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Self-efficacy for symptom management in the acute phase of hematopoietic stem cell transplant: A pilot study

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ABSTRACT

Purpose: Hematopoietic stem cell transplant (HSCT) is an intensive treatment associated with distressing treatment and disease-related symptoms that affect patient outcomes such as functional status and quality of life. Self-efficacy for symptom management (SESM) is a person's belief in their ability to perform behaviors to prevent and relieve symptoms. Presence of SESM can impact symptom distress and functional status. This study describes the changes over time and relationships among SESM, symptom distress, and physical functional status in adults during the acute phase of HSCT.

Methods: Patients (n = 40) completed measures of symptom distress, SESM, and physical function at time points prior to and at days 7, 15 and 30 post-transplant. Clinical outcomes were length of stay and number of readmissions.

Results: Symptom distress, physical function, and SESM changed significantly over time. There was a significant negative relationship between symptom distress and physical function and between symptom distress and SESM at all points. The lowest levels of SESM and physical function were at day 7 when symptom distress was highest. Symptom distress was a moderator for the relationship between physical function and SESM at day 15.

Conclusion: This was the first study to examine SESM in the acute phase of HSCT. Higher SESM was associated with fewer symptoms and increased physical function. Less symptom distress was associated with higher physical function and confidence to manage symptoms. These findings provide the basis for development of patient-centered interventions to enhance SESM when symptoms are at their highest immediately after HSCT.

1. Introduction

Hematopoietic stem cell transplant (HSCT) is an intensive treatment option for some types of cancer. The HSCT process includes high-dose chemotherapy with or without radiation treatments, followed by infusion of stem cells, from the patient themselves (autologous) or from a sibling or unrelated donor (allogenic). Disease diagnosis, stage, and donor availability determine transplant type. Regardless of the type of transplant a person receives, treatment-related symptoms are severe and can have significant effects on patient outcomes such as physical functioning and quality of life (QOL) (Cohen et al., 2012; Kroemeke et al., 2018). The presence of concurrent symptoms is greater during the acute phase (first 30 days) and, along with other factors such as physical, psychosocial, or emotional issues, causes symptom distress (Bevans et al., 2008; Cohen et al., 2012). Helping patients to manage their symptoms and symptom distress may improve the symptom experience and influence patient outcomes (Bevans et al., 2008).

Patients who undergo HSCT experience high symptom burden and symptom distress (Braamse et al., 2014). Symptom distress is the patients' perception of the amount of discomfort caused from symptoms (McCorkle, 1987; Stapleton et al., 2015). Symptoms that are most distressing in the acute phase are both physical and psychological in nature and include fatigue, weakness, sleep disturbances, anxiety, lack of appetite, bowel problems and pain (Bevans et al., 2008; Cohen et al., 2012). Highest symptom intensity occurs between 10 and 14 days after high-dose chemotherapy is initiated and usually returns to baseline by

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30 days post-transplant (Campagnaro et al., 2008). Multiple symptoms can have an additive effect, increasing the burden on patients and their caregivers (Cleeland, 2007). Consequences of symptom distress in cancer patients include decreased survival (NCCN, 2013), non-adherence to treatment (NCCN, 2013), depression (Breen et al., 2009), delay or termination of treatment, increased hospitalizations, and medical costs (Cleeland, 2000). HSCT patients with high symptom distress are more likely to have sleep disturbances, anxiety, and depression (Bevans et al., 2011; Rischer et al., 2009). Symptom distress has been shown to impact blood count recovery and overall health in the acute phase of transplant (Hobfoll et al., 2015). High symptom burden and distress have a negative effect on the QOL domains of physical and mental health and functional status (Cleeland, 2000; Bevans et al., 2014).

Self-efficacy is a persons' belief in their ability to perform behaviors (Bandura, 1997). Self-efficacy for symptom management (SESM) is the ability to implement behaviors to prevent, recognize, and relieve symptoms (White et al., 2017). SESM requires knowledge, skills, cognitive processes, motivation, and confidence (White et al., 2017; Hoffman, 2013). Research on self-efficacy in cancer patients exists but literature in the HSCT population is scarce. Bergkvist et al. (2015), Hochhausen et al. (2007), and Wu et al. (2012) found high self-efficacy was associated with lower symptoms and was a significant predictor of emotional and physical well-being and QOL one year or more after HSCT. O'Sullivan et al. (2018) found that low self-efficacy in the pre-transplant phase was associated with lower QOL up to one year post-transplant. These studies, while different in their objectives, show that self-efficacy influences symptom management in HSCT patients. Enhancing SESM earlier in the transplant process has the potential to influence symptom management when symptoms are most intense. However, no studies were located that evaluated self-efficacy and its relationship to management of symptom distress during the acute phase of HSCT. The relationship between SESM and symptom distress in patients during the acute phase of HSCT is unknown.

