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Quality of life and difficulties of patients encountered after autologous stem cell transplantation*

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Summary

Purpose: *To assess the quality of life (QoL) and difficulties of patients encountered after (at least day 100+) autologous stem cell transplantation (ASCT).*

Methods: *Patients from 4 bone marrow transplantation (BMT) centers in Ankara formed the study group. Data were collected via a socio-demographic form, the European Organization for Research and Treatment of Cancer (EORTC) Quality of Life Questionnaire-Core 30 (QLQ-C30), the Long-term BMT recovery questionnaire and a specific questionnaire adapted from Bush BMT Symptom Inventory for measuring symptom severity and symptom distress related to ASCT. Out of 114 eligible patients 67 (58.8%) responded the questionnaires and were included in the study.*

Results: *The mean time elapsed since transplantation was 16.1 months (range 4-43). Sixteen (23.9%) patients returned to work after transplantation; the mean time from transplantation to active work was 8 months. The symptoms experienced most, interfering with the patients' daily activities related to ASCT were fatigue, dental problems, hair loss, tingling sensation /numbness in hands and feet, mouth/throat problems, taste alterations, cough and skin problems. The majority of them reported fear of infection and disease relapse. Sexual dysfunctions, difficulty of concentration and difficulties of maintaining religious activities were also reported. 76% of patients reported their current QoL was the same or better than before transplantation and rated their current health-related QoL as good to excellent (mean 64.5). Financial difficulties, fatigue, sleeping problems, and pain were the factors most rated affecting QoL.*

Conclusion: *Fear of disease relapse, economical problems and difficulties with physical activities were reported as the most difficult factors to deal with after transplantation, showing the importance of creating multidisciplinary teamwork for these groups of patients.*

Key words: autologous stem cell transplantation, nursing, quality of life

Introduction

Many advances have been made in the field of hematopoietic stem cell transplantation. High-dose chemotherapy followed by ASCT is frequently being used as a treatment modality for a number of malignant diseases [1]. As experience with ASCT has become more widespread and the number of patients who have survived for longer periods after the procedure has increased, data concerning health-related QoL of bone marrow or stem cell transplanted patients have accumulated [2-8]. High doses of antineoplastic agents utilized in stem cell transplantation may cause short-term and long-term side effects that can affect survival and QoL. Recipients of hematopoietic stem cell transplantation face significant short- and long-term morbidity such as fatigue, recurrent infections, endocrine disorders, infertility, sexual dysfunction, altered social relationship, anxiety and depression [2,9,10].

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QoL has become an important outcome measure for evaluating the impact of cancer therapy, especially for aggressive cancer therapies such as hematopoietic stem cell transplantation (HSCT). As escalating numbers of transplantation are performed and individuals live longer post-transplantation, it is important to judge the value of transplantation not only by disease-free interval and survival but also by QoL. Improved data collection and record-keeping have contributed to better statistics regarding the number of post-transplantation survivors. However, QoL is poorly defined, and data regarding the long-term status of survivors remain limited [9]. Studies conducted to date have addressed primarily the initial acute and the early post-transplantation periods [2,6,8,11,12].

As overall survival rates have improved, there has been increased concern with QoL issues. It is important for both patients and their families to know how transplantation might affect their lives later. Nurses' knowledge regarding QoL can influence the information shared with potential recipients, families and also direct the care to be delivered [10,13,14].

QoL is a subjective phenomenon with differences from individual to individual and even in the same individual over time. There is agreement among investigators that the construct of QoL is multidimensional, subjective, and dynamic [15] and remains an abstract and complex issue. It is also noted that all these parameters are related to the individual's own experiences, and consequently the patient should be the most reliable source of information [15-17].

The importance of assessing QoL in patients undergoing stem cell transplantation was emphasized in 2 recent publications [18,19]. One showed that physicians tended to overestimate the QoL in their patients [18], while the concordance between physicians' and patients' estimates regarding the success of transplantation with respect to morbidity and mortality was largely dependent on the information given [19].

