

## ORIGINAL ARTICLE

## Distress, problems and supportive care needs of patients treated with auto- or allo-SCT

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Hematological malignancies and treatment with hematopoietic SCT are known to affect patients' quality of life. The problem profile and care needs of this patient group need clarification, however. This study aimed to assess distress, problems and care needs after allo- or auto-SCT, and to identify risk factors for distress, problems or care needs. In this cross-sectional study, patients treated with allo-SCT or auto-SCT for hematological malignancies completed the Distress Thermometer and Problem List. Three patient groups were created: 0–1, 1–2.5 and 2.5–5.5 years after transplantation. After allo-SCT, distress and the number of problems tended to be lower with longer follow-up. After auto-SCT, distress was highest at 1–2.5 year(s). Patients mainly reported physical problems, followed by cognitive-emotional and practical problems. A minority reported care needs. Risk factors for distress as well as problems after allo-SCT included younger age, shorter time after transplantation and GVHD. A risk factor for distress as well as problems after auto-SCT was the presence of comorbid diseases. Up to 5 years after auto-SCT or allo-SCT, patients continue to experience distress and problems. Judged by prevalence, physical problems are first priority in supportive care, followed by cognitive-emotional and practical problems.

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## BACKGROUND

Each year, approximately 135 000 persons in the United States<sup>1</sup> and 5600 in the Netherlands<sup>2</sup> are diagnosed with hematological malignancies. Auto- and allo-SCT are important treatment options, leading to improved survival in this patient group.<sup>3</sup> At the same time, both hematological malignancies and treatment procedures are known to adversely affect patients' health-related quality of life (QOL). QOL after auto- and allo-SCT is quite well documented.<sup>4–6</sup> Several studies investigated prevalence of symptoms after hematopoietic SCT,<sup>4,5,7–10</sup> reporting on physical symptoms such as infections, fatigue and GVHD, and psychological symptoms including depression and fear of relapse. However, we are not aware of any studies focusing on the entire problem profile of hematopoietic SCT patients, comprising the wide range of physical, psychological, practical, social and spiritual problems. In addition, although variation over time is to be expected, little information is available on whether patients shortly after transplantation report other problems than patients at long-term follow-up.

For some problems, patients may feel a need for help (care need), whereas for other problems, they may not. In case of a need, patients may already receive help to fulfill this need (met need) or not (unmet need). Previous research reported cancer patients to have a range of unmet needs, most frequently in the activities of daily living domain and then, in succession, in the psychological, information, psychosocial and physical domains.<sup>11</sup> Prevalence rates vary greatly between studies, partly because of differences in the classification and measurement of unmet needs, and also as a consequence of differences in disease, treatment and provision of health-care services.<sup>12,13</sup> To provide a more detailed analysis of

tumor-specific unmet needs, it has been argued that needs assessment should be conducted within homogeneous patient samples.<sup>11</sup> In a study in multiple myeloma patients, a quarter of patients reported at least one unmet need. Practical needs such as hospital parking and obtaining (life) insurance were mentioned most.<sup>14</sup> Patients with hematological malignancies at completion of treatment most frequently reported unmet needs concerning managing fear of recurrence, the need for a case manager and communication between treating doctors.<sup>15</sup> To the best of our knowledge, supportive care needs have not been studied in hematopoietic SCT patients specifically.

A clear insight into the problem profile and care needs of hematopoietic SCT patients is a requirement for establishing patient-centered care. We aimed (a) to assess the prevalence and distribution of distress, problems and corresponding care needs up to 5 years after auto- and allo-SCT in patients with hematological malignancies; and (b) to determine risk factors for reporting distress, problems and care needs.

## MATERIALS AND METHODS

## Sample and setting

A cross-sectional design was used. For comparing patients at shorter and longer time periods after transplantation, we *a priori* created three groups: patients at 0–1, 1–2.5 and 2.5–5.5 years after transplantation. The following inclusion criteria were applied: patients treated with auto- or allo-SCT for hematological malignancies at our hospital between 1 January 2006 and 31 October 2011 (allo-SCT) or between 1 January 2006 and 31 December 2011 (auto-SCT); and at least 18 years at the time of transplantation. Patients were excluded if they had insufficient command of the Dutch language to complete questionnaires.