The purpose of this study was to describe the changes over time and relationships among SESM, symptom distress, and the outcomes of physical function, readmission, and length of hospital stay during the acute phase (30 days) post-HSCT. Specific aims were to (1) determine changes over time in SESM, symptom distress, and physical functional status; (2) examine relationships among SESM, symptom distress, and physical function and (3) determine if the relationships among SESM and length of stay, readmission rates, and functional status vary depending on the level of symptom distress.

2. Methods

Design and Participants. This was a longitudinal, descriptive, pilot study. After obtaining institutional review board (IRB) approval, all participants undergoing either autologous or allogenic HSCT from a single center in the Midwestern U.S. were screened for eligibility. Inclusion criteria were that patients were at least 18 years old and met evaluation criteria for undergoing a stem cell transplant. Exclusion criteria were that the patient did not speak English or could not sign their own consent.

All paper/pencil surveys were completed at baseline (prior to high-dose chemotherapy and stem cell reinfusion) and 7, 15 and 30 days after transplant. A brief interview was conducted at baseline and at 30 days to obtain the patient's perspective on SESM during the transplant process. These perspectives have been reported elsewhere (White et al., 2019).

Measures. Variables measured in this study included demographic and clinical data, symptom distress, SESM, physical functional status, length of stay and readmission rates.

Demographic and clinical data. At baseline, demographic and clinical data were collected from the patient and electronic medical record. Comorbidity scores were calculated using the Hematopoietic Cell Transplant-Comorbidity Index (HCT-CI). The HCT-CI score measures health status prior to transplant and considers comorbidities and age as prognostic factors (Sorror et al., 2014). The scores were divided into three risk groups; low (0–2), medium (3–4) and high (≥5) with a higher score indicating a higher mortality risk (Sorror et al., 2005).

Symptom distress. Symptom distress was measured using the Symptom Distress Scale (SDS) (McCorkle, 1987). The tool is a cancer-specific, 13-item self-report questionnaire that uses a scale of one (no distress) to five (extensive distress) to measure the degree of distress from 11 different symptoms including nausea, appetite, insomnia, pain, fatigue, bowel pattern, concentration, appearance, breathing, outlook, and cough. Two items assess the frequency of nausea and pain (McCorkle, 1987). Reliability and validity have been demonstrated previously (McCorkle et al., 1998; Stapleton et al., 2015). Cronbach's alpha was .823 at baseline and ranged from 0.694 to 0.864 in this study.

Self-efficacy for Symptom Management. SESM was measured using the *Self-efficacy for Managing Symptoms* (SEMS) and *Self-efficacy for Managing Medications and Treatment* (SEMMT) instruments selected from the Patient-Reported Outcomes Measurement Information System (PROMIS) Self-efficacy for Managing Chronic Conditions measures (American Institutes for Research, 2016). These are newly developed tools and have limited reporting in the literature. Initial calibrations across chronic conditions show good internal consistency and cross-sectional validity (Gruber-Baldini et al., 2017). Reliability estimates have not been reported for the full item banks.

The SEMS instrument has 28 questions with responses on a scale from one (not at all confident) to five (very confident). The instrument includes items that assess persons' level of confidence to manage their symptoms in different settings including hospital and home, and to keep symptoms from interfering with activities of life such as work, relationships, or recreation (PROMIS, 2015). Cronbach's alpha reliability for this study was 0.973 at baseline and ranged from 0.965 to 0.984 for other points. The SEMMT has 26 questions on the same 5-point scale. The items assess confidence in managing medication schedules, understanding the difference between medication side effects and symptoms, and ability to follow a treatment plan (PROMIS, 2015). Cronbach's alpha reliability for this study was 0.967 at baseline and ranged from 0.975 to 0.988 at other times.

