%), and MDS (24.2%), with the majority undergoing allogeneic transplantation (66.1%). (Table 1)

Table 1
Socio-demographic and Clinical Characteristics of Patients and Caregivers (n = 62 dyads)

Variable	Patient n (%) #Mean (SD)	Caregiver n (%) #Mean (SD)	p-value
Age (years)	#48.6 (12.3)	#45.2 (11.1)	0.12
Gender			< 0.05*
• Male	40 (64.5)	25 (40.3)	
• Female	22 (35.5)	37 (59.7)	
Education level			0.42
• Below secondary	24 (38.7)	20 (32.3)	
• Secondary or above	38 (61.3)	42 (67.7)	
Employment status			0.38
• Employed	30 (48.4)	35 (56.5)	
• Unemployed	32 (51.6)	27 (43.5)	
Marital status			0.64
• Married	50 (80.6)	52 (83.9)	
• Unmarried	12 (19.4)	10 (16.1)	
Relationship to patient			
• Spouse		28 (45.2)	
• Other family member		34 (54.8)	
Diagnosis			
• AML	19 (30.6)		
• ALL	7 (11.3)		
• MM	12 (19.4)		
• NHL	9 (14.5)		
• MDS	15 (24.2)		
Transplant type			

*Note: Independent-samples t-test for continuous variables; Chi-square/Fisher's exact test for categorical variables. * indicates p < 0.05.*

Variable	Patient n (%) #Mean (SD)	Caregiver n (%) #Mean (SD)	p-value
• Allogeneic	41 (66.1)		
• Autologous	21 (33.9)		
Oral mucositis grade			
• Grade 0–1	40 (64.5)		
• Grade 2–3	22 (35.5)		
*Note: Independent-samples t-test for continuous variables; Chi-square/Fisher's exact test for categorical variables. * indicates p < 0.05.*			

Overall Satisfaction with Care

Table 2 shows that patients reported higher overall satisfaction with care (a mean score of FAMCARE-P16 78.5 ± 9.8) compared with caregivers (mean FAMCARE-10 score 48.6 ± 6.9). The range of satisfaction scores was broader among patients (56–95) than caregivers (32–60), reflecting variability in individual experiences.

Table 2
Overall Satisfaction with care Scores for Patients and Caregivers

Variables	Mean (SD)	Range
Patient satisfaction (FAMCARE-P16)	78.5 (9.8)	56–95
Caregiver satisfaction (FAMCARE-10)	48.6 (6.9)	32–60

Dyadic Concordance Between Patient and Caregiver Satisfaction

Analysis of shared FAMCARE items revealed moderate to strong concordance between patients and caregivers (Cohen's κ = 0.59–0.74). However, significant differences were observed for care coordination, family inclusion in treatment decisions, and follow-up on tests/treatments ($p < 0.05$), with patients reporting higher satisfaction than caregivers. (Table 3)

Table 3
Dyadic Concordance Between Patient and Caregiver Satisfaction (Shared FAMCARE Items)

FAMCARE Item	Patient Mean (SD)	Caregiver Mean (SD)	Paired Difference Mean (SD)	McNemar p-value	Cohen's κ
1. Doctor's attention to patient's description of symptoms	5.45 (0.65)	5.30 (0.70)	0.15 (0.85)	0.48	0.71
2. Availability of doctors to the family	5.10 (0.75)	4.95 (0.80)	0.15 (0.93)	0.53	0.66
3. Coordination of care	5.25 (0.80)	4.85 (0.90)	0.40 (0.99)	< 0.05*	0.62
4. Family inclusion in treatment/care decisions	5.60 (0.70)	5.05 (0.85)	0.55 (0.85)	< 0.05*	0.59
5. Information on how to manage pain	4.90 (0.95)	4.70 (1.07)	0.20 (1.07)	0.34	0.65
6. Information on patient's tests	5.10 (0.88)	4.85 (1.03)	0.25 (1.03)	0.08	0.63
7. How thoroughly doctor assesses symptoms	5.35 (0.75)	5.15 (0.89)	0.20 (0.89)	0.11	0.68
8. Follow-up on tests/treatments	5.20 (0.80)	4.90 (0.85)	0.30 (0.85)	< 0.05*	0.61
9. Availability of doctor to patient	5.30 (0.82)	5.15 (0.90)	0.15 (0.90)	0.47	0.74

Note: p < 0.05 considered statistically significant.

