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# The Effect of the Continuous Care on the Self-Care Behavior in Hematopoietic Stem Cell Transplantation (HSCT) Recipients: A Semi-Experimental Study

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**ABSTRACT**

**Background:** Hematopoietic stem cell transplantation strongly affects the care of patients suffering from malignant hematologic disorders and the implementation of interventions such as continuous care can affect the outcomes of treatment in a positive way. The aim of the current study was to determine the effect of implementing a continuous care model on self-care behavior in patients receiving HSCT between 2019 and 2020 in Shariati Hospital affiliated to Tehran University of Medical Sciences.

**Materials and Methods:** This semi-experimental study was conducted on 48 patients who were considered as candidates for HSCT at the Hematology, Oncology and Stem Cell Transplant Research Center, Shariati Hospital. Participants for the present study were selected by the continuous care model based on the inclusion criteria. A 4-stage continuous care model (CCM) developed was used as an intervention in the study. A valid and reliable assessment questionnaire designed to measure the self-care behaviors of the patient (PHLP2) was used for the collection of demographic information. It was completed in the first and fourth stages of implementing the continuous care model. Data were analyzed using SPSS 22 software (Chicago, IL, USA). Moreover, the Chi-square test, pair t-test, and independent samples t-test were used in this study.

**Results:** There was no statistically significant difference between the intervention and control group in terms of demographic variables ($p>0.05$). Prior to intervention, no statistically significant difference was observed in the mean self-care score among HSCT patients in the intervention and control group ($p=0.590$), while, after the intervention, a statistically significant difference was observed in the mean self-care score among HSCT patients in the intervention and control group ($p<0.001$).

**Conclusion:** The study concluded that due to the increase in the number of patients undergoing HSCT across the country in recent years as well as the ease of implementation and low cost of this strategy to promote the self-care of HSCT recipients, relevant authorities ought to do it with the proper planning and policy nationwide. According to the results of the study, the use of a continuous care model on self-care behavior in patients receiving HSCT is recommended.

**Keywords:** Nursing models; Self-care; Bone marrow transplantation

## INTRODUCTION

Hematopoietic stem cell transplantation (HSCT) is the accepted therapy of choice for a variety of malignancies, malignant hematologic disorders and genetic diseases. HSCT is a procedure that aims to prolong survival and achieve cure[1,2].

Approximately, 15000 patients undergo HSCT annually throughout the world[3], and, in Iran, 1400 patients (2 cases/100000 patients per year) undergo HSCT per year [4]. Although HSCT improves the survival outcomes in adults and children, this treatment procedure leading to significant physical, social, psychological, and emotional stress in patients affects the quality of life (QOL) of patients and their family caregivers[5]. Moreover, the above-mentioned side effects reduce the level of adherence to self-care behaviors among patients[6], which results in higher treatment costs and lower effectiveness of treatment.

Self-care involves a wide range of learned and purposeful practices as well as conscious activities such as diet, physical exercises, and timely use of medication, which is done by the person to provide, protect, and promote the health for himself/herself and family members[7-9]. Self-care leads to better management of symptoms such as relieving pain, reducing anxiety, depression and fatigue, feeling healthy and improving life expectancy in patients[10]. Self-care behaviors are the key to transplant results and overall survival, and are associated with reduced physical and psychological symptoms, increased enjoyment of life, and improved quality of life. On the other hand, any failure to follow self-care behaviors increases serious adverse effects, re-hospitalization rates/readmission, and the cost of treatment, which can be considered the most important underlying cause of death in these people[11]. Nurses play an essential role in monitoring self-care behaviors in post-HSCT patients[12]. In Iran, the continuous care model (CCM), designed by Ahmadi et al, focuses on managing patients diagnosed with chronic coronary heart disease[13,14]. The effectiveness of this model has been approved in patients with heart failure[16,17], myocardial infarction[16,17], diabetes[18] and patients undergoing hemodialysis[19]. Due to long-term process of treatment, it is essential for patients to follow-up self-care behaviors after hospital discharge to control the disease and possible HSCT-related adverse effects. Therefore, the present study intends to determine the impact that the continuous care model (CCM) has on self-care behaviors of patients undergoing HSCT (2019) in Shariati Hospital, affiliated to Tehran University of Medical Sciences.