Accurate information regarding the long-term QoL is essential for programs striving to adequately inform potential transplant recipients and family members who are attempting to make decisions regarding transplantation. Awareness of long-term effects that may affect QoL can also guide program revisions to decrease the potential problematic side effects. Despite the growing recognition that QoL is important and a lot of data are available from many countries [9,14], little is known about patients' perceptions about QoL and difficulties after ASCT in Turkey. In this study, we aimed to examine the QoL and the difficulties of patients encountered after ASCT.

Methods

This descriptive study was performed in 4 BMT centers in Ankara, Turkey: Hacettepe University Hospital, Gulhane Military Medical Academy (GATA) Hospital, Numune Hospital, Ankara University Hospital, Department of Hematology and Medical Oncology. Patients selected for the study should have at least primary school education and be capable of giving informed consent. They also should have thorough evaluation tests from day 1 through 100 after ASCT and have achieved disease remission.

Upon obtaining approval from each institution, the records of all the BMT patients (1996-2002) were reviewed. In July 2002 the questionnaires were mailed to all patients who were still alive as of June 31, 2002. A letter describing the study along with 4 wide-ranging questionnaires covering 119 items, as detailed below, were sent to all eligible patients (n=114) and a total of 67 patients (58.8% response) who returned the questionnaire were included. The responders gave also their informed consent.

Instruments

The data were collected via a socio-demographic questionnaire, the Long-term BMT recovery questionnaire, the EORTC QLQ-C30, and a specific questionnaire adapted from Bush BMT Symptom Inventory (Bush$^{©}$ 1994, with permission) for measuring symptom severity and symptom distress related to ASCT.

Demographics (age, sex, educational level, marital status, occupation, insurance, place of living, BMT date, disease, family income, concurrent drugs), issues related to job/working status, returning to active work after transplantation, information before transplantation, information sources, and satisfaction status with the information were included in 26 items.

EORTC QLQ-C30 is an internationally validated 30-item questionnaire specifically designed for multidimensional measurement of QoL in cancer patients [20]. It includes 5 functioning scales (physical, role, emotional, cognitive and social functioning), 3 symptom scales (fatigue, nausea and vomiting and pain), and 6 single items (dyspnea, sleep disturbance, loss of appetite, constipation, diarrhea and financial difficulties). It also includes 2 questions on patient overall QoL and overall physical condition, allowing a global QoL score to be obtained. A Turkish translation of this questionnaire has been available and increasingly being used in Turkish studies [21,22]. Cultural validity and reliability of the scale (version 2.0) has been established by Guzelant et al. [21] in lung cancer patients and Beser and Oz [22] validated the version 3.0 in lymphoma patients receiving chemotherapy. The EORTC QLQ-C30 was scored using the algorithms as reported by Fayers et al. [23]. The total score is calculated from the scales and single items and ranges from 0 to 100. A high total score for functioning scales and global QoL scale indicates a high level of functioning or QoL. For the symptom scales/items a higher score represents a higher level of symptomatology.

Questions-related potential problems after ASCT were adapted from Bush BMT Symptom Inventory (Bush©, 1994, with permission) for measuring symptom severity and symptom distress related to ASCT. This, so-called BMT module questionnaire, developed by the Fred Hutchinson Cancer Research Center [24], is a descriptive inventory of late complications of BMT. This module was translated in Turkish and tested by 3 transplant physician, 2 medical oncologists/hematologists and 3 nurses. After this, 15 items (such as skin, eyes, mouth/throat, joints/muscles, pulmonary problems, hair and nail loss/changes, weight loss, heartburn, abdominal pain, abnormal sense of taste) were scaled as original work. Some items were removed (such as chronic graft-versus-host disease, sinusitis and runny nose). Several items (satisfaction with appearance, fear of infections, disease relapse and dying, difficulties in concentration/thinking clearly, problems with sex and intimacy) were asked as open-ended questions. Problems with religious activities, satisfaction with family/social support were asked and also one specific question was added as "if you were at the pre-transplant stage would you accept to undergo transplantation again?".

