

The Effect of Educational Intervention on Care Dependency and Symptom Management After Hematopoietic Stem Cell Transplantation: A Theory-Based Randomized Controlled Study

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Abstract

The objective of the research was to determine the effect of educational intervention based on Bandura's Social Cognitive Learning Theory on care dependency and symptom management after hematopoietic stem cell transplantation.

Methods. This randomized controlled trial was conducted between January 2019 and February 2020 at the Hematopoietic Stem Cell Transplantation Center. All the patients were randomly divided into two groups: 53 individuals in the intervention group and 53 individuals in the control group. The sociodemographic data collection form, the Edmonton Symptom Assessment Scale and the Care Dependency Scale were used for data collection. Data were collected from the patients one day after hematopoietic stem cell transplantation and 12 weeks later.

Results. There were no statistically significant differences between the groups regarding the mean scores of the Edmonton Symptom Assessment Scale and the Care Dependency Scale at baseline. Twelve weeks after intervention, there were statistically significant differences between the groups regarding the mean scores of the Edmonton Symptom Assessment Scale and the Care Dependency Scale.

Conclusions. Educational intervention along with telephone counseling based on Bandura's theory was found to be an effective way to reduce symptom severity and care dependency in patients who underwent hematopoietic stem cell transplantation and is recommended for all patients after hematopoietic stem cell transplantation.

Keywords

Educational Intervention; Care Dependency; Symptom Management; Bandura's Social Cognitive Theory; Hematopoietic Stem Cell Transplantation

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Introduction

Cancer is a global health issue. Even though the death rates of cancer have significantly decreased in recent decades, its prevalence remains high. According to the World Health Organization's (WHO) GLOBOCAN 2020 report, 19.2 million new cases and 9.9 million cancer deaths occurred in 2020. About 1.3 million of these cases were diagnosed with non-Hodgkin lymphoma, leukemia, multiple myeloma, Hodgkin lymphoma [1].

Hematopoietic stem cell transplantation (HSCT) is a common treatment for hematologic malignancies such as non-Hodgkin lymphoma, leukemia, multiple myeloma, Hodgkin lymphoma. In the United States, by 2014, about

340,000 cumulative HSCTs were reported to be performed and in 2018, 22,729 HSCTs were performed [2, 3]. HSCT trends have increased in non-malignant and malignant diseases as well [4]. However, after transplantation, patients who were hospitalized for 3 or 4 weeks experienced some complications and symptoms that mostly started before transplantation and remained high even 100 days after transplantation; moreover, symptoms lasted for about two years [5, 6].

The reasons for these complications and symptoms were HSCT itself and side effects of therapies used in addition to HSCT, including chemotherapy, radiotherapy, immunosuppression [7–10]. After HSCT, patients experienced physical, physiological, and social problems. Fre-

quently occurring physical symptoms included loss of appetite, skin, eye, and mouth problems, sleep difficulties, fatigue, while physiological problems included distress, anxiety, and depression [7]. Especially patients' physical well-being was adversely affected after the reinfusion phases [11].

In the literature, these symptoms and complications have been reported to negatively affect the patients' quality of life (QoL) [6, 12, 13]. One of the main objectives of nursing care is to improve the patients' QoL. Therefore, nurses need to control these symptoms. Nurses are primarily responsible for general care of patients in the hospital and their education to maintain symptom management when patients are discharged from the hospital [8]. In addition, patient follow-up has been reported to be important to improve the patient's QoL and reduce symptom severity [8, 14, 15].

Patients' care dependency is associated with their symptom burden. As the patient's symptom and its severity increase, patient's dependency on care increases as well [16, 17]. For this reason, symptom management is important to decrease patients' care dependency as well. Treatment-related symptoms of HSCT last for about two years [5, 6]. Thus, self-management is a crucial part of symptom management in these patients. The WHO strongly recommends the implementation of self-management interventions in long-term care [18]. Guiding patients about their self-management is important to increase their self-efficacy.

Bandura's Social Cognitive Learning Theory is a theory of the learning process. The theory states that learning is a cognitive process occurring in a social context because we learn from our interactions with others. There are four steps of learning: attention, retention, reproduction, and motivation. Perceived self-efficacy is an important component of reproduction and motivation [19, 20]. Thus, improving self-efficacy is a key factor to maintain the management of symptoms such as long-term diseases [18]. As evaluating the persons' ability to manage symptoms is a cognitive process, the patients' perception of their ability is a key factor to determine the problems and to improve symptom management. According to Bandura, the development of self-efficacy is the way to create a target behavior in patients [18]. Educational interventions have been reported as an effective way to improve patients' self-efficacy in specific groups of diseases such as asthma, diabetic foot, chronic kidney disease, and some types of cancer [21–25]. However, there is a gap in studies evaluating the effect of educational intervention on self-management in post-HSCT patients.