Physical Function. *PROMIS Physical Function – Short Form 10a* measured physical function. This 10-question form measures self-reported capability with role and physical function. Questions are rated on a 5-point scale from "without any difficulty" to "unable to do." This instrument was found to be valid and reliable across age and race-ethnic groups in research with persons who have cancer (Jensen et al., 2015). Jensen et al. (2015) reported the Cronbach's alpha in cancer patients to be from 0.92 to 0.96, and also high convergent validity and discriminant validity. Cronbach's alpha reliability for this study was 0.855 at baseline and ranged from 0.904 to 0.914 at other times.

Length of stay and readmission(s). Length of stay from stem cell reinfusion (day 0) to discharge, and number and length of readmissions, were tracked via the electronic medical record and by participant self-report. Length of stay was not reported for patients who died prior to or after 30 days post-transplant.

2.1. Data analysis

Descriptive statistics were obtained for all variables (means, standard deviations, frequency distributions and percentages). Normality tests were performed and met the assumptions of the statistical tests in all but one case, which was the SEMS instrument. These data were log transformed for further analysis.

For the first research aim, repeated measures analysis of variance (RM-ANOVA) and paired t-tests were used to examine how SESM, symptom distress and physical function changed over time. Paired samples t-tests were calculated to assess changes in each of the variables between adjacent time points. The second research aim used

Table 1
Demographic and Clinical data (N = 40).

Demographics (Baseline)		N	%
Gender	Women	18	45
	Men	22	55
Race	White	39	97.5
	Non-white	1	2.5
Employment	Full time	27	67.5
	Disability	4	10
	Retired	8	20
	Unemployed	1	2.5
Education	Upper secondary (10–12)	10	25
	Post-secondary (Vocational)	15	37.5
	Associate's Degree	2	5
	Bachelor's Degree	10	25
	Post graduate Degree	3	7.5
Marital Status	Married	28	70
	Single	6	15
	Divorced	5	12.5
	Widowed	1	2.5
Caregiver	Spouse	28	70
	Family member	6	15
	Friend	4	10
	None	2	5
Primary Disease	Acute Leukemia	10	25
	Lymphoma	9	22.5
	Myelodysplastic Syndrome	1	2.5
	Multiple Myeloma	20	50
Transplant Type	Autologous	29	72.5
	Allogeneic		
	Related Allogeneic	7	17.5
	Unrelated Allogeneic	4	10
Comorbidity Score	0–2	9	22.5
	3–4	19	47.5
	≥5	12	30
Readmissions[a]	0	29	72.5
	1	6	15
	2	1	2.5

[a] Three patients were not discharged at 30 days post-HSCT; One patient was deceased.

correlations to examine the relationships between SESM, symptom distress, and physical function. A general linear model was used to examine if baseline SESM predicted changes in symptom distress and physical function over time. For the final aim, interaction effects between SESM and symptom distress predicting physical function were examined. Interaction plots, with inputs of ± 1 standard deviation to indicate low and high values of distress and self-efficacy, were used to interpret significant moderation of the effect of symptom distress on functional status, length of stay, and readmission rates.

3. Results

Hertzog (2008) suggests a minimum sample size of 25 for single group pilot studies. The initial enrollment goal was 30 participants to allow for attrition. When enrollment exceeded expectations, IRB approval was obtained to increase enrollment. Forty-six patients were scheduled to undergo HSCT during the recruitment period. Two patients did not meet inclusion criteria, four declined participation with reasons of "not good at answering questions" and "not interested." The final sample was 40 participants.

Demographic and clinical data are presented in Table 1 and Fig. 1. Approximately half of the sample was female, with a mean age of 58.27 years (SD = 8.73) at baseline, and the race/ethnic distribution was almost exclusively white. Mean length of stay was 12.84 days (SD = 8.33). Specifically, mean length of stay was 12 days for autologous and 16 days for allogenic transplant recipients. One participant died before 30 days post-transplant. The majority were employed full time with the remaining retired, on disability or unemployed. At least 70% had greater than a high school education and were married, with their spouse as their caregiver.