## MATERIALS AND METHODS

The sample size in each group was estimated 20 participants according to the formula ($\alpha < 0.05$, $\beta = 0.2$), but by considering a probable decline (20%) in the study population, 24 participants were placed in each group. The inclusion criteria were: a) being interested in participating in the study, b) being a candidate for HSCT, c) being able to read and speak Persian, d) being aged between 18 and 60 years, e) not being diagnosed with psychiatric disorder or Alzheimer's disease, f) not having participated in HSCT training courses. Those participants experiencing severe physical and mental disabilities after HSCT and failing to participate in the training courses were excluded from the study. Participants were then randomly assigned into either the control group or the intervention group through the use of convenience sampling. In this study, the researcher applied the continuous care model (CCM) developed by Ahmadi et al. as an intervention in the experimental group. This care model was composed of four stages, including orientation, sensitization, control, and evaluation with a continuous and dynamic nature[13,14].

**Orientation:** During this stage, patients begin to get acquainted, become motivated, much more sober in expectations from each other and more aware of problems. One day before scheduled HSCT, patients and their family members attended a 30-minute meeting, which was held for both the control and experimental group. The contact number of the patient and researcher was exchanged and the necessary arrangements for a mutually convenient time were made. Moreover, in this stage, the educational needs of the patients in the experimental group were listed according to the level of the patient information, the patient's place of residence, and the level of access to facilities.

**Sensitization:** The sensitization phase was performed in order to engage patients and their family members in implementing a continuous care approach. At this stage, the measures were taken in the form of care counseling per day for 20 minutes prior to discharge and after discharge by phone at home. Possible questions and new problems of patients were also answered. The content of the sessions included familiarity with the disease process and transplant-related complications, the importance of medication therapy, nutrition, infection control, physical activity and lifestyle, and general education. Training activities were conducted face-to-face in the form of questions and answers and the use of educational pamphlets.

**Control:** This step aims to achieve the goals of the care model tailored to the specific needs of the individual patient by continuing follow-up care consultations on a weekly and continuous basis for two consecutive months via phone (at least 8 calls per patient) or interview in the transplant ward.

**Evaluation:** Evaluation is the fourth and final step of the continuous care model, but it was considered in all stages for the evaluation of patients, the level of adherence to self-care behaviors and knowing whether the researcher has achieved (or even made progress on) the goals . Data obtained from the questionnaire were then entered into a statistical package for social sciences (SPSS) software for analysis. Given the importance of ethics for the conduct of research, all educational issues relative to continuous care in self-care behavior were addressed to the control group during 1-2 sessions.

In the first (Orientation) and fourth (Evaluation) stage of the intervention, the level of self-care among study participants was assessed by completing the self-care questionnaire (HPLP = II). This questionnaire contains 52 questions in six dimensions: health responsibility, physical activity, nutrition, spiritual growth, stress management and interpersonal relationships. A four-point *Likert scale* was used for the possible answers (never, sometimes, usually and always). In Iran, the validity and reliability of the Persian version of this questionnaire were reviewed and confirmed. In the present study, the reported *Cronbach's α coefficient* was 0.82 and 0.64-0.94 for total instrument and subscales, respectively[23]. Walker reported a Cronbach's alpha coefficient of 0.94 for all instrument questions and 0.79-0.94 for its six subscales. Moreover, the test-retest reliability of this tool was calculated to be 0.89 after 3 weeks of re-completing the questionnaire.

