

# Screening Supportive Care Needs, Compliance to Exercise Program, Quality of Life, and Anxiety Level During the COVID-19 Pandemic in Individuals Treated with Hematopoietic Stem Cell Transplantation

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## Research Article

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# Abstract

**Purpose:** Primary aim was to address supportive care needs, compliance to exercise program, quality of life level (QOL), and anxiety level during the COVID-19 pandemic in individuals treated with hematopoietic stem cell transplantation (HSCT). Secondary aim was to investigate differences in outcome measures in terms of gender and to determine associated factors with supportive care needs and compliance to exercise program during pandemic.

**Methods:** The present study included individuals treated with HSCT and previously consulted to physical therapy. Data were collected by interviewing with participants on phone. Supportive care needs were assessed by using Supportive Care Needs Survey-Short Form 29<sup>TR</sup>. Compliance to the exercise program was recorded as percentage of walking duration to the recommended duration during the last week. The European Cancer Research and Treatment Organization Quality of Life Questionnaire-Cancer30 was used to assess QOL. The State-Trait Anxiety Inventory-I and Visual Analogue Scale were used to assess anxiety level.

**Results:** Totally 106 individuals were included. The psychological and physical supportive care needs were predominant in participants. Compliance to exercise program was low during the pandemic. Anxiety level was low, yet anxiety about COVID-19 was moderate severity in participants. Supportive care needs were correlated with anxiety level, performance level, duration after HSCT, and QOL ( $p \leq 0.05$ ). Compliance to exercise program was associated with performance level and QOL ( $p \leq 0.05$ ).

**Conclusion:** Our results offer supportive telehealth interventions should be considered during the COVID-19 pandemic for individuals treated with HSCT to decrease unmet supportive care needs and anxiety, to increase QOL, and to reduce isolation related physical inactivity.

## Introduction

The current COVID-19 pandemic have been affecting a wide range of public and have led to challenges in health care and supportive care services. Several changes have been occurred in the diagnosis, treatment, and supportive care options of various diseases. Face to face appointments have been generally postponed except for critical conditions. Due to the increased risk of infection, hospital visits were considerably limited [1,2]. Similar changes have occurred in the follow-up procedures of patients treated with hematopoietic stem cell transplantation (HSCT). Immunosuppression is highly prevalent in this patient population as a result of HSCT and other received treatments [3]. For these reasons, patients undergone HSCT were considered as a serious risk group for COVID-19 in the recent studies [4].

When considered cancer survivors' follow-up appointments were postponed, these changes may result with the lack of management of disease and related complications. As a result of these challenges, cancer survivors may have several concerns regarding their health during COVID-19 pandemic [1,5]. It has

been reported that emotional status and quality of life (QOL) of cancer patients may be adversely affected during the pandemic [6]. In addition, social isolation during the pandemic may cause physical problems and a decrease in functionality [7]. Accordingly, it is pointed out that health professionals working with cancer patients should examine patients' supportive care needs, physical and psychological status [1,5].

Since HSCT patients had higher risk of infection and other disease related complications, their problems or needs may be higher than other cancer survivors. Accordingly, this patient population was specifically analyzed who were previously consulted to physical therapy in the present study. Therefore, the primary aim was to determine supportive care needs, compliance to the exercise program, QOL level, and anxiety level during the COVID-19 pandemic in individuals treated with HSCT. Secondary aimed was to analyze differences in outcome measures in terms of gender and to determine associated factors with the supportive care needs, and compliance to the home exercise program in the participants.

## **Methods**

The present study conducted at Hacettepe University in Turkey. Patients who treated with HSCT and previously consulted to physical therapy were included. Data were collected by interviewing with the patients on the phone. Exclusion criteria were patients who were not available by phone, who stay in the hospital when called, who were not willing to participate, who were not able to cooperate, who had seriously chronic disease other than cancer, and who were being diagnosed with COVID-19. The Hacettepe University Ethical Committee approved the present study. The informed consent was read to the participants on the phone and their consent was obtained.

### **Outcome Measures**

#### ***Demographic and Medical Information***

Age, gender, height, body weight, educational status, profession, current working status, and marital status of the participants were recorded. The medical data were recorded including diagnosis, duration after diagnosis, HSCT type, duration after HSCT, and complications associated with HSCT.

#### ***Performance Status***

The Eastern Cooperative Oncology Group Performance Score (ECOG) was used to evaluate the overall performance of the participants. The ECOG evaluates globally patients' performance and is scored between 0 and 4 points. Higher scores indicate lower performance level (6).