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## Procedure

Eligible patients were sent a letter describing the study and requesting their participation, along with a questionnaire on sociodemographic data, comorbid diseases, distress, problems and corresponding care needs. Medical-somatic data (type of transplant, conditioning regimen, diagnosis, remission status, presence of GVHD) was collected from medical records. Current presence of acute or chronic GVHD was assessed following the criteria of the National Institute of Health (NIH).<sup>16</sup> We differentiated between no sign of GVHD and any sign of GVHD. As not all patients obtained follow-up treatment in our hospital, information on remission status was only partly available. The study was approved by the Medical Ethical Committee of the VU University Medical Center. Informed consent was obtained from all participants.

## Measures

The Distress Thermometer<sup>17–19</sup> is a well-known tool for initial screening, serving as a single-item question screen to identify distress coming from any source. It has shown good sensitivity and specificity in cancer patients.<sup>20–22</sup> For hematopoietic SCT patients, a cutoff score of 5 on the Distress Thermometer was supported (sensitivity 1.00, specificity 0.68 for detecting psychological distress).<sup>23</sup> The Problem List<sup>24</sup> asks patients to identify their problems in five domains: practical, family, cognitive-emotional, spiritual/religious and physical. We used the Problem List as described in the paper of Tuinman *et al.*,<sup>21</sup> following the recommendations of the Comprehensive Cancer Center in the Netherlands. For study purposes, we additionally asked patients for every domain in which they reported at least one problem, whether they (a) already received sufficient help for this problem (met need); (b) did not receive help yet, but wished to receive help for this problem (unmet need); (c) did not receive help, did not want help at that particular moment, but were willing to consider help later (no need (now)); or (d) did not receive help and did not want help at that particular moment, nor in the future (no need (never)). Recent studies validated the Distress Thermometer combined with the Problem List<sup>20,21</sup> also in patients undergoing BMT.<sup>20</sup>

## Data analysis

Descriptive statistics were used to analyze patient demographics and clinical characteristics. For the first aim of the study, to assess the prevalence and distribution of distress, problems and care needs, descriptive statistics were used.  $\chi^2$ -tests were used to compare the three *a priori* created groups (0–1, 1–2.5 and 2.5–5.5 years after transplantation) with regard to the proportion of patients scoring above the cutoff score of 5 on the Distress Thermometer and the proportion of patients reporting problems in the five problem domains. A one-way between-groups analysis of variance was conducted to compare the mean number of reported problems at the different time points following transplantation. For care needs, the number of respondents in each group was too small to undertake statistical testing.

The second aim of our study was to determine risk factors for reporting distress, problems or care needs. Multiple linear regression analysis was used to determine risk factors for reporting higher distress and more problems. A backward selection procedure with  $P < 0.05$  was applied. The independent variables comprised (a) sociodemographic factors: age, gender, marital status (partner versus no partner), education; (b) medical-somatic factors: number of comorbid diseases, diagnosis, time since transplantation, conditioning (auto-SCT) and GVHD (allo-SCT). For care needs, the number of respondents with unmet needs was too small for statistical testing. All statistical analyses were conducted using IBM SPSS Statistics version 20.0 (IBM SPSS Statistics for Windows, Armonk, NY, USA).

## RESULTS

### Sample characteristics

In 330 patients, 333 allogeneic transplantations were performed (three patients received two allo-SCT's because of secondary graft failure); 140 patients had died and the survival status of 20 patients was unknown. Of the 170 remaining patients, 165 fulfilled our inclusion criteria and were approached for participation in this study. In total, 123 patients agreed to participate and consequently filled out the questionnaire (response rate 74.5%).

In 438 patients, 449 auto-SCTs were performed (13 patients received 2 auto-SCTs); 100 patients had died, the survival status of 52 patients was unknown and an additional 58 patients had been treated with allo-SCT at a later stage. Of the 228 remaining patients, 187 fulfilled our inclusion criteria and were approached for participation in this study. In total, 125 patients filled out the questionnaire (response rate 66.8%). Sample characteristics are described in Table 1.

