

The Effect of Educational Protocol Intended to Promote Illness Perception on Death Anxiety in Patients with Heart Failure: A Clinical Trial Study

Negin Babaei Vahed¹, Mahin Roohani^{*1}, Saeedeh Zenoozian², Elham Faghihzadeh³,
Kourosh Amini⁴

^{*1}Department of Critical Care Nursing, Nursing and Midwifery School, Zanjan University of Medical Sciences, Zanjan, Iran

²Assistant Professor, Department of clinical psychology, Zanjan University of Medical Science, Zanjan, Iran

³Assistant Professor, Department of Biostatistics and Epidemiology, School of Medicine, Zanjan University of Medical Sciences, Zanjan, Iran

⁴Associate Professor, Zanjan Social Department of Health Research Center, Zanjan University of Medical Sciences, Zanjan, Iran

***Corresponding Author Address:** Zanjan University of Medical Sciences, Dr.Sobouti Blvd. School of Nursing and Midwifery, Zanjan, Iran

Tel: 0098-9122415541

Email: Roohani@zums.ac.ir

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Abstract

Background: Exposure to death and the resulting anxiety is a significant dimension of the mental health of patients suffering from chronic diseases, including heart failure.

Objectives: Illness perception affects adherence to health-promoting behaviors and health outcomes. Hence, the purpose of this study was to investigate the effect of a perception-based intervention on death anxiety in patients with heart failure.

Methods: Following a randomized clinical trial design, 120 patients suffering from heart failure, recruited using convenient sampling, were categorized into two groups of control and intervention using the randomized minimization method. The intervention group received three 30-minute sessions of training, while the control group only received routine interventions. Data were collected using a demographic information checklist, brief illness perception questionnaire (BIPQ), and Templer Death Anxiety Scale. Data analysis was administered by independent t-test, paired t-test, chi-square, and Wilcoxon tests using SPSS version 22.

Results: There was a significant difference between the study groups concerning anxiety scores before and after the intervention ($P < 0.001$). Death anxiety scores before the intervention were not significantly different between the two groups ($P = 0.640$), but there was a statistically significant difference in death anxiety scores after the intervention ($P < 0.001$).

Conclusion: Regarding the importance of death anxiety in patients with heart failure, this study demonstrated the importance of using perception-based interventions.

Keywords: *illness perception; death anxiety; heart failure*

Introduction

Heart failure (HF) is a common cardiovascular illness in developed countries, known as a chronic, progressive, and debilitating disorder [1]. HF mainly causes performance limitations, leading to problems in daily activities, including job, family, and social affairs, which translates

into the reduced quality of life [2]. Nearly 20 million people have HF worldwide, which is expected to grow. In addition, about 2% of adults living in developed countries suffer from HF; this number ranges from 6 to 10% among those older than 65 years [3].

Major physical and clinical presentations of HF are shortness of breathing, chest pain, fatigue, tiredness, and sleep disorders [4]. Psychologically, patients with HF also have feelings such as uncertainty, insecurity, and thanatophobia [5]. Emotional distress, such as depression and anxiety, is also common in these patients [6]. Alhurani et al. (2018) reported higher anxiety levels among those who have HF by 60%, compared to healthy elders [7]. Evidence indicates the negative impact of depression and stress on health outcomes of those suffering from HF, leading to a negative loop that intensifies heart bit, blood pressure, chest pain, and other health consequences [8,9].

Several studies mentioned the high prevalence of psychological disorders among those with HF [10]. A meta-analysis study comprising 20 articles on CVDs, found an association between anxiety and CVDs death, i.e., anxious people are at increased risk of death by 48%. Psychologic-economic pressures, frequent hospitalization, and weak prognosis result in chronic HF [11]. Hospital environment [12], fear of permanent defects or disability, and unfamiliarity with clinical procedures, equipment, and processes are reported as sources of anxiety [13]. According to the previous studies, thanatophobia is among the major concerns of those with CVDs, including HF [14]. As a multidimensional concept, thanatophobia is difficult to define; however, it is defined as permanent fear of death, the person or others. In other words, this concept is about predicting the death of the person or others [15]. There is no doubt that everyone thinks of death; however, those who have chronic diseases or are about to die overthink this issue [16]. According to the evidence, nearly 27% of those who have HF experience higher rates of death anxiety, which indicates patients' view of the risk of death from the illness. ValiKhani et al. (2013) reported a prevalence of 30, 28.3, and 41.7% for mild, moderate, and severe thanatophobia, respectively. They also noted that 70% of CVD patients suffer moderate to severe thanatophobia [17]. North American Nursing Diagnosis Association mentioned thanatophobia, particularly regarding the importance of this concept in the context of healthcare services [18,19]. Therefore, thanatophobia occurs when experiencing a risk [20,21].