Long-term BMT recovery questionnaire is 9 item open-ended questionnaire which was translated and used in this study to gather more specific information on re-establishing daily life after ASCT, demands of recovery, coping strategies, limitations, current health problems, QoL and concerns about the future [25]. The translated version of this questionnaire was again tested by 3 transplant physicians, 2 medical oncologists/hematologists and 3 nurses for its content.

All these forms were pre-tested with 10 transplanted patients. Then, the preliminary testing responses were examined and discussed and corrections were made by researchers.

Statistical analysis

Descriptive statistics (frequencies, medians, means) were applied to analyse the correlation between clinical, socio-demographic and QoL data. The independent t-test was used to determine differences in scoring perceived QoL, subscales of QoL and some demographic variables. For all analyses, $p < 0.05$ was considered significant. Partially incomplete data were also included in the analyses and missing values were entered by using techniques as recommended in the EORTC manual [23]. The open-ended questions were grouped into themes and summarized as percentages.

Results

In the reliability analysis, Cronbach α coefficient was 0.84. Twenty forms from Numune Hospital (20/35) and 20 forms from Hacettepe University Oncology Hospital (20/44), 19 forms from GATA Hospital (19/40), and 8 forms from Ankara University Hospital (during outpatient visit) were filled in by patients. The total response rate (67/114) was 58.8%.

The demographics are listed in Table 1. At the time of the survey, the median age of the patients was 37.5 years (range 18-61). The mean time elapsed since transplantation was 16.4 months (range 4-43). There were 36 (53.7%) women and 31 (46.3%) men. Most subjects were married (76.1%) and had received only primary school education (44.8%). Patients' malignancies were non Hodgkin's/Hodgkin's lymphoma (55.4%), multiple myeloma (17%), breast cancer (13.9%) and leukemia (CML-AML-ALL), respectively. Sixteen patients (23.9%) returned to work after transplantation (mean duration from transplantation to active work 8 months; range 1-24).

As can be seen in Tables 2 and 3, the symptoms most interfering with daily activities related to ASCT were fatigue (73.9%), dental problems (51.6%), hair loss (51.6%), tingling sensation /numbness in hands and feet (51.4%), mouth/throat problems (44.4%), taste alterations (44.4%), cough (35.5%), skin problems (34.4%) and weight loss (31.7%). Subjects rated symptoms' severity and distress as mild to moderate (Table 2). The majority of them reported fear of infection (73.1%) and disease relapse (74.2%). Sexual dysfunctions (32.2%), difficulty of concentration (46.2%) and difficulties of maintaining religious activities (23.4%) were also reported (Table 3).

The mean scale and item scores from the EORTC QLQ-C30 and relationship with patient characteristics (age at survey, gender, income, time elapsed since transplantation and working status) are presented in Table 4. The mean scores on functional scales ranged from 69 to 81 and the overall patients' QoL was 64. The mean item score on symptoms scales ranged from 9 to 51. Patients were categorized into 2 age groups at the

Table 1. Demographic characteristics

Characteristic	*Mean*	*SD*	*Range*
Age at the time of the study (years)	37.5	11.5	18-61
Time elapsed since transplantation (months)	16.1	9.4	4-43
Return to active work after transplantation (months)	8	6.5	1-24
Gender	*N*	*%*	
Females	36	53.7	
Males	31	46.3	
Marital status			
Married	51	76.1	
Single	14	20.9	
Divorced	2	3.0	
Educational status			
Primary school	30	44.8	
Secondary/High school	25	37.3	
University	12	17.9	
Diagnosis			
Non Hodgkin's/Hodgkin's lymphoma	36	55.4	
Multiple myeloma	11	17.0	
Breast cancer	9	13.4	
Leukemia (CML/AML/ALL)	6	8.9	
Others*	3	4.6	
Working status/Actively working			
Yes	16	23.9	
No	51	76.1	