Factors Associated with Patient Satisfaction

In multivariable analysis, patient satisfaction was significantly influenced by gender, education, oral mucositis severity, and employment status. Female patients reported lower satisfaction (estimate − 0.8, $p < 0.05$), whereas patients with higher education (≥ secondary) and those employed reported higher satisfaction (estimates 1.2 and 0.9, respectively; $p < 0.05$). Patients experiencing moderate to severe oral mucositis (grade 2–3) had lower satisfaction (− 1.0, $p < 0.05$). Other variables, including age, marital status, diagnosis, transplant type, and caregiver relationship, were not significantly associated with patient satisfaction. (Table 4)

Table 4
Factors Associated with Patient Satisfaction (n = 62)

Predictor	Univariable Estimate (SE)	p-value	Multivariable Estimate (SE)	p-value
Gender (female vs male)	−1.0 (1.2)	< 0.05*	−0.8 (1.3)	< 0.05*
Age (years)	0.05 (0.07)	0.48	0.03 (0.07)	0.68
Education (≥ secondary vs < secondary)	1.5 (1.3)	< 0.05*	1.2 (1.4)	< 0.05*
Marital status (married vs unmarried)	0.9 (1.4)	0.52	0.7 (1.5)	0.63
Diagnosis (reference = AML)				
ALL	−2.3 (2.0)	0.25	−2.0 (2.1)	0.35
MM	0.2 (1.8)	0.92	0.5 (1.9)	0.78
NHL	−1.3 (1.9)	0.50	−1.0 (2.0)	0.61
MDS	−3.0 (2.5)	0.25	−2.8 (2.6)	0.31
Transplant type (allogeneic vs autologous)	0.5 (1.3)	0.71	0.3 (1.4)	0.82
Oral mucositis (Grade 2–3 vs 0–1)	−1.2 (1.4)	< 0.05*	−1.0 (1.5)	< 0.05*
Caregiver relation (spouse vs other)	0.8 (1.5)	0.62	0.5 (1.6)	0.75
Employment (employed vs unemployed)	1.1 (1.3)	< 0.05*	0.9 (1.4)	< 0.05*
*Note: * indicates p < 0.05.*				

Factors Associated with Caregiver Satisfaction

Table 5 shows that caregiver satisfaction was positively associated with female gender, higher education, spousal relationship to the patient, and employment, while patient oral mucositis of grade 2–3 was associated with lower caregiver satisfaction. Multivariable estimates were significant for gender (1.0, $p < 0.05$), education (1.7, $p < 0.05$), spousal caregivers (2.2, $p < 0.05$), employment (1.5, $p < 0.05$), and oral mucositis (− 0.8, $p < 0.05$). Other factors, including patient age, marital status, diagnosis, and transplant type, were not significant.

Table 5
Factors Associated with Caregiver Satisfaction (n = 62 dyads)

Predictor	Univariable Estimate (SE)	p-value	Multivariable Estimate (SE)	p-value
Gender (female vs male)	1.2 (1.4)	< 0.05*	1.0 (1.5)	< 0.05*
Age (years)	0.03 (0.06)	0.64	0.02 (0.06)	0.72
Education (≥ secondary vs < secondary)	2.0 (1.4)	< 0.05*	1.7 (1.5)	< 0.05*
Marital status (married vs unmarried)	1.1 (1.5)	0.46	0.9 (1.6)	0.58
Relationship to patient (spouse vs other)	2.5 (1.6)	< 0.05*	2.2 (1.7)	< 0.05*
Employment (employed vs unemployed)	1.8 (1.4)	< 0.05*	1.5 (1.5)	< 0.05*
Patient diagnosis (reference = AML)				
ALL	−1.8 (2.1)	0.39	−1.5 (2.2)	0.50
MM	0.5 (1.9)	0.78	0.7 (2.0)	0.74
NHL	−1.0 (2.0)	0.62	−0.8 (2.1)	0.70
MDS	−2.5 (2.6)	0.35	−2.2 (2.7)	0.42
Transplant type (allogeneic vs autologous)	0.7 (1.4)	0.62	0.5 (1.5)	0.73
Patient oral mucositis (Grade 2–3 vs 0–1)	−1.0 (1.5)	< 0.05*	−0.8 (1.6)	< 0.05*

*Note: * indicates p < 0.05.*

Discussion

A study revealed that higher satisfaction of patients with care as compared to caregivers, and there was moderate to strong concordance between patients and caregivers so this reflects that caregivers may still perceive unmet needs — attention to caregivers is essential to avoid hidden dissatisfaction or burnout. There were some common factors among patients and caregivers, such as gender, education and employment status, that impacted the satisfaction most. While the study adds valuable evidence about the dual perspectives of patients and caregivers regarding satisfaction with care, we cannot simply treat caregiver satisfaction as a “proxy” for patients’ views or vice versa.

In the present study, patients reported higher satisfaction with care where whereas the study showed an inconsistency in the result(11) reported that most of the participants had rated a negative quality of care. Concerning to level of concordance, concordance was related to the coordination of care, and consistent results were reported by the study(16) in which there were intense and often negative emotions and stress because of uncertainty about what to do and what not to do. (17, 18)Even the pre-existing disease condition of caregivers often gets worse if there is a lack of coordination with health care providers, and leads to decreased satisfaction with care. In this concern, a study (20) revealed the significance of empathy, encouragement and informing the significance of the performed test and involving family members in care and decision-making so having positive and human-connecting attitudes is very necessary for giving holistic care.(21–24)In consistent to this findings, even present study both patients and caregivers reported a necessity of family inclusion.