The objective of the research was to determine the effect of educational intervention on care dependency and symptom management in post-HSCT patients.

Materials and Methods

Study Design

The study was of a randomized controlled design (Fig. 1).

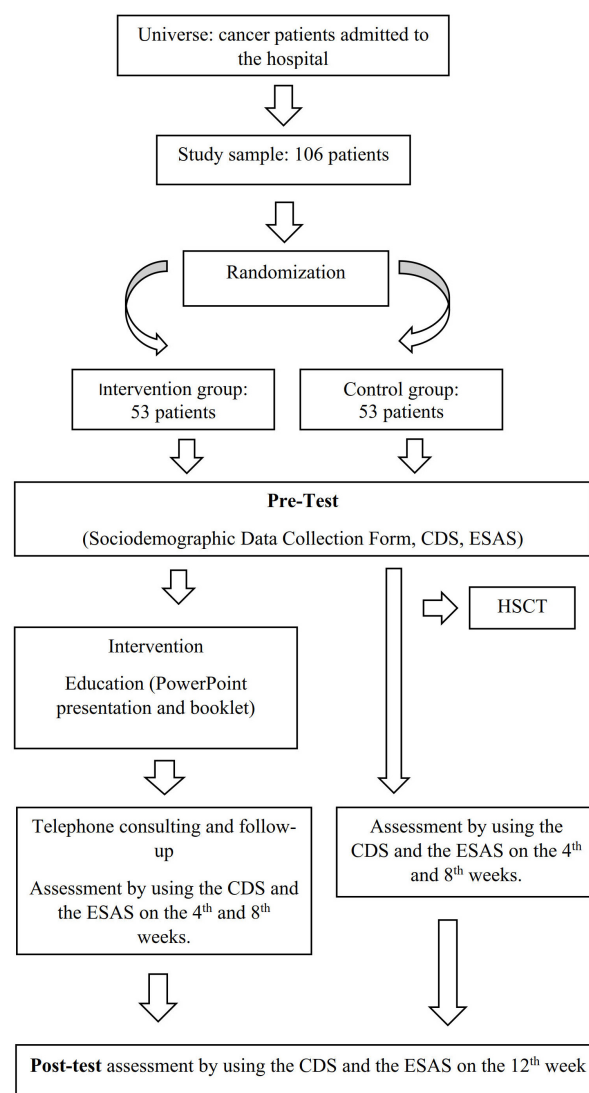


Figure 1. Flow diagram of the study.

Study Setting and Sample

The study was carried out at the Hematopoietic Stem Cell Transplantation Center of University Hospital between January 2019 and February 2020. Power analysis was used for sample determination: the minimum required sample was determined as 45 for each group and 90 in total ($\alpha = 0.05$, 0.95 CI, $d = 0.70$, actual power = 0.95). Considering the potential data lost during the follow-up period, the study was carried out with 106 (53 individuals per group) patients who were divided into two groups, the intervention and control groups, by using computer-assisted simple randomization.

Inclusion Criteria

- patients diagnosed with cancer (for 6 months or more);
- patients selected for treatment with HSCT;
- patients at the age of 18 years and older;
- patients able to communicate in Turkish;
- patients able to use a mobile phone (to answer a phone call and read messages);

- patients agreed to participate in the study.

Data Collection

Data collection started before patients received HSCT at the center. The sociodemographic data collection form was introduced to patients before their treatment. One day after treatment (pre-test), the Edmonton Symptom Assessment Scale (ESAS) and the Care Dependency Scale (CDS) were proposed to patients. The ESAS and CDS assessments were repeated on the 4th, 8th, and 12th weeks after treatment (Fig. 1). Face-to-face interviews were used during the pre-test and the 12th week, while phone calls were used for data collection on the 4th and 8th weeks. However, there was data missing for the 4th and 8th weeks as some patients did not answer phone calls, and other patients rejected to answer any questions. For this reason, the data of these weeks were not analyzed.

Sociodemographic Data Collection Form

This form was developed by researchers after literature review [8, 10, 26, 27] and consisted of 10 items, including age, gender, marital status, number of children, education level, working status, income level, diagnosis, disease duration, and type of transplantation (autologous and allogeneic). All information was self-reported and collected from patients.