Autologous transplant was the most common transplant type and the most common primary disease was multiple myeloma. The highest number of participants had a comorbidity score in the medium risk range. Over 70% of the participants were not readmitted to the hospital after discharge. At baseline, the most frequently occurring symptoms were fatigue, pain, and insomnia (Fig. 1). The most frequently occurring symptoms at days 7 and 15 were lack of appetite, fatigue, and bowel changes. At day 30, fatigue and lack of appetite continued, and pain and changes in appearance also were most frequent.

The first aim was to determine changes over time in symptom distress, SESM and physical functional status. Descriptive statistic means are presented in Figs. 2 and 3. At day 7, the mean score for symptom distress peaked, and the means for self-efficacy and physical function were the lowest. For symptom distress, change over time was significant [F (1.99, 57.64) = 14.94, $p < .001$, $\eta^2 = 0.340$]. There was a significant linear trend ($p = .001$) and a significant quadratic effect ($p < .001$) indicating the slope changed over time. Dependent samples t-tests indicated a significant increase in symptom distress between baseline and day 7, and significant decreases between day 7 and 15, and day 15 and 30 (Table 2; Fig. 2). No statistically significant differences were found between those patients receiving autologous and allogenic transplants in any of the instruments at any time point.

Results from both the SEMMT and SEMS instruments were used to measure SESM. There was a significant change in SEMMT over time [F (2.6, 75.4) = 5.318, p = .003, $\eta^2 = 0.155$]. There was not a significant linear trend, meaning the participants ended where they started, but the quadratic effect was significant ($p = .012$) indicating the slope changed over time. Paired t-tests indicated a significant decline between baseline and day 7, and an increase between day 7 and day 15 (Table 2; Fig. 3). SEMS changed significantly over time [F (2.8, 80.89) = 7.418, $p < .001$, $\eta^2 = 0.204$], with a significant linear trend ($p = .023$) and a significant quadratic effect ($p = .001$). Paired t-tests indicated a significant decline between baseline and day 7, and an increase between day 7 and day 15, and between day 15 and day 30 (Table 2; Fig. 3).

Physical function changed significantly over time [F (2.8, 76.3) = 4.86, $p = .004$, $\eta^2 = 0.153$]. There was not a significant linear trend, but the quadratic effect was significant ($p = .009$). Paired t-tests indicated a significant decline between baseline and day 7. No differences were found between other adjacent times (Table 2; Fig. 3).

The second aim was to examine the relationships between SESM, symptom distress and physical function. Table 3 presents correlation data. Significant negative relationships were found between symptom distress and physical function and between SESM and symptom distress at all points. A significant positive relationship was found between SEMMT and SEMS at each time. SESM and physical function were positively related at all times.

The final aim was to determine if the relationship between SESM, length of stay, readmission rates, and functional status varied depending on the level of symptom distress. No moderating effects of symptom distress were found at baseline, day 7 or day 30. An interaction was found at day 15 between symptom distress and SESM predicting physical function (p < .01). The interaction was marginally significant at day 7 (p = .06). In participants with low symptom distress, higher SESM was associated with higher physical function. In participants with high symptom distress, higher SESM was associated with lower physical function. The moderating effect of symptom distress on the relationship between SEMMT and physical function mirrored that of SEMS.

4. Discussion

This study examined relationships and changes over time in SESM, symptom distress, and physical function for adults receiving HSCT. The findings will now be discussed in relation to clinical data and implications for practice. Symptoms that caused distress in this sample are

