

# The Effect of Participatory Care Program on Self-Care Behaviors and Disease Awareness in Diabetic Patients

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## ABSTRACT

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**Background:** Inadequate self-care and knowledge about diabetes are important causes of chronic complications among diabetic patients. This study aimed to evaluate the effect of a participatory care program on self-care and disease awareness in these patients.

**Methods:** This quasi-experimental study was conducted on 90 diabetic patients referred to Parsian Diabetes Clinic in Mashhad, Iran, 2015. The patients were selected through convenience sampling and randomly assigned to intervention and control (n=45 for each group) groups. The participatory care program entailing four stages of motivation, preparation, involvement, and evaluation was performed for the intervention group through seven 60-90 minute sessions. Data was collected using Diabetes Knowledge scale and Summary of Diabetes Self-Care Activities (SDSCA) questionnaire, which were completed based on interviews with patients before and three months after the intervention. To analyze the data, descriptive statistics, Fisher's exact test, Chi-square, independent and paired t-tests, as well as Pearson's correlation coefficient were used in SPSS, version 20.

**Results:** After performing the participatory care program on the intervention group, the mean scores of disease awareness and self-care significantly increased from 48.0±12.7 to 91.5±7.6 and from 23.5±15.7 to 52.3±13.2, respectively (P<0.001). Moreover, there was a significant difference between the intervention and control groups in terms of these variables (P<0.001).

**Conclusion:** Given the effect of participatory care program on the improvement of knowledge and self-care in patients with diabetes or other chronic diseases, it is recommended to perform this procedure as a customized method based on Iranian culture.

## 1. Introduction

Globally, diabetes is the most common metabolic disease and the fourth main reason for physician visit.<sup>1, 2</sup> The number of patients is estimated to increase from 285 million to 439 million patients from 2010 up to 2030.<sup>3</sup> Diabetes is the fifth leading cause of mortality in western societies due to its severe complications.<sup>4</sup> Therefore, prevention of diabetes complications is essential for health promotion and reduction of the mortality rate among these patients. For this purpose, appropriate self-care behaviors are of paramount importance, since the management of diabetes is patient-dependent.<sup>3</sup>

According to the literature, self-care is not satisfactory among diabetic patients.<sup>5-8</sup> Regarding

the Parham et al. study in 2012, 53.5% of diabetic patients did not adhere to self-care behaviors.<sup>6</sup> In addition, Vosooghi Karkozloo et al. in 2009 demonstrated that self-care behaviors were unacceptable among 68.5% of the patients with type II diabetes.<sup>7</sup> According to former studies, provision of the routine care was not sufficient.<sup>8</sup>

Patients' self-care behaviors are indirectly or directly affected by diverse factors. One of the most important of which is knowledge of the patients as to their disease and the importance of self-care.<sup>9</sup> If patients have adequate knowledge about their disease, they can make informed decisions and engage in appropriate self-care activities.<sup>10</sup>

A cause of treatment failure among diabetic patients is participation in inappropriate treatment

programs.<sup>11</sup> Given the results of studies in Iran, less than 50% of diabetics participated in training sessions about their disease over the past two decades.<sup>12</sup> Additionally, half of the patients had poor adherence to treatment recommendations. It is worth mentioning that the multitude of research projects performed over the past three decades have not contributed to overcoming or reducing this issue. The results of previous studies indicated inadequate knowledge and poor self-care behaviors among these patients.<sup>13, 14</sup>

Meanwhile, diabetic patients need to be empowered in terms of modern lifestyle and psychosocial management of the disease to control, prevent, or postpone the diabetes complications.<sup>5</sup> Diabetic patients should make important decisions about their nutrition, physical activity, medication, blood sugar monitoring, and stress management. Furthermore, a good cooperation between patients and the healthcare system, family members, friends, and colleagues is needed to provide the necessary support for disease management.