Care Dependency Scale

The scale was developed by Dijkstra [28] and includes various physical and psychological aspects, providing a comprehensive assessment of patient's care dependence [28]. The validity and reliability of the Turkish version were assessed by Hakverdioğlu *et al.* [29]. The original version of the scale consists of 15 items assessing eating and drinking, incontinence, body posture, mobility, day and night patterns, getting dressed and undressed, body temperature, hygiene, avoidance of danger, communication, contact with others, sense of rules and values, daily activities, recreational activities, and learning ability. During its Turkish adaptation, two new items, namely memory and pray, were added to the scale and, therefore, the Turkish version consists of 17 items. The responses for the items range from 1 (completely dependent) to 5 (completely independent) points. Accordingly, the scores of the scale range from 17 and 85. Higher points reflect lower patient's dependency. In the current study, Cronbach's alpha value was 0.90.

Edmonton Symptom Assessment Scale

The scale was created by a group of palliative care physicians working at the University of Alberta, Edmonton, Alberta, Canada. The scale was developed to assess the intensity of nine common symptoms experienced by cancer patients, including pain, tiredness, nausea, depression, anxiety, drowsiness, appetite, well-being, and shortness of breath. Patients score the severity of each symptom from 0 to 10, where 0 means the absence of the symptom, and 10 means the worst possible severity of the symptom. The Turkish validity and reliability of the scale were assessed by Sadırlı and Ünsar in 2008. In the Turkish version,

other common symptoms, including skin and nail changes, oral sores, hand numbness, were added. Thus, the Turkish version of the scale consists of 11 items [30]. Cronbach's alpha of the Turkish version of the scale was reported as 0.83 [30]. Cronbach's alpha in this study was found to be 0.82.

Interventions

A printed booklet for educating patients was prepared after reviewing the literature [26, 27, 31, 32]. The booklet was evaluated by 10 different professionals, namely two hematologists, four hematology nurses, and four nursing academicians. The booklet was revised with regards to experts' opinions before its use in patient education.

Prior to HSCT, the researcher introduced herself and the study to the patient. A verbal and written permission was obtained from patients before the study. The sociodemographic data collection form was offered to patients. The ESAS and the CDS questionnaires were used one day after HSCT. This first assessment was considered as the baseline for the study.

In the intervention group, patients were educated by means of a booklet and PowerPoint presentation after the initial assessment. All educations were carried out by the same researcher and took approximately one hour per patient. The training content was as follows: (1) the introduction and discussion of expectations; (2) the identification and types of possible post-transplant complications; (3) common post-transplant symptoms and their management (constipation, diarrhea, hair loss, anorexia, anemia, infection, bleeding, nausea/vomiting, pain, fatigue, mouth and gum problems, sleep difficulties, sexual problems, psychological problems); (4) the measures to alleviate possible post-transplant symptoms; (5) the information about who they can contact when they need support and when they need to apply to the hospital. A PowerPoint presentation was used, and a booklet was provided to each patient. After presentation, the researcher asked patients if they had any questions and all patients' questions were answered by the researcher. After patients were discharged from the hospital, education was followed by telephone counseling. Twice a week, text messages were sent to patients to inform and remind them about symptom management. Patients' questions were answered by the researcher. The frequency of patients' calls for a question ranged between 8 and 17 per week. Patients were assessed on the 4th, 8th, and 12th weeks by using the ESAS and CDS via telephone interviews. There are four sources of information to assess the individuals' self-efficacy: performance outcomes, vicarious experiences, verbal persuasion, and physiological feedback [33, 34]. Performance outcomes were assessed by using the ESAS questionnaire; for verbal persuasion, telephone counseling was used, and patients were encouraged by the researcher; to provide vicarious experiences to patients, other patients' positive outcomes in symptom management due to this education were shared with patients of the intervention group. However, face-to-face meeting and experience sharing were not carried out due to the high risk of infection in these groups.

For patients in the control group, routine hospital care

was provided. These patients were informed by nurses in their wards without any presentation or a booklet. They were offered the ESAS and CDS assessments only after their discharge from the hospital. There wasn't any telephone counseling.

Data Analysis

Data of the study were analyzed by using IBM SPSS v25 software. G-power 3.1.9.4 software was used for sample calculation. Descriptive findings of the study were presented as the number (n), the percentage (%), the mean, standard deviation, the median, and the minimal and maximal values. The Shapiro-Wilk test was used to evaluate the normal distribution of data. After determining the normal distribution of data, the Paired sample t-test was used to determine changes in the ESAS and CDS mean score over time. The Independent sample t-test was used for comparing the mean scores of the ESAS and CDS between the intervention and control groups. The Chi-Square test was used to determine the differences in sociodemographic characteristics between the intervention and control groups.