Data were entered into SPSS software version 16, frequency Tables were used to show the distribution of qualitative data. Chi-square and Fisher's exact tests (to compare the status of demographic and contextual variables classified into two study groups) were used. For quantitative data, the normality of data was first assessed and confirmed using the Kolmogorov–Smirnov test. The central indexes and distribution were calculated and independent t-test was applied to compare the mean score of the self-care questionnaire in both groups before and after intervention.

**RESULTS**

In this study, 48 participants in the intervention (n = 24) and control (n = 24) groups entered the final stage of analysis. The mean age of participants in the intervention and control group was 37.66± 7.96 and 38.45± 92 8.92 years, respectively. The results of the Chi-square test revealed that there was no statistically significant difference between the two groups in terms of gender (P=0.771), degree (P=0.921), marital status (P=0.771), age (P=0.747) , and duration of illness (P=0.536). In other words both groups were homogeneous in terms of these characteristics (Table 1). Moreover, no statistically significant difference was observed in the mean score of self-care behavior among the patients who received HSCT in both experimental and control groups before intervention. Although the improvement of self-care behavior is observed in all six dimensions of self-care in the experimental group, the difference was clearly significant in the dimension of interpersonal communication P<0.001) (Table 2, 3).

**Table 1:** Demographic information and background characteristics in the intervention and control group

| Variable | Group | Intervention | Control | P |
|---|---|---|---|---|
| Gender | Male | 11(45.8) | 10(41.7) | P*=0.771 |
| | Female | 13(54.2) | 14(58.3) | |
| Education | Illiterate | 4(16.7) | 5(20.8) | P*=0.921 |
| | Without a high-school diploma | 2(8.3) | 2(8.3) | |
| | Diploma | 5(20.8) | 7(29.2) | |
| | Associate degree | 13(54.2) | 10(41.7) | |
| Marital status | Single | 11(45.8) | 10(41.7) | P*=0.771 |
| | Married | 13(54.2) | 14(58.3) | |
| Age | Mean±SD | 37.7±66.96 | 38.8±45.92 | P=0.747 |
| Duration of disease | Mean±SD | 4.1±25.53 | 4.1±70.85 | P=0.356 |

**Table 2:** Mean and standard deviation (SD) of self-care behavior and its dimensions among HSCT patients in the control group before and after intervention

| Control group / Variable | Before study | After intervention | Test |
|---|---|---|---|
| Self –care behavior | 87.54±7.60 | 91.45±6.87 | t= -1.815<br>df=23<br>P=0.083 |
| Health responsibility | 12.45±1.44 | 14.00±1.93 | t= -6.040<br>df=23<br>P<0.0001 |
| Physical exercises | 15.6±08.40 | 16.33±2.21 | t= -0.974<br>df=23<br>P=0.340 |
| Neutrition | 16.2±20.48 | 17.12±3.12 | t=-1.893<br>df=23<br>P=0.071 |
| Spiritual growth | 13.2±54.30 | 14.12±2.21 | t=-2.024<br>df=23<br>P=0.055 |
| Stress management | 15.12±2.99 | 15.37±2.22 | t=-0.455<br>df=23<br>P=0.653 |
| Interpersonal relations | 14.1±04.36 | 14.50±2.00 | t=-1.027<br>df=23<br>P=0.315 |

**Table 3:** Mean and standard deviation (SD) of self-care behavior and its dimensions among HSCT patients in the intervention group before and after intervention

| Intervention group / Variable | Before study | After intervention | Test |
|---|---|---|---|
| Self –care behavior | 86.50±6.69 | 103.41±10.42 | t=-6.510<br>df=23<br>P<0.0001 |
| Health responsibility | 12.1±66.12 | 17.00±2.87 | t=-6.637<br>df=23<br>P<0.0001 |
| Physical exercises | 13.2±16.58 | 16.37±3.44 | t=-3.652<br>df=23<br>P<0.001 |
| Neutrition | 16.37±2.06 | 18.41±2.61 | t=-3.303<br>df=23<br>P<0.003 |
| Spiritual growth | 15.04±6.36 | 18.70±2.61 | t=-2.323<br>df=23<br>P<0.029 |
| Stress management | 14.3±95.36 | 16.95±2.59 | t=-3.085<br>df=23<br>P<0.005 |
| Interpersonal relations | 13.29±1.19 | 15.95±2.64 | t=-4.529<br>df=23<br>P<0.0001 |