However, lack of patient involvement in treatment, limited disease awareness, and in turn, unsatisfactory self-care are associated with more complications and early patient death.<sup>6</sup>

The enhancement of self-care is one of the most important steps towards enhancing adherence to standard care and effective learning.<sup>15</sup> According to the previous studies, the training and care interventions in the form of group discussion and educational camps were effective in self-care behaviors of diabetic patients.<sup>7, 16</sup> However, the rate of these behaviors in diabetics is still low due to weak incentive of the patients.<sup>17-19</sup> This lack of motivation might be due to inadequate organized education and consistence of these trainings by the health providers.<sup>20, 21</sup>

Based on the evidence, collaboration of nurses with other healthcare providers is recommended to promote the self-care behaviors and encourage patient participation in treatment.<sup>22-24</sup> In this regard, Mohammadi *et al.* in 2001 presented the concept of participatory care with an emphasis on the participation of patients, families, nurses, physicians, and other healthcare providers.<sup>25</sup>

The participatory care is a coordinated and logical process of effective and dynamic communication between patients and healthcare providers. This method seeks to determine the needs, problems, and expectations in disease management, encourage interns to accept and engage in their responsibilities, and promote patients' health status.<sup>25</sup>

This organized, systematic structure acts as a dynamic set by observing the logical and developing sequences. According to the literature, this four-step

method with specific pragmatic programs is provided to improve quality of life and diminish the disease-related problems among patients with chronic diseases.<sup>26-29</sup>

Given the low level of self-care and the importance of disease awareness, it is essential to develop an educational method to promote the health status of diabetics. This study was carried out to determine the effect of participatory care program on the self-care behaviors and disease awareness of diabetic patients.

## 2. Methods

### 2.1. Design

This quasi-experimental study was conducted on the diabetic patients referred to Parsian Diabetes Clinic in Mashhad, Iran, 2015.

### 2.2. Participants and setting

To compute the sample size, results of a pilot study on 10 participants, who were not included in the study, were used for each variable of disease awareness and self-care. The sample size was estimated using comparison of two means with 80% power and 95% confidence level.

Based on the largest calculated sample size (mean change in self-care score,  $m_1=27.3$ ,  $m_2=14.6$ ,  $S_1=29.6$ , and  $S_2=9.7$ ), 39 subjects were considered as the standard sample size for each group. Finally, 45 cases were allocated to each group due to the possibility of subject attrition.

The participants were selected through convenience sampling method and were randomly assigned to two groups of intervention and control. In this regard, a random number table, presented by Altman, was used for randomized allocation of the subjects.

The inclusion criteria entailed age more than 18 years, clinically and biochemically confirmed diabetes by a physician, at least six months elapsed from diagnosis, no history of mental or other chronic diseases such as cancer, stressful life events over the past six months, and acute diabetes complications. The exclusion criteria included absence for one session, failure to communicate with the patient, patient decease, history of other diseases, stressful life events, and travelling.

### 2.3. Instruments

In this study, data was collected using a demographic form, Diabetes Knowledge Scale (DKS), and Summary of Diabetes Self-Care Activities (SDSCA). The demographic characteristics included age, marital status, educational level, level

of income, role within the family, insurance status, source of information, family history of diabetes, method of disease diagnosis, and duration of diabetes.

In 2011, the DKS was designed and its reliability and validity were confirmed by Rahimian Booger *et al.* based on Zou Scale (2005) (Cronbach's alpha of 0.95).<sup>30, 31</sup> In this study, the reliability of the mentioned tool was calculated as  $\alpha=0.96$ . This instrument contains ten items scored using an 11-point scale ranging from zero (never) to 100% (always). The participants completed this scale to determine their level of knowledge about each item.

The Summary of Diabetes Self-Care Activities (Toobert and Glasgow, 1992) contains 11 items assessing different aspects of the diabetes regimen entailing general and specific diets, medication consumption, exercise, blood-glucose testing, foot care, and smoking. The participants scored the frequency of each item during the last week from zero to seven. Totally, the mean score of the 11 items about the subjects' self-care indicated their performance. The highest possible score was 105, demonstrating the highest level of self-care.<sup>31</sup> To determine the level of self-care, the raw scores were estimated based on 100. Thereafter, the level of the patients' self-care was categorized into three groups of 76 to 100 (good), 51 to 75 (medium), and greater than or equal to 50 (weak).<sup>7</sup> The reliability of this scale was confirmed by Nikoorafar and Eshaghi in 2012 ( $\alpha=0.65$ ).<sup>23</sup> In the present study, the estimated Cronbach's alpha was 0.86.