### Allo-SCT

Distress tended to be lower with longer follow-up: the percentage of patients scoring above the cutoff point of 5 on the Distress Thermometer was highest in the patient group 0–1 year(s) after allo-SCT, and lowest in the group 2.5–5.5 years after allo-SCT. The differences between groups with regard to the number of patients scoring above the cutoff point of 5 reached borderline statistical significance ( $\chi^2 = 5.07$ ,  $P = 0.08$ ) (see Figure 1). Younger age, having no partner, shorter time since transplantation (0–1 versus 2.5–5.5 years) and presence of GVHD were significant risk factors for a higher score on the Distress Thermometer (see Table 2).

Overall, 96.7% of allo-SCT patients reported at least one problem. When separated per domain, the percentages of patients reporting problems varied from 16.7% for spiritual problems to 95.1% for physical problems (see Figure 2). These differences in proportions for the five problem domains were statistically significant ( $\chi^2 = 211.24$ ,  $P < 0.001$ ).

Specific problems were mainly in the physical domain (see Table 3). During every time period after transplantation, the physical problems *being out of shape/condition*, *fatigue* and *muscle strength* were in the top three. Cognitive-emotional problems and practical problems were reported as well, but less frequently. The mean number of reported problems was 14.27 (s.d. 7.62) at 0–1 years after allo-SCT, 12.83 (s.d. 10.60) at 1–2.5 year(s) after allo-SCT and 7.90 (s.d. 6.28) at 2.5–5.5 years after allo-SCT. These group means differed significantly from each other ( $F(2, 119) = 7.45$ ,  $P = 0.001$ ), with a medium effect size (0.11, calculated using  $\eta^2$ ). *Post hoc* comparisons using the Tukey's HSD (honestly significant difference) test indicated that the mean scores for the groups 0–1 and 1–2.5 year(s) both differed significantly from 2.5 to 5.5 years. Risk factors for higher number of reported problems were female gender, younger age, shorter time since transplantation (0–1 versus 2.5–5.5 years) and presence of GVHD (see Table 2).

Of the allo-SCT patients reporting at least one problem, the percentage reporting unmet care needs ranged from 0 to 10.6% for the separate problem domains (see Figure 3). Approximately half to three-quarters of the patients with problems did not report a need for care (no need). Half of these patients mentioned not having any need for care (never), whereas the other half reported possibly needing care in the future. Patients had relatively many met needs in the physical and practical domains compared with the other problem domains.

### Auto-SCT

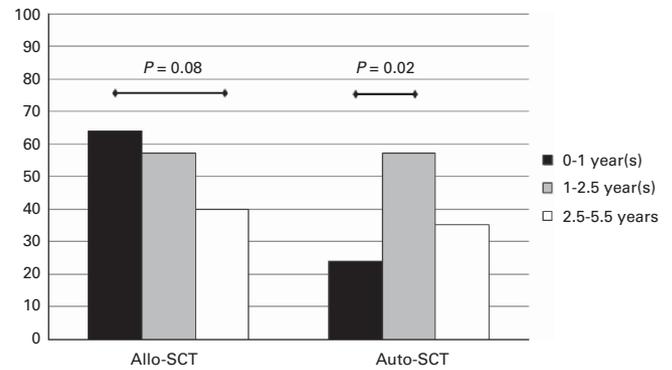
The group 1–2.5 year(s) after auto-SCT had the highest percentage of patients scoring above the cutoff point on the Distress Thermometer (57.1%, see Figure 1). The difference between the three groups was significant ( $\chi^2 = 7.92$ ,  $P = 0.02$ ). Male gender, more comorbid diseases and time since transplantation (1–2.5 year(s) as compared with the groups 0–1 and 2.5–5.5 years) were significant risk factors for a higher score on the Distress Thermometer (see Table 2).