## DISCUSSION

This study aimed to determine the effect of continuous care model (CCM) on self-behavior in patients undergoing HSCT. The results of the study indicated that the mean score of self-care behavior in all dimensions among patients receiving HSCT in experimental group was statistically higher than the control group after intervention. The study also showed that the self-care behavior among all patients in both the control and intervention groups before transplantation was so poor, indicating the importance of improving the self-care behavior in these patients. However, in the control group, self-care behaviors, except physical activity, increased slightly, but it was not significant and even after transplantation physical activity slightly decreased. This finding of this survey is consistent with the results of the studies conducted by Zeighami et al. (2014), Ghavami et al (2006), Baghaei et al. (2015), and Fini et al (2011)[15,21,22].

The greatest change in the dimensions of self-care model was related to interpersonal communication. The study showed that the continuous care improves interpersonal relationships. Studies also show that these patients require more support from their family members and health care professionals[23]. The findings of our study are in line with the study of Nasrabadi et al. (2019). In this study, one of the major problems of patients was the unsupportive behaviors of their families and relatives, and patients stated that excessive monitoring and control caused them to feel confined[19]. Continuous care along with emotional and social support in patients undergoing hematopoietic stem cell transplantation leads to better acceptance of the treatment process in these patients. Most patients develop mobility disorders after transplantation, which is due to their isolation after transplantation, feeling weakness, and reduced level of energy[5,24]. In the present study, the intervention of continuous care model increased the physical activity, one of the dimensions of self-care behavior, and physical health among transplant patients, while the physical activity of patients in the control group decreased, which indicated the importance of continuous care.

Like the present study, the implementation of the continuous care model in patients with myocardial infarction[8,12] and heart failure[23] improved the physical activity for more than one year. In the present study, nutrition, another self-care

dimension, statistically improved following continuous care.

Nutritional status in patients undergoing HSCT becomes more severe due to complications such as mucositis and loss of appetite. In Shahsavari and Foroughi study, the nursing care and the follow-up program for the patients with diabetes led to better dietary adherence in these patients[25].

Spiritual growth was another dimension of self-care that was enhanced by the continuous care following HSCT. The study conducted by Karimi et al (2019) and Sayyadi et al (2019) revealed that most patients felt closer to God, had a greater reliance on religious principals, and experienced enhanced spiritual insight after HSCT[4,5]. The present study also demonstrates that the continuous care increases the spiritual growth.

Stress, another dimension of self-care, significantly changed by the continuous care in the intervention group during the study. Previous studies have shown that stress in HSCT recipients can affect the process of treatment. The current study has shown that the continuous care reduces the level of stress after HSCT. Consistent with our findings, in a study conducted by Azizi & Adib, there was a statistically significant difference between the two groups in terms of total score, dimensions of adaptation, decision-making, and stress reduction after the training of self-efficacy. The intervention group had greater improvements in self-efficacy compared to the control group[21].

In this study, the continuous care in creating healthy habits, thinking about health, a positive attitude towards life and having a healthy diet as a part of health responsibility had a vital role compared to the control group[5]. Although both groups had significant improvements in this dimension, this improvement was significant in the experimental group.

Due to the reduction of cases such as treatment adherence in these patients, which plays a vital role in responding to treatment[6] promoting this dimension of self-care is essential. In a study conducted by Azizi et al., continuous training also caused the self-efficacy among these patients [21].