*osteosarcoma, ovary and testicular carcinoma

Table 2. The most frequent symptoms related to autologous stem cell transplantation

Symptom	*Frequency N (%)**	*Severity** Mean/SD*	*Distress** Mean/SD*
Fatigue	49 (77.7)	2.38/1.0	2.08/1.03
Dental problems	32 (51.6)	2.03/1.09	1.85/1.11
Hair loss	32 (51.6)	2.22/1.36	1.86/1.17
Numbness in hands and feet	30 (47.6)	1.77/0.94	1.74/0.96
Mouth/throat problems	28 (44.4)	1.68/0.89	1.63/0.9
Taste alterations	28 (44.4)	1.87/1.12	1.65/1.09
Cough	22 (35.5)	1.5 /0.8	1.42/0.76
Skin problems (dryness)	21 (34.4)	1.59/0.9	1.65/0.9
Weigh loss	20 (31.7)	1.54/0.9	1.5/0.9

*Frequency rates are defined as the percentage of items endorsed at the "2", "3" and "4" level of the scale (1= not at all, 2= a little bit, 3=quite a bit, 4=very much)
**Scale: 1= not at all, 2= a little bit, 3=quite a bit, 4=very much

Table 3. Other problems (n=67)

Problem	*N*	*%*
Fear of infection	49	73.1
Fear of disease relapse	49	74.2
Difficulty of concentration	31	46.2
Sexual dysfunction	19	32.2
Maintaining religious activities	15	23.4

time of survey: 18-39 and 40-61 years old. Younger patients had poorer scores than older ones. There was a significant difference between males and females in global health/QoL, physical and emotional functioning and symptoms scores (independent t-test, $p < 0.05$). Female patients had lower scores in functioning and global health than males and higher scores in symptoms. Generally, patients who actively worked reported better scores in functioning and symptoms than patients who were not working. Despite the high incidence rate of some symptoms, 82% of subjects rated their global health and QoL as good to excellent (mean 4.87, SD: 1.69; Figure 1).

Long-term BMT Recovery Questionnaire showed that 59.7% of patients reported that their current QoL was better than before transplantation, and 16.4% as not changed and/or worse. One third of patients who stated that they faced changes in their daily life listed the positive changes; the remaining listed negative changes, such as difficulties with physical activities, psychological distress, leaving their job, avoiding public areas and changes in social life. Fear of disease relapse, economical problems and difficulties with physical activities were reported as the most difficult factors to deal with after transplantation (Table 5).

When asked if they would choose again to under-

Table 4. Mean scale and item scores from the EORTC QLQ-C30

Scales	*Total sample* $\bar{x}$±*SD*	*Age at survey (years)****		*Gender****		*Income*			*Time elapsed since transplantation (months)*			*Working status****	
		18-39	*40-61*	*Male*	*Female*	*Poor*	*Moderate*	*Good*	*4-12*	*13-24*	*25-43*	*Yes*	*No*
Number of patients	*67*	*33*	*34*	*31*	*36*	*34*	*17*	*8*	*27*	*27*	*13*	*16*	*50*
Functioning Scales*													
Cognitive	81.5±22.5	79	84	86	78	78	82	96	85	79	70	85	80
Emotional	73.5±23.8	71	77	**80**	**68**	75	69	85	70	79	70	79	71
Physical	69.1±24.8	67	69	**75**	**64**	68	65	85	68	72	62	**80**	**66**
Role	71.2±39.1	**61**	**82**	72	71	68	76	75	67	73	77	75	70
Social	72.5±29.9	**63**	**82**	73	72	69	78	77	69	74	77	81	70
Global health /QoL*	64.1±27.3	64	65	**72**	**58**	63	64	80	62	68	60	62	65
Symptom scales**													
Financial impact	36.4±25.7	55	48	63	**41**	65	31	25	56	42	60	40	55
Fatigue	9.3±15.5	40	33	31	**41**	40	33	32	37	36	37	35	37
Pain	19.7±28.5	25	15	12	**26**	23	17	8	25	16	15	20	20
Insomnia	15.6±25.6	23	16	11	**27**	21	24	21	20	18	23	23	19
Appetite loss	15.6±26.3	21	10	13	18	19	18	0	17	12	21	15	16
Constipation	14.1±24.8	16	15	10	20	17	20	8	11	20	15	12	17
Diarrhea	51±41	16	12	17	12	19	9	4	11	18	13	10	15
Dyspnea	19.7±28.6	10	9	3	15	11	8	13	9	10	10	15	8
Nausea/vomiting	9.6±19.2	11	8	6	13	9	12	4	13	5	10	10	9