#### ***Supportive Care Needs***

The Supportive Care Needs Survey-Short Form 29<sup>TR</sup> (SCNS-SF29) was used to identify supportive care needs of participants [8]. The SCNS-SF29 asks four different aspects of supportive care needs including healthcare and information (14 items), daily life (5 items) sexuality (3 items), and psychological needs (7

items). Each item is scored between 1 and 5 points (1=Not suitable for me, 2=Sufficient for me, 3=I need a little, 4=I need quite, and 5=I need very much). Higher scores indicate higher supportive care need in that aspect. As an alternative use, the questionnaire can also be used to determine the number of the perceived unmet needs (3 or higher scoring is considered unmet need) [9]. In addition, participants were asked how much they needed to be informed regarding COVID-19 (no need - a little needed - quite needed - very much needed).

### ***Compliance to the Exercise Program***

Among the participants who previously prescribed with a home exercise program (n=61) were asked on phone regarding the compliance to the program. Home exercise program was consisted of brisk walking, strengthening, and stretching exercises which were adjusted to the individual needs and performance level. Individuals were interviewed regarding their compliance to exercise prescription on phone. Compliance to brisk walking program that how much minute/week did they walk during the last week when compared to the recommended duration was recorded (0% compliance to 100% compliance).

### ***Quality of Life Level***

The European Cancer Research and Treatment Organization Quality of Life Questionnaire-Cancer30 (EORTC QLQ-C30) was used to assess health-related QOL. The questionnaire includes a total of 30 items which are scored between 1 (not at all) and 4 (too much) points. Three different scores are calculated for general health, functionality, and symptoms as a result of the questionnaire. Higher scores represent higher general health and functional scores. On the other hand, higher scores indicate higher symptom severity [10]. The Turkish version of the EORTC QLQ-C30 was conducted and it was found to be valid and reliable [11].

### ***Anxiety Level***

The State-Trait Anxiety Inventory-I (STAI-I) was used to determine anxiety level of the participants. The emotions or behaviors expressed in the 20 items are scored 1 (none) to 4 points (completely). The total score is between 20 and 80 points. Higher scores indicate higher anxiety level. The STAI-I was adapted to Turkish language and was found valid and reliable (9,10). The cutoff value was determined as 39 points for STAI-I [12]. Besides the STAI-I, a question of how worried individuals regarding COVID-19 was asked by using Visual Analogue Scale (0: not at all worried to 10: too much worried).

### **Statistical Analysis**

Statistical analysis was performed by using the Statistical Program for Social Sciences (SPSS) Version 23. The level of significance was set at 0.05 for all statistical analyses and the results were expressed as percentage (%) or Mean  $\pm$  Standard Deviation. The Kolmogorov-Smirnov test was used to determine normality of distribution. Since data did not meet parametric assumptions, the Mann Whitney U test was used to compare numerical data. The Spearman correlation coefficient test was used to assess associations between the recorded outcomes.

## Results

Among the 108 individuals who previously consulted to physical therapy and responded to the phone call, a total of 106 participants were included. Two persons were excluded because of staying in the hospital for a second HSCT (n=1) and being diagnosed with COVID-19 (n=1). Among the participants, 61 of those prescribed with home exercise program previously. When discussed with the patients regarding their compliance to the exercise prescription on phone, very few patients reported that they performed strengthening or stretching exercises. Demographic and medical characteristics of the participants were presented in Table 1. Participants were middle-aged and mainly diagnosed with multiple myeloma or lymphoma. Their mean duration after HSCT was over than one year. Most of the participants treated with autologous HSCT, had no comorbidity, and had no HSCT-related complication.

The mean supportive care needs, compliance to the exercise program, QOL level, and anxiety level of the individuals and differences in these measured outcomes according to gender were presented in Table 2. As a result of comparisons, female participants had significantly lower functionality score and higher symptom severity score than male participants ( $p \leq 0.05$ ). In addition, their psychological supportive care need was significantly higher than male participants ( $p \leq 0.05$ ). There was no significant difference in other outcome measures between female and male individuals. The most reported supportive care needs were shown in Figure 1. The most common supportive care needs of the participants were uncertainty about the future, fears about the cancer spreading, worry that the results of treatment are beyond their control, not being able to do things that they used to do, and anxiety.