On the other hand, patients develop an organized model of health-related beliefs after diagnosis of a disease, called illness perception, which forms their feature behaviors regarding illness management [22]. Such beliefs affect treatment adherence. Positive perception about the illness results in a realistic understanding regarding symptoms and other dimensions of the disease, leading to strengthening health-related behaviors and better illness management, which translates into improved health outcomes [23]. While pharmacological options are widely used to address negative psychological consequences, including thanatophobia; however, these options also cause consequences [24], which impose high costs to health systems. In this line, some studies investigated non-pharmacological options and prioritizing non-pharmacological, non-invasive therapies with no side effects and extra charges for patients [25]. Increasing patients' perception decreases the duration of returning to work, increases willingness to gain more perception about the illness and its stages and motivation for rehabilitation [23,26]. The common-sense model of self-regulation, initially developed by Leventhal et al. (1997), is developed to facilitate understanding the effect of illness perception on quality of life and health-related behaviors. According to this model, the ill person plays a dynamic role in the illness perception, which seeks to reach a balance in the face of an illness risk (diagnosis or presenting symptoms) by addressing the risk [27]. Promoting interventions to improve illness perception and beliefs may improve treatment adherence, appropriate disease management, and reduce mortality [28].

Regarding the importance of thanatophobia, particularly among those with chronic diseases such as CVDs, special attention should be paid to the psychological dimensions of chronic diseases. The purpose of this study was to investigate the effect of a perception-based intervention on thanatophobia in patients with heart failure.

Methods

The study population of this clinical trial with pre- and post-test was patients with heart failure hospitalized at the Coronary Care Unit and Internal Department of the Ayatollah Mosavi Hospital of the Zanjan in 2020. The sample size was calculated by the power analysis method

using Gpower software version 3.1.9. The sample size was estimated as 60 subjects per group, based on the effect size of 0.57, alpha error of 0.57 (confidence interval of 95%), 0.85 statistical test power, and attrition rate of 5% [23]. The participants (n=120) were divided into two groups with 60 subjects. Sampling was performed using the convenient sampling technique. The inclusion criteria were definitive diagnosis of heart failure by a cardiologist, ejection fraction (EF) of $\leq 40\%$, using echocardiography, stable hemodynamics and clinical status, willingness to participate, being 35 years old and more, being aware of time and place, ability to fill the questionnaire and participation in meetings (either physically or clinically), not losing a loved one during the past months, not participating in another study, no history of psychological disease, not using a drug that affects the psychological status, and low illness perception. The exclusion criteria were early hospital discharge, unwillingness to continue the study, traveling to another city, death, and intensified clinical status. Of 132 eligible cases, 120 included the study and were randomized into two groups of intervention and control, using the randomized minimization method.

Data were collected using the demographic and clinical information checklists (age, gender, marital status, education, employment status, time since of illness inception, frequency and duration of hospitalization, EF, and prescribed drugs), brief illness perception questionnaire (BIPQ), and Templer Death Anxiety Scale (TDAS). Initially, all patients filled the Illness Perception Questionnaire, and those with a score lower than 40 were included in this study. The IPQ was developed by Weinman et al. (1996) based on the Leventhal model [29]. Then, Moss-Morris (2002) revised this questionnaire, known as IPQ-R. The IPQ contains:

- Dimensions of Nature of the disease (perception of symptoms of the illness).
- Timeline (acute/chronic).
- Consequences of the disease
- Personal control.
- Treatment control.
- Illness coherence.
- Timeline cyclical (cyclical nature).
- Emotional representations and causes [30].