*Higher score indicates better function, **Higher score indicates more symptoms, ***p<0.05, bold numbers indicate statistical significance

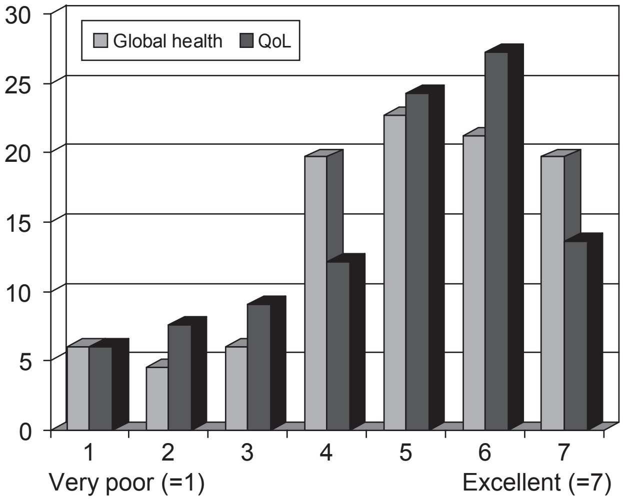

Figure 1. Subjects' perceptions of their own physical condition and degree of quality of life.

go transplantation, the majority of the patients (93%) stated they would make the same decision.

Discussion

This study had a number of limitations impacting the interpretation of the results. The Cronbach α coefficient of 0.84 would indicate a high degree of reliability for the EORTC QLQ-C30 in this study. Although the EORTC QLQ-C30, version 3.0, has been validated and cross-culturally tested in various cancer ethnicities including Turkish, Bush BMT module and Long-term BMT recovery questionnaires have not been validated. The total response rate of the survey (58.8%) could have been higher if all patients had been interviewed face to face. Patients who did not respond to the survey had either changed place of living without forwarding their new address or did not want to participate in the survey.

The overall finding was that most patients reported a good level of QoL as assessed by the EORTC QLQ-C30. This is consistent with other prospective reports [2,4,5,26,27] describing that most HCT recipients report good to excellent QoL following treatment despite ongoing physical and psychological sequelae [9]. In a sample of 58 autologous HSCT recipients 1 year post-transplantation, 36% were dissatisfied with their sexual activity, 27% reported sleep problems, and 5% reported frequent colds; however, the mean QoL was 8.9 on a 10-point scale [11].

Our study showed that patients were more concerned and concentrated about their physical status, which could be mostly attributed to the treatments they had. However, it is important to note that the disease, earlier treatment, transplantation, or continued treatment had a great impact on their lives. Cancer is a chronic illness involving long-lasting treatments and we do not have baseline pre-transplant QoL data. Lack of baseline data regarding the QoL of the patients in this study and lack of other studies from Turkey concerning this group of patients made it difficult to

Table 5. Subjects' answers/reports to long-term bone marrow transplantation recovery questionnaire