Significant associated factors with the supportive care needs, compliance to the exercise program, and QOL level were presented in Table 3. According to the correlation analysis, supportive care needs were negatively correlated with anxiety and duration after HSCT ( $p \leq 0.05$ ). There was positive and low to moderate correlation between the ECOG performance status and supportive care needs ( $p \leq 0.05$ ). Supportive care needs were moderately and negatively correlated with functionality score of the EORTC QLQ-C30, while positively correlated with symptom score of the EORTC QLQ-C30 ( $p \leq 0.05$ ). General health score of the EORTC QLQ-C30 was negatively and moderately correlated with supportive care needs, while positively and moderately correlated with anxiety level ( $p \leq 0.05$ ). Compliance to the home exercise program was negatively correlated with the ECOG performance score and symptom score of the EORTC QLQ-C30, while positively correlated with general health and functionality score of the EORTC QLQ-C30 ( $p \leq 0.05$ ).

## Discussion

The present study screened the supportive care needs, compliance to the exercise program, QOL level, and anxiety level in individual treated with HSCT during the COVID-19 pandemic. The most common supportive care needs were related to psychological and physical limitations. Compliance to the home exercise program during the pandemic was considered as low level. Female participants were more vulnerable than male in terms of psychological needs and QOL. Anxiety was also low level in participants,

yet anxiety regarding the COVID-19 was moderate level. Supportive care needs were associated with performance level, duration after HSCT, QOL level, and anxiety level in the participants. In addition, compliance to the home exercise program was correlated with performance level and QOL level of participants.

The current and previous cancer cases have been experiencing unique challenges during the COVID-19 pandemic. It was previously reported that patients who had undergone HSCT were more fragile population than other cancer diagnosis for getting infected with the COVID-19 due to their poor immune system [4]. In consequence of these unexpected conditions, the physical and psychological impacts of the pandemic on patients with chronic illnesses were recommended to be investigated recently [13]. Since unique challenges may have been experienced by individuals who treated with HSCT, we aimed to screen this population in the present study. Our results showed the short-term impact of the pandemic on HSCT survivors after over than one year since transplantation.

When look at the unmet supportive care needs of the participants, psychological and physical needs were predominant in the present study. It was previously reported that physical and psychological needs may be higher than other health related needs during the pandemic in vulnerable populations such as cancer [13]. In the view of physical well-being, patients especially complained a problem in terms of the things that they were used to do in daily life. As a physical therapist, we suggest that a multidisciplinary team approach is needed to support individuals who treated with HSCT during the pandemic in terms of limitations during daily life and to reduce isolation related physical inactivity. On the other hand, compliance to the exercise program was considered as low in patients who previously received home exercise prescription. Telehealth technologies can help individuals to maintain regular exercise participation and to increase their motivation during the pandemic. In addition, identification of symptoms and side effects by using telehealth technologies during the pandemic may help to prevent the occurrence of severe adverse events needing hospital visit [14,15]. Patients treated with HSCT are needed supportive interventions during the pandemic more than ever not only to decrease symptoms, but also to reduce side effects of isolation and associated physical inactivity.

It was previously reported that delaying treatments or cancelled hospital visits because of prioritization of COVID-19 cases may cause distress in cancer patients regarding potential negative outcomes of their disease [6]. Anxiety level determined was low, however anxiety regarding the COVID-19 was moderate severity in our study population. We suggest that anxiety in patients should be further investigated that the main reason related with being infected with COVID-19 or challenges regarding postponed hospital visits. On the other hand, gender was found as an independent indicator for supportive care needs and QOL in the present study. Female participants had more supportive care need in psychological aspect than male and their QOL was also more diminished. Similar findings were found in female HSCT patients as their QOL, psychological health, and physical functions were lower than men [16]. Female individuals had higher stress than male in a previous study conducted in China during the COVID-19 outbreak [17]. Accordingly, female HSCT patients need more attention than male in terms of psychological status and

QOL during the COVID-19 pandemic. Additional research is warranted to understand underlying mechanism regarding impact of gender on psychological health and QOL.

Correlation analysis revealed that supportive care needs of the participants were associated with anxiety level, performance status, and duration after HSCT. As duration after HSCT increased, their supportive care needs decreased. This trend was similar with the previous studies in which individuals within earlier period after HSCT had higher adverse events related with HSCT [18]. In addition, the ECOG performance level was correlated with the supportive care needs suggesting that participants who had lower performance level had higher supportive care need. Similarly, patients who had lower performance was associated with lower compliance to the exercise prescription. Especially participants with poor performance level and who were within the earlier period after HSCT should be screened more frequently in terms of supportive care needs and to maintain regular exercise participation during the pandemic.