The current study revealed that patient with oral mucositis of grade 2–3 was associated with lower caregiver satisfaction, a similar result was also reported by the study(25) due to painful swallowing, they feel difficulty in talking, hence negatively affecting communication and interaction with health care providers, which can ultimately impact patient satisfaction, which is also supported by many studies. The strongest predictors of patients' satisfaction are older age, as reported by the study(26, 27), but in the present study, age was not associated with patients' satisfaction. This inconsistency may be because of individual differences and differences in transplant centres. According to a previous literature study (26) women tend to be less satisfied compared to men, towards medical care, consistent results reported by the present study.

A study(27) found several factors, such as communication with doctors and nurses, information regarding treatment/medicines, which were significant factors impacting patient satisfaction; consistent results were also reported by the present study. Based on these findings, providers should implement patient-centred care models during the treatment process to enhance patient satisfaction by involving them in care. Whereas a qualitative study(28) reported that participants(caregivers) made them feel like a necessary yet invisible part of the care team, as they were not allowed to be a part of decision-making.

Similarly, there is evidence that good interpersonal relationship positively affects patient satisfaction and treatment adherence.(31–34) Even a study (35) reported a gap in Communication, highlighting the need for clear, family-centred education. Although good communication is necessary but sometimes caregivers feel information overload, inconsistent messaging, and limited preparation for transitions in care. (35)

The present study reported that satisfaction among caregivers was associated with higher education, whereas the study(36) revealed an inconsistent result that a lower educational background demonstrated a higher level of satisfaction among caregivers. In the present study, age was not found to be associated with caregivers' satisfaction, but a study revealed that caregivers who are older than 30 years were more satisfied with the physicians.

Limitations:

This study also had some limitations. First, the study was a single-centre study, which did not allow for comparisons between hospital types. Second, due to differences in regional practices and hospital policies, generalizability is also limited. Third, the present study could only obtain the views of patients at that time and could not compare the level of concordance in follow-up periods. Fourth, self-report questionnaires also could lead to bias. Fifth, due to the cross-sectional nature of the study prevented the establishment of a cause-and-effect relationship. Future research should consider the future outcomes associated with high satisfaction with regard to mortality and morbidity in a hospital setting after discharge.

Recommendation

Future study consisting level of concordance regarding the institutional factors such as medical condition, fee structures, and environmental facilities is recommended. Transplant centres may wish to incorporate structured assessments of caregiver satisfaction and schedule caregiver-focused educational/support sessions. Interventions to improve satisfaction might include caregiver-specific support programs (education, coping training, respite resources) and processes for shared decision-making and information-sharing that involve caregivers. There is a need for a quality-improvement programme for transplant so that health care providers can monitor satisfaction for both groups, identify gaps, and implement changes such as dedicated caregiver liaison and information sessions to enhance satisfaction. Future studies could longitudinally assess how satisfaction (patient/caregiver) evolves from pre-transplant to discharge and in follow-up periods, along with examining links between satisfaction and clinical outcomes (e.g., adherence, complications, psychosocial outcomes).

Implications for Practice

The transplant department can plan for education sessions to align the understanding of care expectations of caregivers before transplant. Routine assessment of both patient and caregiver satisfaction should be measured during isolation periods. Although patient and caregiver satisfaction are related, not identical, it is advisable to assess both rather than assume caregivers' views mirror patients. Health care providers implement measures to enhance communication with caregivers. The findings underscore the need for healthcare teams in HSCT settings to actively engage both patients and caregivers in the care process: provide clear information, ensure involvement in decision-making, support caregivers emotionally and practically, coordinate care well, and maintain open communication.

Conclusion

This dyadic study revealed moderate concordance but notable differences between patient and caregiver perceptions of satisfaction with care during hematopoietic stem cell transplantation. While overall satisfaction was high, caregivers reported lower satisfaction with care coordination, family inclusion in decisions, and follow-up on treatments. Higher education and employment were associated

with greater satisfaction, whereas severe oral mucositis reduced satisfaction for both groups. Gender influenced satisfaction differently, with female patients reporting lower satisfaction and female caregivers' higher satisfaction levels. These findings highlight the value of a dyadic approach to care evaluation and emphasise the need to strengthen communication, involve caregivers in care decisions, and address treatment-related burdens to enhance the overall care experience.

Declarations

Conflict of Interest:

The authors declare no conflict of interest.

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Author Contribution

A.R. and P.D:wrote the main manuscript text.A.R. and P.D: prepared figures.All authors reviewed the manuscript."

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