Current QoL compared with QoL prior to transplantation	*n=67*	*%*
Better than before	40	59.7
Same/not changed	11	16.4
Worse	11	16.4
Not responded	5	7.5
Changes in daily life after transplantation (n=56)	*n= 60**	*%*
Feeling better and being positive about life	20	33.3
Difficulties with physical activity	16	26.7
Psychological distress (feeling down, worry about future, stress)	10	16.7
Leaving their job or school	8	13.3
Avoiding public areas and changes in social life	6	10.0
Most difficult factors to deal with since return home (n=57)	*n=71**	*%*
Worries about disease and relapse	16	22.5
Economical problems /not able to work	15	21.1
Physical activity	14	19.8
Symptoms	8	11.2
Psychological distress and communication problems	8	11.2
Social problems	5	7.1
Infections	5	7.1
Worries about the future	*n=39*	*%*
Relapse of the disease	27	69.3
Job/economical problems	7	17.9
About sterility	3	7.7
Others (being dependent to someone, fear of death)	2	5.1

* Some items had multiple answers, QoL: quality of life

discuss and compare our results. Further prospective and longitudinal-design studies are needed in order to gain more reliable information and conclusions.

Patients were mostly concerned about fatigue, fear of recurrence/ infection, and financial difficulties after ASCT; all these had a negative impact on QoL. Fatigue ranked first as the most experienced and distressing symptom on QoL scale. In a study by Hjermstad and colleagues health-related QoL, fatigue and psychological distress were prospectively assessed in 248 cancer patients treated with allogeneic SCT (n= 61), or ASCT (n=69) or conventional chemotherapy (n=118) of whom 128 completed the assessments after 3 years. The authors observed only minor changes after the first year [28]. ASCT patients reported poorer functioning and more fatigue compared with the allogeneic SCT group after 3 years [29]. This study suggested a need for a closer follow-up of these patients with special emphasis on functional status and fatigue [29].

Younger patients have poorer scores than older ones. Role and social functioning scores are significantly higher in older groups [5].

Female patients have usually lower scores in functioning and global health and higher scores in symptoms compared with males. It is known from studies [28,30] that women tend to report more symptoms and lower functional scores than men, which is consisted with our results. In contrast to these results Hensel et al. did not identify any significant difference between genders [5].

Fear of disease relapse, economical problems and difficulties with physical activities reported as the most difficult factors to deal with after transplantation. Andrykowski et al. examined the psychosocial concerns in 110 stem cell transplanted patients (87% autologous) who were younger females and evidenced a poorer performance status and a larger number of post-transplantation concerns. The stronger concern was the possibility of recurrence of their malignant disease [30].

In a sample of 172 HSCT recipients, less than 50% reported that they felt back to normal, 32% reported not being back to normal, and 20% reported "almost" back to normal [31]. Those who reported that they did not feel back to normal cited decreased energy and physical strength, infertility, sexual dissatisfaction, lung problems, anxiety, depression, altered relationships, and employment issues. Twenty percent of those who felt "almost" normal listed the following problems: fear of relapse, restrictions of previous physical activities, and employment difficulties. When asked if they would choose again HSCT, 93% maintained they would make the same decision again [31]. In our study majority of the patients responded that they would choose again to undergo transplantation.

Conclusion

At the best of the authors' knowledge this is the first multicenter study in Turkey, which could be taken as a reference for further studies on QoL for patients undergoing ASCT. We suggest that sequential examinations of QoL in ASCT patients before, during and after transplantation are necessary to gain more insight.

As the findings of this study emphasized, financial difficulties, role, social and physical functions were significantly impaired in our patients. These findings show the importance of having multidisciplinary teamwork for these groups of patients. Our questionnaires and forms have outlined the topics we should work on, and develop programs to meet the patients' needs. Nurses and physicians should talk and ease the problems every time they see the patients. Better communication and creating more time to discuss the patient's fears will ease the problems.

Although QoL is affected by the physical changes following ASCT, we should not overlook the psychological and social effects in post-transplantation patients. Therefore, educational and counseling programs are very important to restore and improve QoL in these patients.

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