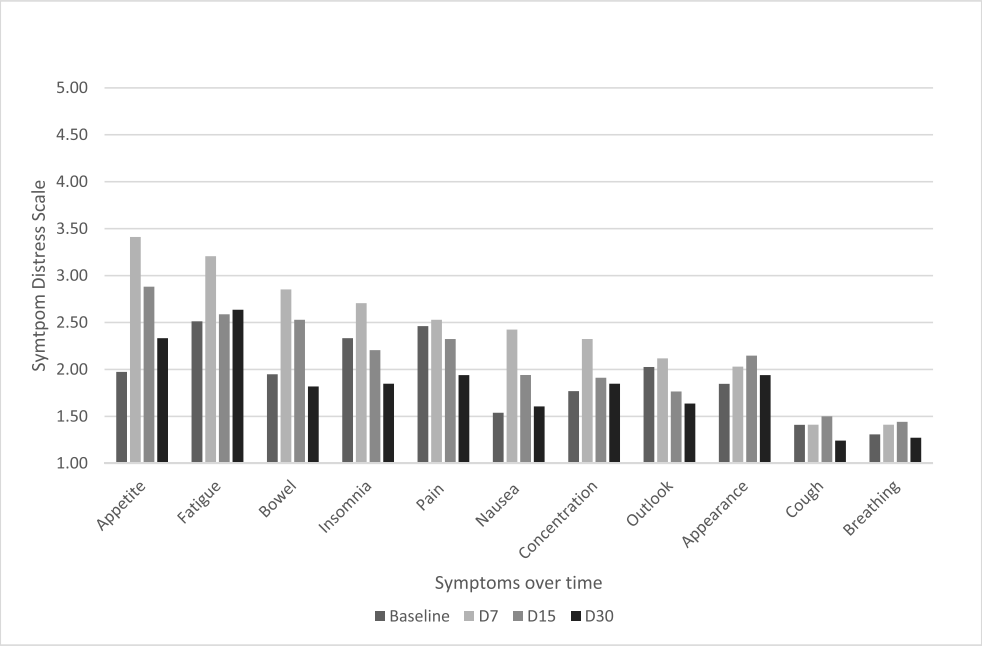

Fig. 1. Average symptom distress.

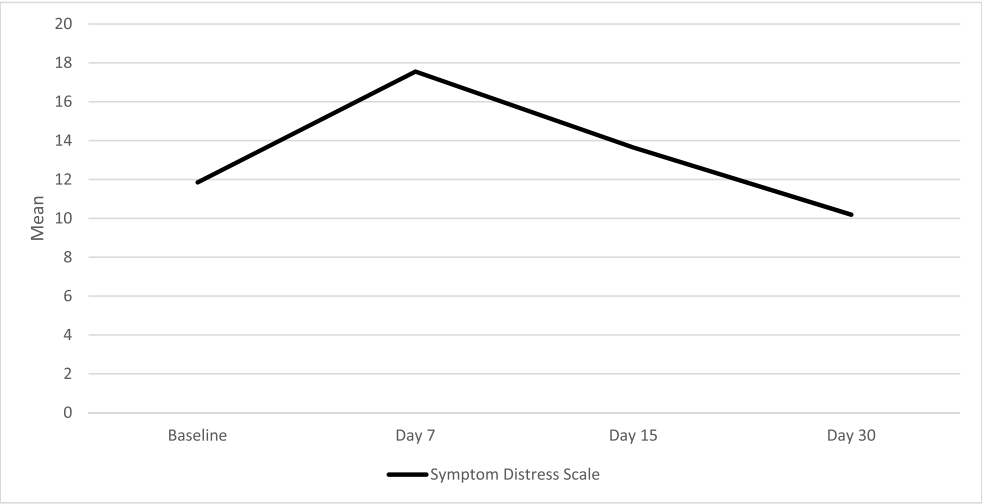

Fig. 2. Symptom Distress Changes over time.

similar to what has been reported in other studies with lack of appetite, fatigue, insomnia, and bowel changes common at day 15 and lack of appetite, fatigue, and insomnia common at day 30 (Andersson et al., 2011; Cohen et al., 2012). These studies did not report most common symptoms at day 7.

The first aim determined that there were significant changes over time in symptom distress, which is consistent with findings from other studies where symptom distress peaked at day 7 and returned to baseline levels by day 30 (Cohen et al., 2012). Physical function also changed over time, which is consistent with studies that found HSCT patients with higher symptom distress have lower physical and mental health status (Andersson et al., 2011; Bevans et al., 2014).

Measuring SESM with two instruments contributed to a complete picture of SESM that included managing symptoms with medications and a treatment plan (SEMMT), judgment regarding symptom management, recognizing and managing new symptoms, and performing daily activities, despite having symptoms (SEMS). SESM was lowest when symptom distress was highest, a time when symptom management is vital for outcomes. Changes over time in SESM have not previously been studied during the acute phase of HSCT.