One of the major reasons for the increase in severity and complications of treatment in patients with chronic diseases is lack of knowledge about self-care and preventive behaviors. On the other hand, this type of training creates a sense of emotional and social support in patients undergoing hematopoietic stem cell transplantation, leading to better acceptance of the treatment process in these patients.

Developments in training and information about hematopoietic stem cell transplantation through the implementation of the continuous care model and the support of the treatment team and patients' families after discharge will enable them to go through the critical stages of treatment with better relaxation and more effective adaptation. New living conditions permit them to increase the sense of control over the disease, which in turn leads to improved self-care in these patients.

## CONCLUSION

According to the results of the present study, it can be concluded that the application of the *continuous* care model to patients undergoing HSCT is essential and the feeling of being supported by relatives and care providers results in reduced physical and mental complications and improved better social life in patients undergoing HSCT. Therefore, due to the increase in the number of patients undergoing HSCT across the country in recent years as well as the ease of implementation and low cost of this strategy to promote the self-care of HSCT recipients, relevant authorities ought to *do* it with the *proper planning* and policy nationwide.

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## CONFLICTS OF INTEREST

The authors declare no conflict of interest.

**REFERENCES**

1. Ahmadi F, Ghofranipour FA, Abedi HA, et al. The design of continous care model for the control of coronary artery disease Pathobiol Res. 2001; 4(2):97-104.
2. Akbari O, Vagharseyyedin SA, Saadatjoo SA, et al. Effect of continuous care model on the self-efficacy of patients with myocardial infarction in controlling disease complications. Med surg Nurs *J.* 2014; 3(4): 185-194.
3. Akbari O, Vagharseyyedin SF, Kazemi T , et al. Continuous care model and the self-management in post-myocardial infarction patients: A randomized controlled trial. *J Chronic Dis Care.* 2017; 6(1): e37555.
4. Azizi Fini E, Adib Hajbaghery M, Salahshoorian Fard A, et al. The effect of health-promotion strategies education on self-care self-efficacy in patients with bone marrow transplantation. Iran J Crit Care Nurs. 2011; 4(3):109-116.
5. Baghaei R, Khalkhali HR, Mashalahi A. The effect of applying continuous care model on the quality of life in heart failure patients. J Urmia Nurs Midwifery Fac*. 2015;* 13(8): 666-75.
6. Borji M, Tavan H, Azami M, et al. The effect of continuous care model on blood pressure and quality of life in patients on hemodialysis. Biomed Pharmacol J.2016; 9(2): 689-95.
7. Azizi Fini E, Adib-Hajbaghery M, Khachian A. The effect of health-promotion strategies education on self-care self-efficacy in patients with bone marrow transplantation. *Iran J Crit Care Nurs*. 2011; 4(9): 109-16.
8. Gholamzadeh S, Pourjam E, Najafi Kalyani M. Effects of continuous care model on depression, anxiety, and stress in Iranian elderly in Shiraz. Int J Community Based Nurs Midwifery. 2019;7(1):13-21.
9. Honarpajouh, Ozra. 2020. 'The relationship between health literacy, social support, self-care and quality of life in patients undergoing hemodialysis: A systematic review', Tabriz University of Medical Sciences, School of Health.
10. Horowitz M, Schreiber H, Elder A, et al. Epidemiology and biology of relapse after stem cell transplantation. Bone Marrow Transplant. 2018;53(11):1379-1389.
11. Inamoto Y, J Lee S. Late effects of blood and marrow transplantation. Haematologica. 2017;102(4):614-625.