The supportive care needs of the participants were closely related with all aspects of the QOL in the present study. The results revealed that QOL level was higher in participants who had lower supportive care need. In addition, since higher compliance to the home exercise program was associated with higher QOL, patients treated with HSCT should be supported to regularly participate in an exercise program. There is enough data suggesting possible beneficial effects of supervised or non-supervised exercise programs on not only QOL but also physical, psychological, cardiopulmonary functions for patients undergoing HSCT [19,20]. Telehealth technologies are now facilitated to be used by health care professionals to screen cancer patients' health care and supportive care needs [21,22]. The American Medical Association has encouraged the use of tele health technologies by health care professionals to enhance health care maintenance during the COVID-19 pandemic [5]. In a recent study, virtual exercise sessions were reported as an essential therapy for especially cancer cases during the pandemic and the feasibility and effectiveness of tele-rehabilitation during the pandemic were recommended to investigated [23]. For these reasons, individuals treated with HSCT are needed to screen regarding their health and supportive care needs during the COVID-19 pandemic. Even contacting with a phone call with the patients to discuss their symptoms, psychological status, functionality, and participation to regular exercise program may help patients to increase QOL level and to reduce COVID-19 related anxiety and isolation related physical inactivity.

In conclusion, patients treated with HSCT had unmet supportive care needs mainly regarding psychological and physical wellbeing during the pandemic. Compliance to the home exercise prescription was low and it was related with performance level and QOL level in the participants. Female patients, individuals who had lower duration after HSCT and lower performance level were considered to be more vulnerable population in terms of unmet supportive care needs. Individuals treated with HSCT are needed supportive telehealth interventions to mitigate physical and psychological care needs and to promote patients to do exercise regularly during the COVID-19 pandemic. Virtual exercise interventions should be considered as essential for cancer cases during the pandemic not only to decrease symptoms and anxiety but also to reduce side effects of isolation related inactivity.

# Declarations

**Funding:** None.

**Conflicts of interest/Competing interests:** The authors indicated no potential conflict of interest.

**Ethics approval:** The Hacettepe University Ethical Committee approved the present study.

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## Tables

Table 1 Demographic and Medical Characteristic of Participants

<b>Outcomes</b>	<b>Mean±SD (Min-Max)</b>
Age, years	50.29±12.15 (20-70)
BMI, kg/m <sup>2</sup>	26.76±4.74 (16.41-45.78)
Duration after diagnosis, month	31.91±16.97 (9-84)
Duration after HSCT, month	16.99±10.48 (1-48)
Gender, n (%)	
Female	42 (39.6)
Male	64 (60.3)
Diagnosis, n (%)	
MM	36 (33.9)
Lymphoma	36 (33.9)
Leukemia	31 (29.2)
MDS	3 (2.8)
ECOG Performance Status	
0: Active	19 (17.9)
1: Limited vigorous physical activity	62 (58.5)
2: Symptomatic, independent in ADL	23 (21.7)
3: Limited ADL	2 (1.9)
Marital status, n (%)	
Married	94 (88.6)
Single	12 (11.4)
Education level, n (%)	
Illiterate	6 (5.6)
Elementary school	36 (33.9)
Secondary school	11 (10.3)
High school	29 (27.3)
Graduate	22 (20.7)
Postgraduate	2 (1.8)
Comorbidity, n (%)	
Yes	21 (19.8)
No	85 (80.2)
Transplantation type, n (%)	
Autologous	71 (67)
Allogeneic	35 (33)
Complication after HSCT, n (%)	
Yes	17 (16)
No	89 (83.9)
Current occupational status	
Yes	15 (14.2)
No	91 (85.8)

BMI: Body mass index, HSCT: Hematopoietic stem cell transplantation, MM: Multiple myeloma, MDS: Myelodysplastic syndrome, ECOG: The Eastern Cooperative Oncology Group Performance Score, ADL: Activities of daily living.