Overall, 88.0% of the auto-SCT patients reported at least one problem. This percentage varied per domain, from 9.1% reporting spiritual problems to 82.4% reporting physical problems (see Figure 2). These differences in proportions for the five separate domains were statistically significant ( $\chi^2 = 185.34$ ,  $P < 0.001$ ).

**Table 1.** Sample characteristics

	Allogeneic (n = 123)	Autologous (n = 125)
Gender, female, n (%)	75 (61.0)	71 (56.8)
Age (years), mean (s.d.)	55.4 (10.8)	57.8 (9.6)
BMI, mean (s.d.)	24.9 (4.3)	26.7 (4.5)
<i>Marital status, n (%)</i>		
Single	14 (11.4)	16 (12.8)
Married/partnership	97 (78.9)	94 (75.2)
Divorced/widowed	12 (9.7)	15 (12.0)
Ethnicity, from Dutch origin, n (%)	116 (95.1)	116 (93.5)
<i>Education, n (%)</i>		
Primary school	6 (4.9)	9 (7.3)
Secondary school	81 (65.8)	76 (61.3)
College	23 (18.7)	29 (23.4)
University	13 (10.6)	10 (8.1)
<i>Employment status, n (%)</i>		
Full-time/part-time	19 (15.4)	29 (23.2)
On (temporary) medical leave or disability	47 (38.2)	42 (33.6)
Full-time homemaker	10 (8.1)	13 (10.4)
Retired	34 (27.6)	32 (25.6)
Other	13 (10.6)	9 (7.2)
<i>Diagnosis, n (%)</i>		
Acute leukemia	42 (34.1)	6 (4.8)
Chronic leukemia	13 (10.6)	—
Non-Hodgkin's lymphoma	23 (18.7)	51 (40.8)
Hodgkin's lymphoma	—	5 (4.0)
Multiple myeloma	27 (22.0)	62 (49.6)
Myelodysplastic syndrome	11 (8.9)	—
Miscellaneous	7 (5.7)	1 (0.8)
<i>Time since transplantation, n (%)</i>		
0–1 year(s)	26 (21.1)	21 (16.8)
1–2.5 years	36 (29.3)	42 (33.6)
2.5–5.5 years	61 (49.6)	62 (49.6)
<i>Medical comorbidities, n (%)</i>		
None	25 (20.3)	33 (26.4)
1	69 (56.1)	55 (44.0)
2	20 (16.3)	28 (22.4)
3 or more	9 (7.3)	9 (7.2)
<i>Remission status</i>		
CR	89 (72.4)	34 (27.2)
Very good partial response	5 (4.1)	12 (9.6)
Partial response/PR	1 (0.8)	2 (1.6)
Stable disease	1 (0.8)	3 (2.4)
Relapse after CR	5 (4.1)	2 (1.6)
Progressive disease	3 (2.4)	3 (2.4)
Unknown	19 (15.4)	69 (55.2)
<i>GVHD, n (%)</i>		
Acute GVHD	1 (0.8)	—
Chronic GVHD	67 (54.5)	—
No	36 (29.3)	—
Unknown	19 (15.4)	—
<i>Conditioning (allo-SCT), n (%)</i>		
Myeloablative	8 (6.5)	—
Non-myeloablative	110 (89.4)	—
Unknown	5 (4.1)	—
<i>Conditioning (auto-SCT), n (%)</i>		
HDM	—	63 (50.4)
BEAM (± radioimmunotherapy)	—	54 (43.2)
BU/cyclofosfamide	—	6 (4.8)
High-dose cytarabine	—	2 (1.6)

Abbreviations: BMI = body mass index; HDM = high-dose melphalan.

**Figure 1.** Percentage of patients scoring above the cutoff point of 5 on the Distress Thermometer.

As after allo-SCT, specific problems reported by auto-SCT patients were mainly in the physical domain (see Table 3). During every time period after transplantation, the top four comprised the problems *being out of shape/condition, fatigue, muscle strength and tingling in hands and feet*. Cognitive-emotional and practical problems were reported as well, but less frequently. The mean number of reported problems was 7.19 (s.d. 5.83) at 0–1 year(s) after auto-SCT, 8.60 (s.d. 7.40) at 1–2.5 year(s) after auto-SCT and 6.56 (s.d. 5.79) at 2.5–5.5 years after auto-SCT. These group means did not differ significantly from each other ( $F(2, 122) = 1.27, P = 0.28$ ). Younger age and more comorbid diseases were significant risk factors for a higher number of reported problems (see Table 2).