Broadbent et al. (2006) developed the Brief Illness Perception Questionnaire because the original form had several items and required a long time to be filled [31]. BIPQ has nine items that cover nine dimensions of illness perception. Five dimensions cover cognitive response of the patient: consequence (first item); timeline (acute/chronic) (second item); personal control (third item); treatment control or treatability (fourth item); and identify the symptoms (fifth item). Two dimensions are related to emotional response, including concerns about the illness (sixth item), emotional representations (eighth item); illness coherence (seventh item); and cause (ninth item, which is an open-ended question). Except for the cause domain, all other dimensions are assessed using a Likert scale from zero to 10, yielding a total score of zero to 80. For items 1, 5, 6, and 8, higher scores indicate weak illness perception, i.e., the person considers the illness as severe. Items three, four, and seven are reverse scored. The validity and reliability of this questionnaire are evaluated by Broadbent et al. and confirmed these items [31]. SeyedRasouli et al. reported a Cronbach alpha of 0.86 for this questionnaire [28]. The Persian version of the BIPQ is prepared by Bazazian et al., and its validity and reliability are approved. Using a sample of 300 patients with diabetes, they reported a Cronbach alpha of 0.8 and test-retest reliability of 0.42 to 0.75 for various items in six weeks [32]. In this study, intra-class correlation was evaluated using Cronbach alpha (0.73), which was 0.74 for sub-scale one (consequences), 0.74 for timeline, 0.52 for personal control, 0.52 for treatment control, 0.82 for identity, 0.74 for illness concern, 0.51 for illness coherence, and 0.66 for emotional representations.

Templer developed the TDAS in 1970. This scale has 15 items, scored on a two-point scale (i.e., yes or no; the former indicates anxiety, and the former is an opposite score). A yes score has a value of one, while a score of no has a value of zero. The total score of this scale ranges from zero (lack of anxiety) to 15 (high anxiety), where high death anxiety=7-15, moderate death anxiety=6-7, and low death anxiety=0-6 [33]. Several Iranian studies used this scale, which reported its validity and reliability and mainly reported a Cronbach alpha greater than 0.8 [34]. In this study, a Cronbach alpha of 0.70 was obtained.

Written informed consent was obtained from all participants before entering the study and after a comprehensive introduction to the study protocol. In addition, the research purpose and methodology were subjected to scrutiny by the Research Ethics Committee of Zanjan University of Medical Sciences. Then, the demographic information questionnaire, IPQ, and DAQ were filled by face-to-face interviews. The intervention group received three 30-minute sessions of individual face-to-face training by the researcher at CCU and the internal department. The training sessions were based on the common-sense model of self-regulation of Leventhal et al., which

contains five components of identity, cause, consequences, timeline, and control/treatment. These components form the illness perception. Identity and cause were discussed in the first session; consequences, timeline, and control/treatment in the second session; and control and treatment (care plan) were provided in the last session (Table 1). Both groups again filled BIPQ and Death Anxiety Scale. The Illness Perception manual, based on the Leventhal model, was provided to controls to observe ethical issues. Data analysis was administered by chi-square, independent t-test, paired t-test, and Wilcoxon using SPSS version 22.

Table 1: The intervention

Session	Intervention
Session one (First day)	This session was provided on the day of selecting an eligible patient. It was mainly about the identity and nature of the disease (two (out of five) components of the Leventhal model). Then, factors that can intensify symptoms (intense activity, physical and mental stress, poor diet, smoking, problems related to drug use, etc.) were discussed from the patient's point of view.
Session two (Second day)	After reviewing the previous session, all questions asked by patients were answered. Then, the patient's beliefs about the consequences, duration, control, and treatment (three (out of five) components of the Leventhal model) of the illness were discussed according to the patient's perception. Afterward, the patients were informed that the next session was the last one.
Session three (Third day)	A treatment plan (the fifth component of the Leventhal model) was provided, and previous sessions were discussed. In addition, a series of information on Covid-19 prevention were provided. At the end of the third session, an educational booklet containing pathophysiology, risk factors, symptoms of heart failure as well as the most commonly used drugs, their adverse effects, and how to use them, treatment control, nutritional restrictions, necessary interventions that must be respected, anxiety control, and finally Covid-19 prevention methods, was provided to all participants. Then, the patient was asked about the impact of the intervention and new experiences as well as potential problems and barriers.