#### 2.4. Data Collection

After obtaining informed consent and according to the inclusion criteria, the researcher selected the subjects out of the patients referred to the selected clinic. Prior to the study, the participants were informed of the objectives of the study, and the intervention group was invited to come to the selected clinic at the appointed time. At the pre-test stage, data was collected by filling in the demographic form, DKS, and SDSCA based on interviews. The participatory care program was performed according to the model presented by Mohammadi *et al.* in 2002. Seven 60-90 minute group-sessions were held for 14 weeks (every two other weeks) at the conference hall of the clinic, which had audio-visual facilities and the necessary physical conditions for gathering the team members, including nurses, researcher, physicians, and patients. Meanwhile, the control group received only the routine trainings.<sup>25</sup>

The participatory care model-based educational program is presented in Table 1. The educational content was provided in the form of brochures and booklets, and the subjects were asked to implement the contents at home. The appraisals were carried out at the beginning and end of each session. At the post-test stage, the same questionnaires were completed by both groups three months after the intervention to evaluate the effect of this program on self-care and disease awareness among the diabetic patients.

**Table1.** The content of the follow-up sessions

<b>Motivation</b>	Goal: to motivate the patients by delineating the care issues, current situation, threats, and disease complications, Content of the session: providing the patients with information about their role in the care process and the relationship between healthcare team members using films and lectures (90 min) and dividing the participants into nine-member groups according to pre-test results
<b>Preparing</b>	Goal: to the end of this session the interns should be able to explain the importance of participatory care, self-care, and its effect on the disease process, Content of the session: disease complications, group discussion about the benefits of participatory care, the necessity of patient empowerment in terms of self-care and its effect on the disease process, access of the patients to the required data, and determining the content of future sessions (90 min)
<b>Involving</b>	Holding the participatory educational sessions First session (first visit by physician), Goal: the interns should be able to explain different types of diabetes and their management methods, Content of the session: patient visit and defining diabetes, its causes, types, complications, treatments, importance of maintaining blood sugar within the normal range, and detection of symptoms of hypo- and hyper-glycemia by nurses with the help of educational tools and lectures (60 min) Second session, Goal: The interns should participate in the treatment and care processes (diet and physical activity), The content of the session was provided using educational videos and lectures by researchers, questions and answers, problem solving, and brochures, At the end of the second session, both groups were visited by the physician. Additionally, the patients were required to ask their inquiries about the content (90 min). Third session: Goal: providing the patients with information about the importance of medication consumption and their side-effects, blood sugar screening using glucometer, and describing how to use the urine glucose and hemoglobin dipsticks Content of the session was provided to the patients using educational videos and lectures by the researcher, questions and answers, problem solving, and brochures (50 min).
<b>Evaluating</b>	First session of care follow-up (fourth visit): Goal: continuation of the care program and involvement of the interns Content of the session: assessing the level of knowledge of the patients about self-care principles (diet, medication, and exercise), providing feedback, and evaluation of level of participation of the patients Second session of care follow-up (fifth visit): Goal: continuation of the care program and involvement of the interns, Content of the session: assessing the patients' perception about the role of care and treatment on the disease process, review of the benefits of the therapy, proper care, disadvantages of inappropriate treatment, and understanding the importance of self-care (90 min)