Of the auto-SCT patients reporting at least one problem, the percentage with unmet care needs ranged from 0 to 8.0% (see Figure 3). Approximately half to three-quarters of the auto-SCT patients with problems did not report a need for care (no need). Half of these patients mentioned not having any need for care (never), whereas the other half reported possibly needing care in the future. Patients had relatively many met needs in the physical and practical domains compared with the other problem domains.

## DISCUSSION

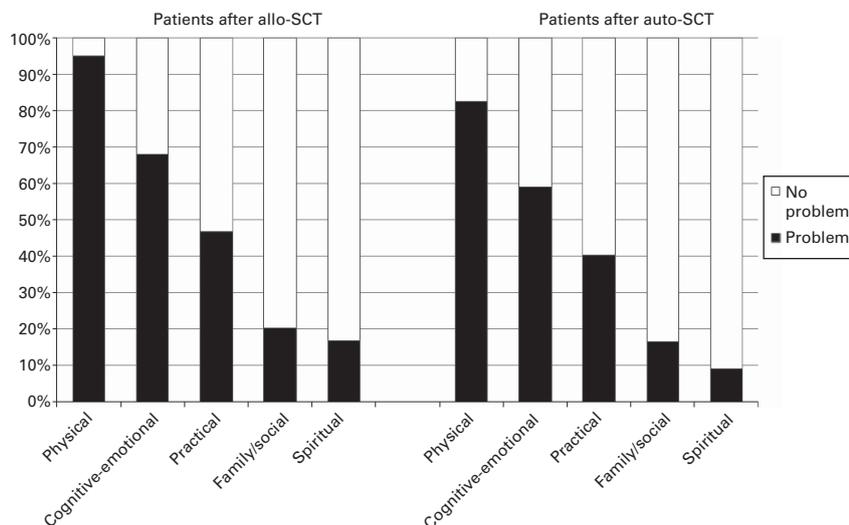
For establishing patient-centered care, elucidating the problem profile of hematopoietic SCT patients is needed, as well as a clear insight into their care needs. The results of this study show that up to 5 years after auto- or allo-SCT, patients continue to experience distress and problems, mainly in the physical domain. Being out of shape/condition, fatigue, muscle strength and tingling in hands and feet were most frequently reported. Cognitive-emotional problems like tension, memory and concentration difficulties, and practical problems such as housekeeping were reported as well, but less frequently. A minority reported (unmet) care needs. Risk factors for distress and/or problems after allo-SCT included female gender, younger age, no partner, shorter time after allo-SCT and presence of GVHD. Risk factors after auto-SCT included male gender, younger age, more comorbid diseases and time after auto-SCT.

*Allo-SCT:* Patients' distress tended to be lower with longer follow-up. Also the mean number of problems was lowest at 2.5–5.5 years after transplantation. Problems with physical condition and fatigue were consistently reported: even 2.5–5.5 years after transplantation, 60.3–66.1% of patients experienced these problems. These percentages, as well as those of problems with muscle strength, were higher than in previous studies investigating hematopoietic SCT survivors.<sup>8,25,26</sup> Other former studies investigated outpatients with hematological malignancies, not necessarily treated with hematopoietic SCT.<sup>27,28</sup> Compared with these studies, allo-SCT patients had similar levels of energy