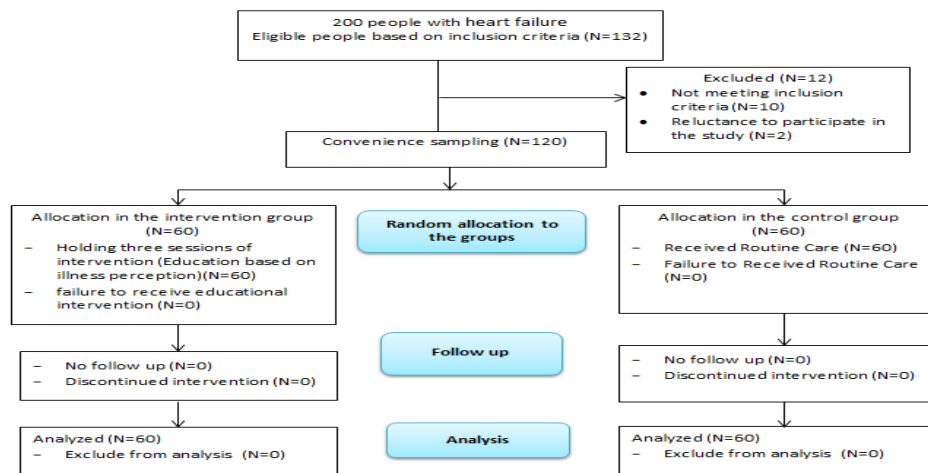


Figure 1: Consort Statement on patients' selection

Results

The mean age of participants in the intervention and control groups was 64.73 (± 12.21) and 67.08 (± 13.2) years, respectively. Of all participants, 101 were married, and one (1.7%) was single. There was no significant difference between the

study groups concerning the number of hospitalizations ($p=0.287$), with a mean of 6.21(± 4.51) for the intervention group and 4.99 (± 3.41) for controls. In addition, study groups were similar concerning demographic information ($p>0.05$) (Table 2).

Table 2: Demographic information, separated by the study group

Variable	Intervention		Control		P-value (chi-square)	
	N	%	N	%		
Gender	Male	38	63.3	38	63.3	P= 1.000
	Female	22	36.7	22	36.7	X ² = <0.001
Marital status	Single	1	1.7	0	0	P = 0.540
	Married	51	85	50	83.3	X ² = 1.232
	Deceased partner	8	13.3	10	16.7	
Education	Illiterate	33	55	36	60	P = 0.466
	Elementary	14	23.3	15	25	X ² = 4.608
	Middle & High School	6	10	3	5	
	Diploma	3	5	5	8.3	
Employment status	Academic	4	6.7	1	1.7	
	Unemployed/ Disabled	10	16.7	9	15	P = 0.891
	Retired	14	23.3	11	18.3	X ² = 0.626
	Employed	16	26.7	18	30	
Residence area	Housewife	20	33.3	22	36.7	
	Urban	36	60	42	70	P = 0.251
Economic status	Rural	24	40	18	30	X ² = 1.319
	Bad	8	13.3	7	11.7	P = 0.814
	Moderate	47	78.3	46	76.7	X ² = 0.411
Main income source	Good	5	8.3	7	11.7	
	Personal income	18	30	20	33.3	P = 0.701
	Family or friends	18	30	20	33.3	X ² = 1.420
Social support	Other	24	40	20	33.3	
	Low	8	13.3	9	15	P = 0.400
	Moderate	28	46.7	34	56.7	X ² = 1.835
Living status	Good	24	40	17	28.3	
	Alone	4	6.7	6	10	P = 0.509
	Family	56	93.3	54	90	X ² = 0.436

Comparing the mean scores of illness perception in both groups before the intervention revealed no significant difference, and there was no statistically significant difference in all dimensions ($p=0.326$) (Table 3).

There was a statistically significant difference between the study groups concerning the mean score of illness perception before and after the intervention ($P<0.001$) (Table 3).