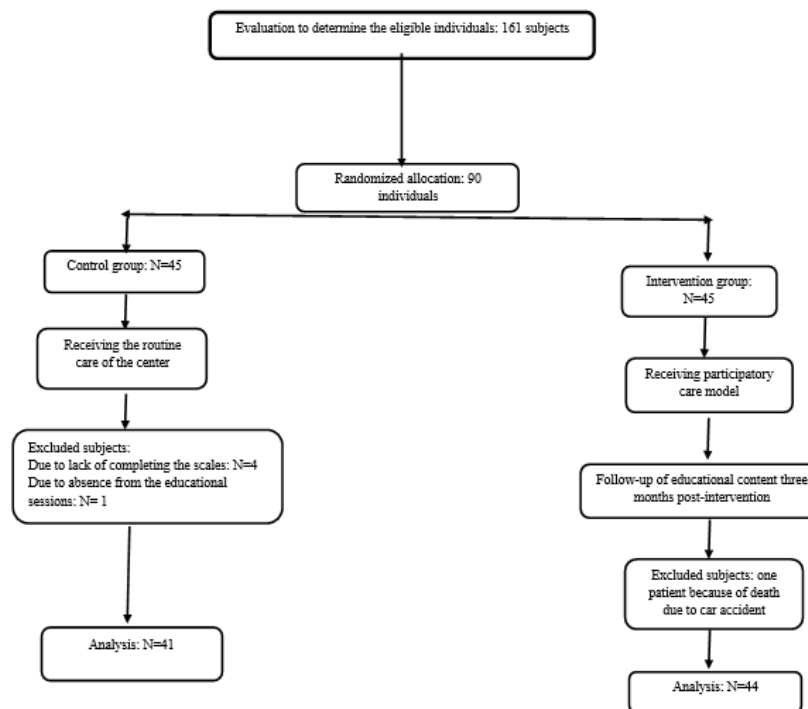


Diagram 2. Research procedures

### 2.5. Ethical Considerations

Prior to initiation of the intervention, informed consents were obtained from all of the participants, and the Ethics Committee of the Research Council, Mashhad University of Medical Sciences, Mashhad, Iran, approved the study. We explained about the aims of the study to the participants and assured them of confidentiality of the data. Moreover, after the study, all the contents of the educational sessions provided to the intervention group were given to the control group, as well.

### 2.6. Statistical Analysis

Data analysis was performed in SPSS software, version 11.5, using descriptive statistics, Chi-square test (to compare both groups in terms of gender, marital status, educational level, level of income, role within family, information source, family history of diabetes, and method of diagnosis), Fisher's exact test (to compare the study groups in terms of insurance status, age, duration of diabetes, mean score of disease-related knowledge, and self-care behaviors), paired t-test (to compare the mean scores of disease-related knowledge and self-care pre- and post-intervention), and Pearson's correlation coefficient (to evaluate the relationship

between variables of disease-related knowledge and self-care behaviors).

### 3. Results

In this study, one subject in the intervention group and four participants in the control group were excluded during the second stage of data collection due to hospital admission and lack of completing the data collection tools, respectively. Finally, 85 individuals in two groups of intervention (n=44) and control (n=41) were evaluated.

As demonstrated in Table 2, in which the patients' demographic data is presented, no significant differences were observed between the groups in terms of the studied variables (Table 2). After performing the participatory care program, the mean scores of disease awareness and self-care behaviors increased more in the intervention group in comparison to the control group ( $P < 0.001$ ; Table 3).

However, no significant difference was found between the two groups in terms of alterations in disease awareness and self-care scores and the patients' demographic variables. Moreover, a significant correlation was observed between changes in mean scores of disease awareness and self-care behaviors of the participants ( $P < 0.001$ ,  $r = 0.42$ ).

**Table2.** The demographic characteristics of the participants

Variable	Group	Intervention	Control	P-value
		N(%)	N(%)	
Gender	Female	18(40.9)	12(29.3)	0.263*
	Male	26(59.1)	29(70.7)	
Marital status	Single	2(4.50)	0(0)	0.232*
	Married	40(91.0)	38(92.7)	
	Other	2(4.5)	3(7.3)	
Educational level	Primary school	16(36.4)	22(53.7)	0.130*
	Junior high school	6(13.6)	3(7.3)	
	Senior high school	12(27.3)	13(31.7)	
Level of income (at least six-thousand tomans)	Higher education	10(22.7)	3(7.3)	0.306*
	Less than enough	4(9.0)	7(17.1)	
	Just enough	40(91.0)	33(80.5)	
Role within family	More than enough	0(0.0)	1(2.4)	0.311*
	Father	18(40.9)	12(29.3)	
	Mother	24(54.5)	29(70.7)	
Insurance	Child	2(4.6)	0(0.0)	0.527**
	Yes	39(88.6)	38(92.7)	
Information source	No	5(11.4)	3(7.3)	0.627*
	Physician	25(56.8)	30(73.2)	
	Personal research	4(9.1)	0(0.0)	
Family history of diabetes	Educational session	15(34.1)	11(26.8)	0.501*
	Yes	36(81.8)	30(73.2)	
	No	8(18.2)	11(26.8)	
Method of diagnosis	Randomly	24(54.5)	25(61.0)	0.342*
	With symptoms	15(34.1)	13(31.7)	
	With complications	5(11.4)	3(7.3)	
Age (year)	M±SD****	56.4±10.7	52.6±6.2	0.281****
Duration of diabetes (month)	M±SD	87.05±62.91	67.29±55.02	0.134****