**Table 2.** Risk factors for distress and number of problems

	b	s.e.	$\beta$	P-value
<i>Allo-SCT—distress</i>				
Age	-0.050	0.025	-0.189	0.05
Marital status	-1.568	0.648	-0.226	0.02
Time since SCT (1–2.5 versus 0–1 years)	-0.920	0.752	-0.148	0.22
Time since SCT (2.5–5.5 versus 0–1 years)	-1.687	0.687	-0.298	0.02
GVHD	1.274	0.558	0.214	0.03
				Adjusted $R^2 = 0.18$
<i>Allo-SCT—number of problems</i>				
Gender	-3.376	1.668	-0.195	0.05
Age	-0.183	0.072	-0.233	0.01
Time since SCT (1–2.5 versus 0–1 years)	-1.062	2.228	-0.057	0.64
Time since SCT (2.5–5.5 versus 0–1 years)	-4.991	2.062	-0.296	0.02
GVHD	3.727	1.695	0.210	0.03
				Adjusted $R^2 = 0.18$
<i>Auto-SCT—distress</i>				
Gender	0.949	0.451	0.182	0.04
Number of comorbid diseases	0.839	0.238	0.307	0.001
Time since SCT (0–1 versus 1–2.5 years)	-1.492	0.667	-0.216	0.03
Time since SCT (2.5–5.5 versus 1–2.5 years)	-1.135	0.501	-0.219	0.03
				Adjusted $R^2 = 0.13$
<i>Auto-SCT—number of problems</i>				
Age	-0.120	0.059	-0.180	0.04
Number of comorbid diseases	1.254	0.595	0.186	0.04
				Adjusted $R^2 = 0.04$

Independent variables in initial models allo-SCT: age, gender, marital status (no partner versus partner), education, number of comorbid diseases, diagnosis, time since transplantation (1–2.5 and 2.5–5.5 years after SCT versus reference group 0–1 years after SCT) and presence of GVHD. Independent variables in initial models auto-SCT: age, gender, marital status (no partner versus partner), education, number of comorbid diseases, diagnosis, time since transplantation (0–1 and 2.5–5.5 years after SCT versus reference group 1–2.5 years after SCT) and conditioning.



**Figure 2.** Problems after allo-SCT and auto-SCT.

problems, pain and numbness in hands and feet. However, allo-SCT patients reported many more mouth sores. This could be explained by the presence of oral lichenoid-like chronic GVHD. Concentration difficulties and nervousness were comparable; allo-SCT patients reported less depression/sad mood.<sup>27,28</sup>

*Auto-SCT:* The highest percentage of patients with distress was measured at 1–2.5 year(s) after auto-SCT. This result has, to our knowledge, not been reported before. A potential explanation is that patients may expect recovery until a year after auto-SCT. A longer lasting recovery process could be experienced as

disappointing, as a result of which more problems may be reported. Also, various kinds of social support may decline after the first year. Another contributing factor could be the occurrence of relapse, mostly 1–2 year(s) after auto-SCT. Besides, the number of patients at 0–1 year after auto-SCT is relatively small ( $n = 21$ ): the low number of problems in this group may be an incidental finding.

Physical problems were consistently present, with 38.2–46.7% of patients reporting problems with physical condition, fatigue and muscle strength at 2.5–5.5 years after auto-SCT.