Table 2 Supportive Care Needs, Compliance to the Exercise Program, Quality of Life Level, and Anxiety Level During the COVID-19 Pandemic in Participants

Outcomes	Mean±SD (Min-Max)	Female	Male	Z	P
SCNS-SF29 Total Score	49.93±14.33 (29-70)	52.42±14.07	48.29±14.37	4.131	0.106
ADLN	10.28±5.31 (5-20)	11.00±5.09	9.81±5.43	-1.325	0.185
PN	14.77±4.70 (8-26)	16.28±4.46	13.78±4.62	-2.404	0.016*
HSCIN	21.38±6.29 (12-30)	21.30±6.21	21.43±6.38	-0.113	0.910
SN	3.49±1.12 (3-9)	3.83±0.84	3.26±0.78	-0.504	0.610
EORTC QLQ-C30, score					
General health	78.40±15.89 (33.33-100)	75.59±15.22	79.94±16.38	-1.654	0.098
Functionality	91.67±10.55 (22.22-100)	87.77±13.32	94.06±7.74	-3.366	0.001*
Symptom	7.55±9.35 (0-51.28)	10.62±11.65	5.56±7.14	-2.449	0.014*
STAI-I, score	36.90±3.75 (31-45)	36.19±3.43	37.37±3.90	-1.249	0.212
Anxiety regarding COVID-19 (0-10)	4.17±1.69	4.35±1.77	4.03±1.65	0.325	0.201
Compliance to EX (0-100%)	29.43±16.37	30.46±15.72	27.85±17.50	-2.607	0.460

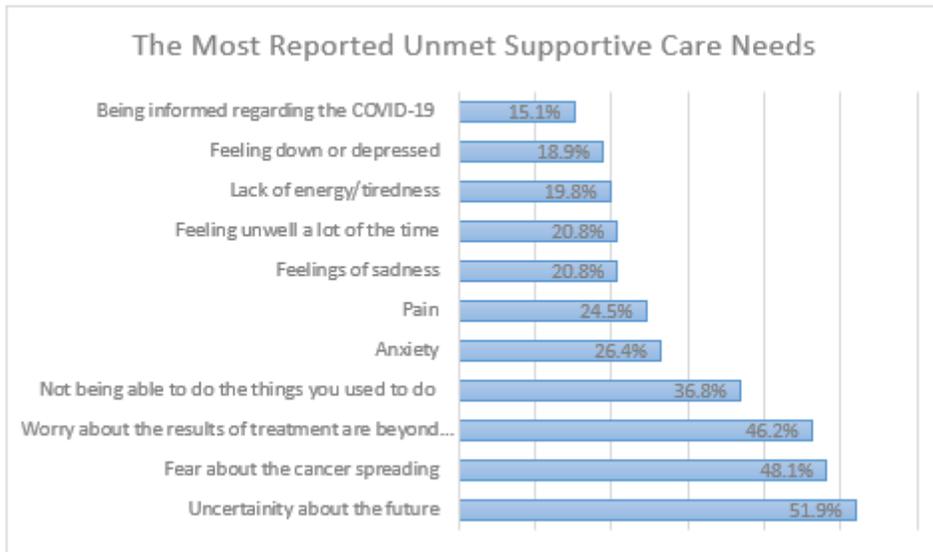
Quality of Life Questionnaire-Cancer30, STAI-I: State-Treat Anxiety Index-I, EX: Exercise program, Mann Whitney U test, \*p<0.05. SCNS-SF29: The Supportive Care Needs Survey-Short Form 29<sup>TR</sup>, ADLN: Activities of daily life need, PN: Psychological need, HSCIN: Health care service and informing need, SN: Sexuality need, EORTC QLQ-C30: European Cancer Research and Treatment Organization

Table 3 Significant Associated Factors with Supportive Care Needs, Quality of Life, and Compliance to the Exercise Program During the COVID-19 Pandemic in Participants

Outcomes	R value
SCNS-SF29 & STAI-I	-0.297*
SCNS-SF29 & ECOG	0.365**
SCNS-SF29 & duration after HSCT	-0.295*
SCNS-SF29 & functionality	-0.397**
SCNS-SF29 & symptom	0.497**
SCNS-SF29 & general health	-0.611**
Compliance to EX & ECOG	-0.392**
Compliance to EX & functionality	0.369*
Compliance to EX & general health	-0.280*
Compliance to EX & symptom	0.254*

SCNS-SF29: The Supportive Care Needs Survey-Short Form 29<sup>TR</sup>, STAI-I: State-Treat Anxiety Index-I, ECOG: The Eastern Cooperative Oncology Group Performance Score, HSCT: hematopoietic stem cell transplantation, EX: Exercise program. Spearman correlation coefficient test, \*p<0.05, \*\*p<0.001.

## Figures



**Figure 1**

The Most Reported Unmet Supportive Care Needs During the COVID-19 Pandemic in Participants