Results

Sociodemographic and disease-related characteristics of patients in the intervention and control groups are demonstrated in Table 1. Both groups did not differ significantly in all characteristics.

There was no statistically significant difference between the groups in the ESAS mean scores at baseline ($p > 0.05$); there was a statistically significant difference between the groups in the post-test regarding the mean scores of the ESAS and symptoms ($p < 0.05$) (Table 2).

There was no statistically significant difference between the groups in the CDS mean scores at baseline ($p > 0.05$); there was a statistically significant difference between the groups in the post-test regarding the CDS mean scores and its subdomains ($p < 0.05$) (Table 3).

The interventional group was characterized by significantly lower mean score value of the ESAS and higher mean score value of the CDS 12 weeks after intervention (Table 4). Educational intervention had a large effect on the severity of symptoms (Cohen's $d = 1.364$) and patients' care dependency (Cohen's $d = 0.815$).

Discussion

HSCT is a common treatment worldwide [2]. However, it causes many symptoms experienced by patients following the treatment and discharge [5, 8]. These symptoms persist for up to two years and require behavior change [5, 6]. Bandura, in his Social Cognitive Learning Theory, has suggested that increasing individual's self-efficacy is a key point to achieve outcomes [33]. In the current study, educational intervention, one of the best ways to increase self-efficacy, was used to increase patients' self-efficacy in symptom management [33]. Patients' performance outcomes were measured via evaluating the severity of their symptoms with the ESAS. We measured patients' care dependency as well since we expected a decrease in their care

dependency with an increase in their symptom management.

In the current study, we found that tiredness had the highest score on the ESAS scale followed by well-being, appetite, and depression. Fatigue was one of the most common symptoms among cancer patients, especially after treatment. Accordingly, fatigue has been reported as a common symptom in cancer patients after HSCT [35–37]. In a study conducted by Mosher *et al.* (2011), among QoL concerns, the two most common complaints were "I get tired easily" with 56.4% and "I have lack of energy" with 42.1% [38]. Our findings on tiredness were consistent with the literature in this respect. Cohen *et al.* (2012) have reported that patients' physical, social, and functional well-being decreased after HSCT [6]. Similarly, Janicsák *et al.* (2013) have reported that patients' physical, social, emotional, and functional well-being decreased after HSCT [39]. In a study comparing the symptoms of cancer patients who underwent HSCT and those who did not undergo HSCT, Ward *et al.* (2020) have reported that the "lack of appetite" score in patients who underwent HSCT was 10.66 ± 23.2 , while other cancer patients' score was 6.07 ± 15.6 [40]. After HSCT, protective isolation was needed and this contributed to the physiological problems among patients [41]. Mosher *et al.* (2011) have reported that patients undergoing HSCT were likely to develop depression and females were at higher risk than males [38]. The common symptom profile of our study was in line with the literature.

The mean ESAS scores after transplantation were 46.22 ± 23.82 in the intervention group and 42.98 ± 22.11 in the control group. Ovayolu *et al.* (2013) have reported that there was an increase in all ESAS symptoms, except for anxiety, after transplantation [13]. According to Kako *et al.* (2018), the optimal cut-off values for pain, tiredness, drowsiness, nausea, lack of appetite, and dyspnea were 4, 4, 4, 2, 5, and 4, respectively [42]. In our study, all the scores of these symptoms in the intervention group, except for lack of appetite, were over the cut-off score. In the current study, higher symptom severity scores after transplantation (pre-test) were similar to those from the literature. In the pre-test assessment, the mean CDS scores were 55.87 ± 24.92 in the intervention group and 56.90 ± 29.38 in the control group. Several studies have shown that an increase in symptoms and their severity led to an increase in care dependency [43, 44]. Accordingly, patients' care dependency was high in both groups.

In this study, we found that educational intervention and telephone counseling based on Bandura's theory were effective to decrease the severity of symptoms and care dependency. Akgün Şahin and Ergüney (2016) have reported that educational intervention was found to be effective in reducing symptom frequency and severity, discomfort level in cancer patients [45]. According to Qiao *et al.* (2021), patient education was effective in cognitive symptom management [25]. Cioce *et al.* (2020) have found that educational intervention was effective in terms of QoL and some symptoms experienced by patients who underwent HSCT such as anxiety and depression [31]. A study con-

Table 1. Comparison of the ESAS and CDS mean scores between groups and pre-test and post-test.