**Table 3.** Problems after allo-SCT and auto-SCT

Allo-SCT		Overall (n = 123)		0–1 years (n = 26)		1–2.5 years (n = 36)		2.5–5.5 years (n = 61)	
1	Out of shape/condition (PP)	69.5%	Fatigue (PP)	88.0%	Fatigue (PP)	71.4%	Out of shape/condition (PP)	66.1%	
	Fatigue (PP)	69.5%							
2	Muscle strength (PP)	58.8%	Out of shape/condition (PP)	80.8%	Out of shape /condition (PP)	66.7%	Fatigue (PP)	60.3%	
3	Concentration (EP)	39.0%	Muscle strength (PP)	76.9%	Muscle strength (PP)	64.7%	Muscle strength (PP)	47.5%	
4	Tingling in hands and feet (PP)	37.4%	Concentration (EP)	62.5%	Tingling in hands and feet (PP)	54.3%	Pain (PP)	36.2%	
5	Mouth sores (PP)	35.9%	Tension/nervousness (EP)	60.0%	Concentration (EP)	50.0%	Sexual (PP)	28.1%	
6	Weight change (PP)	34.8%	Memory (EP)	58.3%	Weight change (PP)	48.4%	Mouth sores (PP)	27.1%	
	Pain (PP)	34.8%							
7	Memory (EP)	34.7%	Housekeeping (PRP)	56.0%	Memory (EP)	45.7%	Weight change (PP)	26.8%	
	Tension/nervousness (EP)	34.7%							
8	Housekeeping (PRP)	33.3%	Fears (EP)	50.0%	Mouth sores (PP)	44.1%	Housekeeping (PRP)	25.0%	
					Tension/nervousness (EP)	44.1%			
9	Sexual (PP)	32.2%	Tingling in hands and feet (PP)	48.0%	Skin dry/itchy (PP)	37.5%	Skin dry/itchy (PP)	23.2%	
10	Sleep (PP)	29.9%	Eating (PP)	45.8%	Pain (PP)	36.4%	Concentration (EP)	22.4%	
			Feeling swollen (PP)	45.8%	Sexual (PP)	36.4%	Sleep (PP)	22.4%	
			Mouth sores (PP)	45.8%			Daily activities (PP)	22.4%	
Auto-SCT		Overall (n = 125)		0–1 years (n = 21)		1–2.5 years (n = 42)		2.5–5.5 years (n = 62)	
1	Out of shape/condition	53.3%	Muscle strength (PP)	66.7%	Out of shape/condition (PP)	61.9%	Fatigue (PP)	46.7%	
2	Fatigue (PP)	49.2%	Out of shape/condition (PP)	57.9%	Fatigue (PP)	52.4%	Out of shape/condition (PP)	45.8%	
3	Muscle strength (PP)	47.4%	Tingling in hands and feet (PP)	52.9%	Muscle strength (PP)	51.2%	Tingling in hands and feet (PP)	42.6%	
4	Tingling in hands and feet (PP)	45.9%	Fatigue (PP)	50.0%	Tingling in hands and feet (PP)	47.5%	Muscle strength (PP)	38.2%	
5	Memory (EP)	35.3%	Weight change (PP)	41.2%	Concentration (EP)	37.5%	Memory (EP)	35.1%	
6	Tension/nervousness (EP)	32.5%	Tension/nervousness (EP)	38.1%	Memory (EP)	36.8%	Tension/nervousness (EP)	31.5%	
7	Pain (PP)	32.2%	Memory (EP)	33.3%	Pain (PP)	34.1%	Pain (PP)	30.2%	
			Pain (PP)	33.3%	Sexual (PP)	34.1%			
8	Concentration (EP)	29.6%	Skin dry/itchy (PP)	31.6%	Housekeeping (PRP)	31.0%	Fears (EP)	24.6%	
9	Sexual (PP)	25.0%	Taste (PP)	29.4%	Tension/nervousness (EP)	30.8%	Concentration (EP)	24.1%	
10	Housekeeping (PRP)	23.0%	Concentration (EP)	28.6%	Depression (EP)	26.3%	Depression (EP)	23.2%	

Abbreviations: EP = emotional problems; PP = physical problems; PRP = practical problems.

These numbers were higher compared with previous studies investigating hematopoietic SCT survivors.<sup>8,25,26</sup> Overall, 45.9% reported numbness in hands and feet, which could be a sign of peripheral neuropathy caused by chemotherapy. This percentage was comparable to outpatients with hematological malignancies,<sup>27,28</sup> as were the percentages of patients with lack of energy and pain. Auto-SCT patients seemed to report more sexual problems, less depression/sad mood and comparable percentages of concentration problems and nervousness.<sup>27,28</sup> Overall, the application of different patient selection criteria and assessment methods hindered direct comparison with other studies.