The second aim found significant relationships among SESM, symptom distress and physical function during the acute phase of HSCT with higher SESM associated with fewer symptoms and increased physical function. As was found in other studies with HSCT patients, high self-efficacy was associated with better general health and lower symptom occurrence and self-efficacy predicted greater physical well-being (Bergkvist et al., 2015; Hochhausen et al., 2007). However, these studies were with persons between one- and five-years post-transplant. Wu et al. (2012) reported in patients who were greater than one-year post-transplant, better subjective cognitive functioning was associated with greater self-efficacy for symptom management and led to less depressed mood, reduced anxiety, and higher QOL. Other studies found those with lower levels of self-efficacy reported higher symptom severity, distress, pain, fatigue, and worse physical condition and performance (Kelleher et al., 2016; Mystakidou et al., 2010). These studies were with patients with cancer, not receiving HSCT and not during acute treatment or hospitalization. The results of this study are significant in that they establish that SESM impacts symptom distress

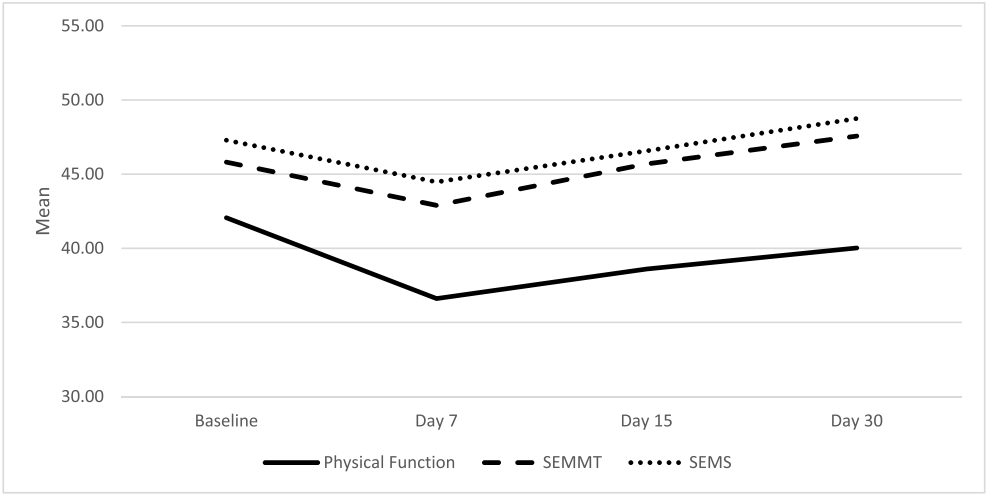

Fig. 3. Physical Function and Self-efficacy for Symptom Management Changes over time SEMMT = Self-efficacy for Managing Medications and Treatments; SEMS = Self-efficacy for Managing Symptoms.

Table 2
Dependent Samples t-tests (p-values, effect sizes) at all time points.

Dependent Samples t-tests (p-values, effect sizes)				
Instrument	Baseline–Day 7	Day 7–15	Day 15–30	Baseline-Day 30
SDS	< .001[a], .694	.003[a], .582	< .001[a], .812	.083, .311
Physical Function	< .001[a], .753	.187, .251	.426, .145	.107, .288
SEMMT	.044[a], .359	.031[a], .406	.157, .252	.430, .139
SEMS	.008[a], .481	.027[a], .417	.024[a], .413	.406, .146

Abbreviations: SDS = Symptom Distress Scale; SEMMT = Symptom Management for Managing Medications and Treatments; SEMS = Self-efficacy for Managing Symptoms.

[a] Significant at the .05 level.

Table 3
Correlation between symptom distress, physical function, and self-efficacy.

Correlation to SEMS scale r(p)				
		Physical Function	SEMMT	SEMS
Symptom Distress	Baseline	-.530[a] (.001)	-.324[b] (.044)	-.605[a] (< .001)
	Day 7	-.499[a] (.004)	-.320 (.065)	-.469[a] (.005)
	Day 15	-.677[a] (< .001)	-.272 (.120)	-.614[a] (< .001)
	Day 30	-.463[a] (.007)	-.439[b] (.011)	-.602[a] (< .001)
Physical Function	Baseline		.268 (.094)	.367[b] (.020)
	Day 7		.265 (.150)	.376[b] (.037)
	Day 15		.136 (.457)	.539[a] (.001)
	Day 30		.331 (.060)	.526[a] (.002)
SEMMT	Baseline			.541[a] (< .001)
	Day 7			.655[a] (< .001)
	Day 15			.559[a] (.001)
	Day 30			.757[a] (< .001)

SEMMT = Self-efficacy for Managing Medications and Treatments; SEMS = Self-efficacy for Managing Symptoms Scale.