	Intervention group n (%)	Control group n (%)	χ^2/p
Age groups, years			
18-28	10 (18.9)	11 (20.7)	1.341/0.512
29-39	16 (30.2)	17 (32.1)	
40-50	14 (26.4)	14 (26.4)	
51-61	9 (17.0)	8 (15.1)	
62 and older	4 (7.5)	3 (5.7)	
Gender			
Female	25 (47.2)	25 (47.2)	0.641/0.423
Male	28 (52.8)	28 (52.8)	
Marital status			
Married	36 (67.9)	34 (64.2)	0.216/0.398
Single	17 (32.1)	19 (35.8)	
Having a child			
Yes	33 (62.3)	32 (60.4)	1.135/0.287
No	20 (37.7)	21 (39.6)	
Education level			
Primary school	25 (47.2)	24 (45.3)	1.096/0.578
High school	20 (37.7)	22 (41.5)	
University degree	8 (15.1)	7 (13.2)	
Profession			
Employee	32 (60.4)	34 (64.2)	1.390/0.499
Housewife	15 (28.3)	12 (22.6)	
Retired	6 (11.3)	7 (13.2)	
Income Level			
Income is higher than the expenses	16 (30.2)	14 (26.4)	0.526/0.432
Income is equal to the expenses	29 (54.7)	30 (56.6)	
Income is lower than the expenses	8 (15.1)	9 (17.0)	
Disease			
Multiple myeloma	13 (24.5)	12 (22.6)	1.395/0.228
Lymphoma	14 (26.4)	16 (30.2)	
Leukemia	26 (49.1)	25 (47.2)	
Disease duration			
0-1 year	17 (32.1)	14 (26.4)	1.604/0.691
1-2 years	25 (47.2)	27 (50.9)	
2 years or more	11 (20.7)	12 (22.7)	
Transplantation type			
Autologous	26 (49.1)	24 (45.3)	1.135/0.287
Allogenic	27 (50.9)	29 (54.7)	

Table 2. Mean scores of the ESAS in groups before and after education.

	Pre-test			Post-test		
	Intervention group	Control group	p	Intervention group	Control group	p
Pain	4.03±2.11	4.67±2.48	0.103	2.80±1.10	5.12±2.15	0
Tiredness	5.95±2.73	5.14±2.06	0.215	3.04±1.79	6.00±2.44	0
Nausea	2.40±2.26	2.55±2.10	0.167	1.16±0.80	3.95±1.26	0
Depression	5.13±2.18	5.30±2.33	0.181	2.71±1.05	5.32±2.30	0
Anxiety	4.80±2.53	4.26±2.07	0.205	3.53±1.94	5.10±2.43	0
Drowsiness	5.12±2.14	5.05±2.15	0.328	3.66±2.14	5.48±2.16	0.002
Lack of appetite	5.53±2.99	4.19±2.72	0.96	3.12±1.70	5.22±2.01	0
Well-being	5.80±2.34	5.25±2.01	0.236	3.14±1.86	6.37±2.99	0
Shortness of breath	2.43±2.72	2.11±2.26	0.772	1.30±0.75	3.54±1.30	0.003
Skin and nail changes	1.90±0.35	1.58±0.21	0.788	0.83±0.31	2.16±1.02	0.001
Oral sores	1.53±0.74	1.05±0.73	0.103	0.50±0.46	1.98±0.94	0.003
Hand numbness	1.60±0.73	1.83±0.99	0.096	1.01±0.91	2.30±1.22	0.008

Table 3. Mean scores of the CDS in groups before and after education.