12. Khosravan SH, Alami A, Golchin Rahni S. Effects of continuous care model based non-pharmacological intervention on sleep quality in patients with type 2 diabetes mellitus: a randomized controlled clinical trial. Int J Community Based Nurs Midwifery. 2015;3(2):96-104.
13. Kjellström S, Golino H. Mining concepts of health responsibility using text mining and exploratory graph analysis. Scand J Occup Ther. 2019;26(6):395-410.
14. Koirala B, Dennison Himmelfarb CR, Budhathoki CH, et al. Heart failure self-care, factors influencing self-care and the relationship with health-related quality of life: A cross-sectional observational study. Heliyon. 2020;6(2):e03412.
15. Lee E, Park E. Self-care behavior and related factors in older patients with uncontrolled hypertension. Contemp Nurse. 2017;53(6):607-621.
16. Matarese M, Lommi M, Grazia De Marinis M, et al. A Systematic Review and Integration of Concept Analyses of Self-Care and Related Concepts. J Nurs Scholarsh. 2018 May;50(3):296-305.
17. Mills J, Timothy W, Fraser JA. Exploring the meaning and practice of self-care among palliative care nurses and doctors: a qualitative study. BMC Palliat Care. 2018;17(1):63.
18. Mohammadi Zeidi Isa , Pakpour Hajiagha A, Mohammadi Zeidi B. Reliability and validity of Persian version of the health-promoting lifestyle profile. *J Maz Univ Med Sci*. 2011; 21(SUPPLEMENT 1): 103-13.
19. Morrison CF, Martsolf DM, Borich A, et al. Follow the Yellow Brick Road: Self-management by Adolescents and Young Adults After a Stem Cell Transplant. Cancer Nurs. 2018;41(5):347-358.
20. Morrison CF, Martsolf DM, Wehrkamp N, et al. Medication adherence in hematopoietic stem cell transplantation: a review of the literature. Biol Blood Marrow Transplant. 2017;23(4):562-568.
21. Nikbakht Nasrabadi A, Karimi Rozveh A, Ghyasvandian SH, et al. Enclosed by Others: Post Haematopoietic Stem Cell Transplantation Patients Experience-A Phenomenological Study. J Clin Diagn Res. *2019;* 13(1):LC04-LC07.
22. Simone dos Santos N, José Lopez Montesinos M, Mendes Pedroso VS, et al. Adherence to nursing guidelines in relation to home care of bone marrow transplantees in the ecosystem perscpective. Texto Contexto Enferm .2020: 29: e20180310.
23. Rezamand F, Shahnazi H, Hassanzadeh A. Effectiveness of continuous-care model on self-care in patients with heart failure: application of line follow-up. Scand J Caring Sci. 2019;33(4):940-948.
24. Riegel B, Moser DK, Buck HG, et al. Self-care for the prevention and management of cardiovascular disease and stroke: A scientific statement for healthcare professionals from the American Heart Association. J Am Heart Assoc. 2017;6(9):e006997.
25. Karimi Rozveh A, Nikbakht Nasrabadi A, Ghiyasvandian SH, et al. Resiliency, the lived experience of patients undergoing hematopoietic stem cell transplantation. Int J Hematol Oncol Stem Cell Res. 2019;13(4):189-195.
26. Sayadi L , Zamanzadeh V, Valizadeh L, et al. Caring process in hematopoietic stem cell transplantation: a grounded theory study Int J Hematol Oncol Stem Cell Res. 2019;13(2):83-94.

27.Mohammed Assen S. Health-related quality of life and extent of self-care practice among heart failure patients in Ethiopia. Health Qual Life Outcomes. 2020;18(1):27.
28. Shahsavari A, Foroghi S. The effectiveness of telenursing on adherence to treatment in patients with type 2 diabetes. Iran J Endocrinol Metab. 2015;17(2):138-145.
29. van der Lans Mariska CM, Witkamp FE, Oldenmenger WH, et al. Five phases of recovery and rehabilitation after allogeneic stem cell transplantation: a qualitative study. Cancer Nurs. 2019;42(1):50-57.
30. Zakeri MA, Khoshnood Z, Dehghan M, et al. The effect of the Continuous Care Model on treatment adherence in patients with myocardial infarction: a randomised controlled trial. J Res Nurs. 2020;25(1):54-65.