[a] Correlation is significant at the .01 level (2-tailed).

[b] Correlation is significant at the .05 level (2-tailed).

during the acute phase of transplant.

For the final aim, an interaction was present between the moderator variable of symptom distress, SESM and physical function at day 15, which may be due to symptom distress being at the highest level at day 7. In participants with low symptom distress, high SESM was associated with higher physical function. Having less symptom distress has an impact on overall feelings of health and physical function and may increase confidence to manage symptoms. When patients feel their worst, they may be unable to participate in symptom management activities. By day 15, patients' symptom distress is starting to lessen, and physical function and self-efficacy are improving, resulting in the moderation effects seen here. This conclusion is verified by the patients' perspective as patients described feeling too poorly to participate in their care (White et al., 2019). For example, when talking about his symptoms, one patient stated, “I was sicker than a dog … there was no way I could have pulled myself through or anything I could have done to make myself feel better.” Another patient stated, “For a long time in this process I was not self-sufficient, and that's tough.” As patients improve (day 15), the interaction between symptom distress, SESM and physical function may be more apparent and then return to baseline levels as symptoms lessen by day 30.

Evidence shows that interventions to reduce distress improve patients’ ability to follow treatment regimens and improve outcomes of care (Holland and Alici, 2010). Patients are being discharged from the acute care setting earlier and are expected to manage their symptoms and treatment plans, but not all are able to do so. Having a plan of care that includes assessment of SESM before HSCT will allow for patient-centered interventions to enhance SESM and reduce symptom distress in the acute phase. Using the SESM assessment, multidisciplinary interventions that are patient-specific can be developed by the oncology care team. These interventions can include areas that alter SESM such as symptom awareness, feelings of anxiety or depression, setting goals and acting to meet them. Knowledge of how to manage treatment regimens and communicate with care providers also may be included (White et al., 2017). Education level could be an important factor in the development of self-efficacy and further research is needed to understand the connection between SESM and education in the acute transplant phase. Ideally, implementation of these interventions would occur when symptom distress is low, as high physical and psychological symptom distress, especially in the presence of cognitive impairment, is a barrier to SESM (Wu et al., 2012).

4.1. Limitations

This study was a single-center study with a small sample size. Most of the participants received autologous transplants. Allogenic HSCT patients tend to have more severe symptoms and a longer recovery time (Wong et al., 2010). This study focused on symptom distress related to physical symptoms and did not include psychological components of symptom distress such as depression or anxiety. Depression has been associated with greater symptom distress in the acute phase post HSCT (Artherholt et al., 2014). Use of the HCT-CI scale in this study on autologous patients is a limitation as previous studies validated the use of the HCT-CI in allogenic patients (Sorror et al., 2005, 2014). Another limitation is the lack of ethnic diversity, which is common in clinical care and HSCT studies (Schriber et al., 2017). Generalizability is limited, given that white, non-Hispanic, and married persons tend to score self-efficacy at higher levels (Gruber-Baldini et al., 2017).

4.2. Strengths

This is the first known report on SESM and symptom distress during the acute phase after HSCT. Participation was high and questionnaire completion rates were 90%, with a small amount of missing data due to participants being too ill to complete the surveys. Symptom and SESM data from these patients would have been valuable as their symptom experience was likely more severe. To the author's knowledge, this is the first study to use PROMIS self-efficacy tools to measure SESM in the HSCT population. The combination of the SEMS and SEMMT instruments for measuring SESM provided a comprehensive view of the concept.

This small study supports the relationship between SESM, symptom distress and functional status in the acute phase of HSCT and provides a foundation for future intervention research. Enhancing SESM during all phases of transplant, especially when symptoms are at their most distressing, has potential to improve symptom management and ultimately patient outcomes. For HSCT patients with severe symptoms and complex treatment regimens, the transplant team can assess and implement patient-centered interventions to enhance SESM. Facilitation of self-efficacy will enable patients to manage their symptoms effectively and lead to improved outcomes including functional status, QOL, and decreased utilization of heath care resources.

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Disclosures/conflict of interest

No conflict of interest has been declared by the authors.

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