	Pre-test			Post-test		
	Intervention group	Control group	p	Intervention group	Control group	p
Eating/drinking	3.22±1.52	3.54±1.09	0.15	4.34±1.90	2.00±1.39	0
Incontinence	3.11±1.10	3.18±1.41	0.135	4.88±1.73	3.14±1.44	0
Body posture	3.73±1.59	3.20±1.85	0.183	4.63±1.80	3.24±1.13	0
Mobility	3.65±1.48	3.54±1.19	0.171	4.32±1.66	2.82±1.28	0
Day/night pattern	3.19±1.04	3.60±1.68	0.284	4.69±1.54	3.20±1.43	0
Getting (un)dressed	3.07±1.75	3.48±1.27	0.366	4.52±1.85	2.50±1.37	0.001
Body temperature	3.65±1.51	3.42±1.55	0.537	4.90±1.49	3.46±1.93	0
Hygiene	2.00±1.56	2.34±1.11	0.258	3.97±1.01	3.56±1.98	0
Avoidance of danger	2.44±1.43	2.52±1.07	0.439	3.42±1.42	2.44±3.09	0
Communication	4.00±1.81	3.95±1.03	0.708	4.94±1.31	3.08±1.02	0.001
Contact with others	3.90±1.48	4.02±1.99	0.291	4.51±1.39	3.90±1.96	0.003
Pray	3.44±1.93	3.50±1.70	0.11	4.97±1.58	3.30±1.25	0.005
Sense of rules/values	3.37±1.06	3.50±1.45	0.099	4.23±1.77	3.30±1.20	0.004
Daily activities	2.44±1.93	2.50±1.04	0.134	3.15±1.61	2.30±3.06	0.003
Recreational activities	3.44±1.80	3.50±1.29	0.336	4.20±1.01	3.30±3.97	0.003
Memory	3.82±1.05	3.69±1.13	0.552	4.37±1.00	3.60±2.85	0.004
Learning ability	3.40±1.77	3.46±1.80	0.237	3.95±1.48	3.41±2.62	0.003

Table 4. Comparison of the ESAS and CDS mean scores between groups and pre-test and post-test.

		Intervention group	Control group	t	p
ESAS	Pre-test	46.22±23.82	42.98±22.11	-0.218	0.623**
	Post-test	26.80±14.81	52.54±22.22	6.139	<0.001**
	t	-2.662	3.171		
	p	0.010*	0.002*		
CDS	Pre-test	55.87±24.92	56.90±29.38	0.134	0.579**
	Post-test	73.98±25.11	52.55±27.40	-5.703	<0.001**
	t	6.94	10.659		
	p	0.001*	0.003*		

Notes: * Paired-sample t-test; ** Independent sample t-test.

ducted by Sherman *et al.* (2012) has revealed that psychoeducation plus telephone counseling was effective to improve patients' overall health, psychological well-being, and social adjustment [46]. On the other hand, according to several studies, educational intervention was an effective way to improve self-efficacy in various conditions as well [22, 24, 25]. Hoffman (2013) has reported that enhancing self-efficacy was essential for optimizing cancer outcomes in patients [18]. An increase in self-efficacy is known to lead to an increase in patients' self-management. As patients' self-management increase, their care dependency and symptom decrease. For nurses, it is difficult to manage symptoms after HSCT and to decrease the patients' level of care dependency; however, theories, especially best-studied theories such as Bandura's Social Cognitive Learning Theories, help nurses manage such challenging conditions, as they explain the learning process of the individuals and which inputs and interventions are needed to improve knowledge and to develop behavior [8, 18, 22, 24]. Performance outcomes (symptom severity and care dependency) in our study supported Bandura's Social Cognitive Learning Theory.

We found that educational intervention had a great effect on symptom severity and care dependency in patients

after HSCT. However, the framework for the study was that of a complex intervention as described by the UK Medical Research Council [47]. Within this framework, it is difficult to isolate the effect of intervention. A single study reveals only one aspect of intervention and multiple studies are required to elucidate any effect more clearly. Thus, more studies are needed to support this effect on symptom severity and care dependency.

Limitations

The study was carried out in a single-center design; the sample of the study was limited and consisted of 106 patients. Further studies involving larger groups and different populations are needed.

Conclusions

Patients' care dependency and symptom severity after HSCT were high. Educational intervention based on Bandura's theory was found to be an effective way to decrease patients' care dependency and symptom severity.

Recommendations

Nurses are recommended to use Bandura's theory in educating patients after HSCT, combining this education and telephone counseling. Nursing curricula need to include these types of theories, e.g., Bandura's Social Cognitive Learning Theory, to manage such complex patients' conditions. These theories should be incorporated into clinical training for nurses as well.

Ethical Statement

Prior to the research, ethical approval from the the İnönü Üni-versity Non-Interventional Clinical Research Ethics Comi-tee (Date:15.11.2018; Decision Number: 2018-11/20) and written permission from the institution where the research was conducted were obtained. The study was conducted by following the Principles of the Declaration of Helsinki.

Informed Consent

The informed consent forms were applied after the partic-ipants were informed about the study and their informed consent was obtained.

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Conflict of Interest

The authors declare that no conflicts exist.

Financial Disclosure

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