The paired test showed no significant difference in the intervention group before and after the intervention ($P<0.001$). For the control group, a significant difference was found for dimensions of personal control ($P=0.039$), treatment control ($P<0.01$), identity (), and the total score ($p=0.001$) (Table 3).

Table 3: Comparing mean score of illness perception before and after the intervention, separated by the study group (n=60 subjects in each group)

Variable	Group	Before the intervention		After the intervention		Paired t-test	t-test after the intervention
		Mean	SD	Mean	SD		
Consequence	Intervention	8.65	1.62	7.40	1.88	P<0.001 t=6.088	P<0.001 t=-3.679
	Control	8.75	1.84	8.66	1.88	P=0.340 t=0.962	
timeline (acute/chronic)	Intervention	5.21	2.90	2.65	2.38	P<0.001 t=7.009	P<0.001 t=-4.462
	Control	4.93	2.67	4.81	2.90	P=0.458 t=0.748	
Personal control	Intervention	6.16	2.07	8.51	1.38	P<0.001 t=-10.799	P<0.001 t=6.872
	Control	6.00	1.66	6.38	1.96	P=0.039 t=-2.116	
Treatment control	Intervention	7.95	1.96	9.65	0.91	P<0.001 t=-8.242	P<0.001 t=5.501
	Control	7.60	1.87	8.10	1.98	P<0.001 t=-3.809	
Identity	Intervention	8.71	1.66	5.65	2.60	P<0.001 t=11.640	P <0.001 t=-7.191
	Control	9.03	1.43	8.66	1.93	P=0.040 t=2.100	
Concerns about the disease	Intervention	8.21	2.60	5.63	2.84	P<0.001 t=9.869	P<0.001 t=-5.244
	Control	8.26	2.62	8.28	2.69	P=0.867 t=-0.168	
Coherence	Intervention	1.28	1.89	7.96	1.46	P<0.001 t=-24.709	P< 0.001 t=17.593
	Control	1.60	1.89	1.83	2.27	P=0.080 t=-1.781	
emotional representations	Intervention	6.63	3.10	4.71	2.72	P<0.001 t=6.857	P< 0.001 t=-4.849
	Control	7.13	2.40	7.03	2.50	P=0.496 t=0.685	
Total score	Intervention	27.90	7.89	50.25	9.51	P<0.001 t=-25.97	P<0.001 t=13.69
	Control	27.8	6.95	28.85	7.49	P=0.001 t=-3.57	

Nearly 45% of controls and 40% of subjects in the intervention group had high death anxiety. The chi-square test showed no significant difference between the study groups ($p=0.642$). Those in the intervention group showed a Severe death anxiety was reduced to mild death anxiety after receiving

the intervention, which was statistically significant according to the Wilcoxon test (CI: 95%; $p<0.001$) (Table 4). Overall, the results demonstrated the positive impact of the intervention on illness perception and reduced death anxiety.

Table 4: Comparison of death anxiety before and after the intervention, separated by the study group

Group	Time	Score of death anxiety			P-value (chi-square)	P-value (Wilcoxon test)
		0-6	6-7	7-15		
Intervention/control	Before	N	27	9	p=0.642 X ² =0.887	P < 0.001 Z= -3.957
		%	45	15		
	After	N	43	9		
		%	71.7	15		
Control	Before	N	22	11	p< 0.001 X ² =15.543	P = 0.285 Z= -1.069
		%	36/7	18/3		
	After	N	22	15		
		%	36.7	25		

P-value 1: inter-group comparison (before and after the intervention between the two groups)

P-value 2: Intragroup comparison (before and after intervention in each group)

Discussion

According to the results, the perception-based intervention could improve patients' illness perception and resulted in anxiety control in patients suffering from heart failure. Najafi-Gezelje and colleagues report similar results. Dimension of identity obtained the lowest mean score. On the other hand, the consequences dimension obtained the highest mean score, followed by concerns. Most participants mentioned stress and psychological problems as the main reasons for the disease [35]. Dimensions of consequences and identity/severity of symptoms obtained the highest mean scores, while illness coherence obtained the lowest mean score. Concerning the cause dimension, more than half of patients mentioned stress and psychological problems as the main reason for the disease. Based on comparing the mean score of illness perception, patients emphasized the significant impact of the illness on their life, emotions, and morale; they also noted the long-term presence of the disease. The findings also indicated the severity of symptoms and high anxiety of patients, which can be attributed to the fact that most patients had HF of class IV with low EF, which is life-threatening, with significant impact on daily activities through weak physical and mental status that in turn causes more anxiety. The intervention presented a positive impact on clinical outcomes of those in the intervention group. For instance, in a study titled the effect of education based on Leventhal's model on the perception of disease in diabetic patients, Giasvandian, Sadeh-Tabarian, and colleagues (2018) reported the significant impact of the