Judged by prevalence, our findings suggest an additional focus in supportive care on physical problems and, to a lesser extent, cognitive-emotional and practical problems. However, only a minority of patients reported unmet care needs. Explanations could be that patients already had received help, meeting their needs. This could reflect a good fit between offered care from the hospital department and patients' needs, and/or the capability of patients to ask professionals or their own social support system for help. Further, patients might, despite experiencing problems, just

not wish to receive help. Previous research has shown that most people react with resilience to potentially traumatic events, or recover after initial distress.<sup>29</sup> Finally, patients could be unaware of possibilities for receiving supportive care. For example, a patient still experiencing fatigue 3 years after transplantation might think that this is something he has to learn to live with, whereas improvements might be possible with targeted interventions. The fact that many patients were willing to consider help later indicates that timing is important when offering help. It is important to note that our results have to be seen in the light of the health-care system in the Netherlands, which differs in many aspects from, for example, the US system. The fact that all Dutch citizens are obliged to have health-care insurance may have led to a relatively low number of problems and unmet needs.

Our findings suggest a need for interventions targeting specific problems. Risk factors for distress and problems identified in the present study could help in selecting patients who might benefit from these interventions.<sup>30</sup> Problems with physical condition and muscle strength might be targeted with exercise programs.<sup>31,32</sup> Concentration and memory difficulties could be treated with

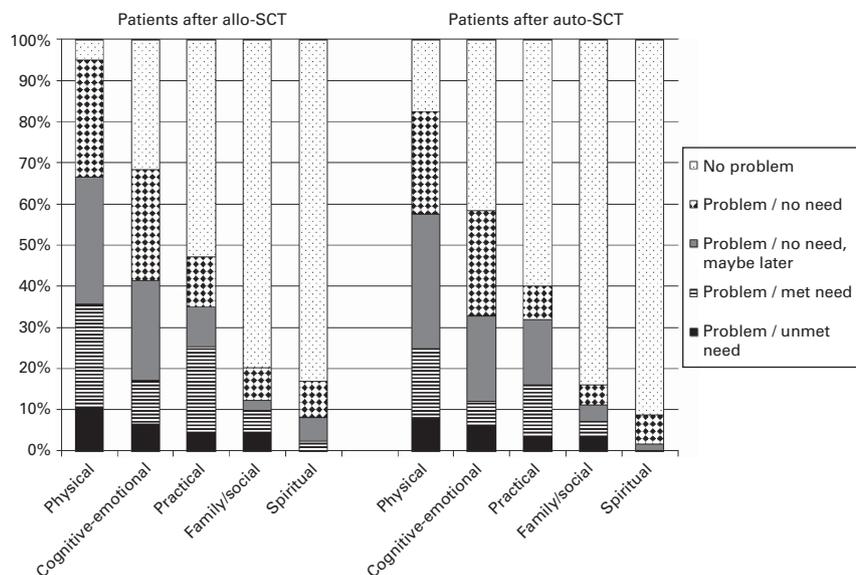


Figure 3. Care needs after allo-SCT and auto-SCT.

cognitive rehabilitation, which aims at compensating cognitive impairments.<sup>33</sup> In case of sexual problems, medical as well as behavioral treatment options exist.<sup>34</sup> Psychological treatment could improve nervousness or depression.<sup>35</sup>

With the current study, we reached a large number of hematopoietic SCT survivors willing to report on their problems and care needs. Consequently, we were able to study differences between patient groups at consecutive time periods after transplantation. The patients in this study reflect a relatively young, yet debilitated group: only a small percentage was working part-time or full-time at the time of assessment. Some limitations have to be taken into account. Using a questionnaire like the Problem List might have resulted in sensitive issues like sexuality to be under-reported.<sup>36</sup> The generalizability of our results could be limited since all patients were treated at the same hospital. Because of our cross-sectional design, no conclusions about the course of problems and needs within individual patients can be made. Further research is needed to explore the nature of patients' problems and care needs, to elucidate their help-seeking behavior.

In conclusion, up to 5 years after auto- or allo-SCT, patients continue to experience physical problems, as well as cognitive-emotional and practical problems. A minority reports unmet care needs, however. Judged by prevalence, physical problems are the first priority in supportive care, followed by cognitive-emotional and practical problems. Risk factors for both distress and problems after allo-SCT included younger age, shorter time after transplantation and presence of GVHD. A risk factor for distress as well as problems after auto-SCT was the presence of comorbid diseases.

#### CONFLICT OF INTEREST

The authors declare no conflict of interest.

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