\*Chi-square, \*\*Fisher's exact test, \*\*\* Independent t-test, \*\*\*\*Mean and standard deviation

**Table 3.** Comparison of mean scores of disease awareness and self-care behaviors between study groups

Variables	Group	Intervention	Control	P-value*
		M±SD	M±SD	
Disease awareness	Pre-intervention	48.0±12.7	50.2±4.6	0.38
	Post-intervention	91.5±7.6	64.6±4.9	<0.001
	Mean changes	43.4±13.1	14.3±4.0	
	P-value**	<0.001	<0.001	
Self-care behaviors	Pre- intervention	23.5±15.7	19.4±12.6	0.26
	Post- intervention	52.3±13.2	7.8±32.5	<0.001
	Mean changes	28.7±21.2	13.1± 8.6	
	P-value**	<0.001	<0.001	

\*Independent t-test, \*\*Paired t-test

#### 4. Discussion

According to the obtained results, the participatory care model increased the levels of disease awareness and self-care more than the routine procedures. Consistent with our study, Wu *et al.* in 2014 demonstrated that use of models and structures based on the cultural, social, economical, and political health infrastructures of a society could effectively improve self-care among diabetics.<sup>21</sup> Likewise, Hasanvand *et al.* in 2011 reported that active participation of the patients in the educational programs could enhance self-care behaviors, and consequently, improve control of blood sugar level and reduce diabetes complications.<sup>32</sup>

The results obtained by Parizad *et al.* in 2013 indicated that the education and follow-up of the patients with type II diabetes were associated with improved self-care at a wide scale.<sup>33</sup> Mazlum *et al.* in 2012 determined that mean disease scores of disease awareness and self-care significantly

increased after the educational program based on behavior modification.<sup>34</sup> These results were in congruence with our findings; however, in the current study a significant raise was noted in the mean self-care score after the intervention. This inconsistency might be due to the use of different educational methods and longer duration of sessions held in the present study. According to the sources, the longer the duration of the educational courses and the higher the number of sessions, the stronger is their effect on patients' learning. On the other hand, in this study, the post-test was performed three months post-intervention, which is a longer period in comparison to those reported in the literature.<sup>35</sup> This was mainly due to the fact that behavioral alteration is time-consuming and depended on individual and environmental conditions.<sup>36</sup>

Rahimiam Booger *et al.* in 2011 demonstrated the direct effect of disease awareness on self-



management.<sup>30</sup> In addition, Borhannejad *et al.* in 2015 proposed that providing educational programs to develop disease awareness is essential to enhance self-care behaviors.<sup>37</sup> Nevertheless, Kim *et al.* in 2013 indicated that disease awareness is necessary, but not sufficient, for making behavioral alterations. Active participation of patients in training programs and enhancing their confidence in their own care abilities is an essential factor for active self-management.<sup>38</sup>

Ultimately, in the current study, the patients created effective communication with the healthcare team, which encouraged them to cooperate to achieve the group objectives.

The major limitations of this study include inter-individual variability and the patients' previous experiences about self-care programs, which affect their learning. Moreover, generalizability of the results is limited due to performing the study in only one center and selecting the subjects through convenience sampling.

## 5. Conclusion

Implementation of the participatory care program could enhance disease awareness and self-care among patients. Therefore, it is recommended

to use this model, which is based on the cultural context of the society, among the patients with diabetes or other chronic diseases.

## Conflicts of interest

The authors declare no conflicts of interest.

## Authors' contributions

Seyedeh Toktam Masoumian Hoseini: designing and implementation of the intervention, data analysis, production of article draft. Zahra Sadaat Manzari: participation in designing and implementing the study. Ali Bazi: participation in implementing the intervention and data analysis.

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