intervention. They also mentioned the positive effects of the intervention on patients' treatment adherence, leading to lower consequences [36], which is consistent with the findings of the present study. It should be noted that the present study was conducted on patients with heart failure and intended to investigate the effect of anxiety on clinical outcomes.

Participants of both groups had a low illness perception before providing the intervention. After receiving the intervention, the results showed a significant difference in the intervention group for both the overall score and each dimension. As both groups were homogenous concerning the illness perception at the beginning of the study, it can be argued that the intervention, which was based on Leventhal's model, resulted in significant changes in comparison to the control group.

Another important finding was death anxiety, which regarding the high mental impact of the CVDs and the permanent risk of the disease, which even may result in death, was not unexpected. In the same vein, Robah K et al. (2017) reported that awareness of imminent death is a major threat to humans, particularly regarding our strive for survival. Hence, death anxiety can decline wellbeing. While death anxiety is a global phenomenon, its perception varies from one person to another [37]. In the same vein, Sadeghi et al.'s study (2014) reported higher levels of death anxiety in hemodialysis patients. They also mentioned higher levels of stress among patients with chronic disease, mainly due to the nature of the disease and the problems they are faced with, which death anxiety is one of them [38]. In this

study, HF patients had higher levels of death anxiety before receiving the intervention, which indicates the impact of stress in patients with chronic diseases. Mika J et al. (2016) also reported similar results, i.e., all components (psychological and non-psychological) of cardiovascular interventions resulted in a slight but positive reduction [39]. Based on Soleimani et al.'s study (2018), which intended to investigate illness perception on death anxiety in hemodialysis patients, those in the intervention group experienced reduced death anxiety. In other words, the findings indicated the positive effect of the intervention, as a non-pharmacological and valuable method, in reducing death anxiety and improving clinical outcomes in hemodialysis patients. These findings are consistent with those of the present study; however, this study was performed on HF patients and the mean score of death anxiety was considerably reduced after receiving the intervention. Zhang et al. (2016) mentioned a positive association between severity and illness perception. It seemed that people with more severe illnesses use dysfunctional coping strategies with weaker illness perceptions, suffer from more pressures, face higher levels of psychological problems, such as anxiety and depression, and experience a lower quality of life [40]. Concerning the impact of educational interventions on illness perception, Akbari et al. (2019) noted that the intervention could considerably improve illness perception in the intervention group, compared to the controls, and HF patients showed a considerable treatment adherence [41]. Similar results are reported by Zakerimogadam et al. (2015), i.e., regarding the positive impact of interventions intended to improve illness perception on self-care behaviors in patients with HF. There was no significant difference between the study groups concerning the mean score of illness perception before and after the intervention, which their results showed a significant difference between the study groups eight weeks after initiating the intervention [42]. The findings showed a lower level of death anxiety among those who received the intervention.

Conclusion

It is suggested that nurses should consider interventions to examine patients' illness

perception and develop plans to modify them based on the patient's needs. Such interventions may result in more prolonged survival and improved quality of life. Hence, we recommend using Leventhal et al.'s model for this purpose. It is necessary to mention some limitations and biases of our study, including sampling limitations caused by restrictions imposed to control the Covid-19 epidemic, such as the closure of universities, barriers to discussing the concept of death, and sources of death anxiety, as it may intensify the stress. Even in some patients, noting the death intensified their psychological state (e.g., crying, prolonged silence), lead to interruptions in training. Another important limitation is the lack of long-term follow-up after providing the intervention.

Further studies are needed to extend our knowledge regarding the impact of interventions intended to improve illness perception with longer follow-up periods.

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Conflict of interest

There is no conflict of interest in publishing this article.

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