### **ORIGINAL PAPERS**

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## Significance of education and self-management support for patients with chronic heart failure in family physician practice

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A – Study Design, B – Data Collection, C – Statistical Analysis, D – Data Interpretation, E – Manuscript Preparation, F – Literature Search, G – Funds Collection

Summary Background. Chronic heart failure (CHF) is a disease that requires self-management by the patient, thus it is understood that when they are diagnosed, they need access to relevant information about their disease.

Objectives. The purpose of this paper was to ascertain the sources and content of education for patients with CHF and evaluate the use of patient education for self-management support of patients with CHF in primary care.

Material and methods. Patients were identified from a patient registry and physician referrals. 371 individuals responded to the questionnaire, and we estimated the effectiveness of patient education.

Results. Whilst 91% of patients reported receiving education at the time of diagnosis, it is a concern that 9% say they were not provided information. Only a few patients said they had received education from hospital consultants. After the training, the percentage of patients who kept a diary of introspection increased almost three-fold, the percentage of patients measuring blood pressure and heart rate increased four-fold and measuring body mass increased six-fold.

Conclusions. CHF education was mainly delivered in primary care by family physicians. While there have been a growing number of efficacious interventions for patients with CHF, their effectiveness will be limited without self-management support to assist patients in adopting behaviors that contribute to improved health.

**Key words:** education, heart failure, self-management.

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## **Background**

Chronic heart failure (CHF) is a disease that requires self--management by the patient. Some education programs have been shown to improve self-care, general health status and well-being in patients. Education programs have also been used to target the reduction of risk factors, such as weight, blood pressure and serum lipids, but with less success [1, 2].

Self-management support is defined as the systematic provision of education and supportive intervention by healthcare staff to increase patients' skills and confidence in managing their health problems, including regular assessment of progress and problems, goal setting and problem-solving support [3]. The goals of self-management are changes to behavior to promote improved functioning and quality of life. However, while there is a growing body of evidence for the efficacy of self-management strategies (e.g. patient education, coping skills, action plans for decompensation, exercise programs) among patients with CHF, few interventions have been specifically designed to promote and sustain change of behavior [4, 5].

The determinants and processes associated with self-management behavior are complex, comprising a number of factors such as health beliefs, self-efficacy and motivation. These factors have been examined in a number of studies of patients with CHF using qualitative and quantitative methods. But studies for the development of cognitive-behavioral intervention are lacking in literature on self-management support of CHF [6, 7].

### **Objectives**

The purpose of this paper was to ascertain the sources and content of education for patients with CHF and evaluate

the use of patient education for self-management support of patients with CHF in primary care.

### Material and methods

This study was conducted at the Kharkiv Medical Academy of Postgraduate Education. All participants were recruited from the Kharkiv region in Ukraine.

The study was a cross-sectional survey, carried out from September 2014 to March 2015, of patients categorized as having CHF. Patients were identified from a patient registry and physician referrals. The register is held in a Microsoft Office Access database and holds information on patients' age, gender, ethnicity and functional class of CHF. We selected 395 newly diagnosed patients, with the year of diagnosis being 2011-2013, all of them between 45 and 83 years of age and categorized as having CHF. These patients were cared for by 36 family physicians.

Eligibility was initially determined from a review of medical records, including echocardiographic results and for other clinical characteristics that may prevent participation. Potentially eligible subjects were sent an introductory letter of invitation to participate and subsequently contacted by telephone to schedule an enrolment visit. After obtaining written informed consent, final determination of eligibility was made using the following inclusion and exclusion cri-

Participants who were included were diagnosed with New York Heart Association class II or III CHF, agreed to education and follow-up care and would be available by phone.

Participants who were excluded were those who experienced significant worsening of their disease and were transferred to the intensive care unit, were hospitalized for greater than 1 month, had a chronic disease other than CHF or were diagnosed with a mental illness.

**371 persons responded** to the questionnaire and expressed their desire to participate in the program. Each of them filled out the questionnaire utilizing the pen and paper method, and then we clarified the situations on the key issues of self-management (Table 1).

### **Table 1. Key points of self-management**

Does the patient keep a diary of introspection?

Does the patient measure BP at least 1 time in 2 days?

Does the patient measure HR at least 1 time in 2 days?

Does the patient measure BM at least 2 times a week?

Does the patient observe the recommendations of BD?

Does the patient observe the recommendations of FA?

BP – blood pressure, HR – heart rate, BM – body mass, BD – balanced diet, FA – physical activity.

A questionnaire was developed asking a series of questions including basic demographic data, a series of questions regarding the education received, who provided it and self-perceived knowledge. The questionnaire focused on important aspects of care for diabetes, such as diet, blood glucose, blood pressure, cholesterol, foot care, eye care, exercise and smoking.

Patients were evaluated with SECC-scale assessment (the scale of evaluation of clinical condition in CHF) modified by V. Mareev, 2000 (Table 2) [8].

# Table 2. The scale of evaluation of clinical condition in CHF (SECC) (modification by V. Mareev, 2000)

Dyspnea: 0 – none, 1 – during exercise, 2 – at rest

If the weight changed for the past week: 0 – no, 1 – increased

Complaints about the arrhythmia: 0 - no, 1 - yes

What position was the individual in bed: 0 – horizontal, 1 – with a raised head (2 + pillows), 2 – plus waking from suffocation, 3 – sitting

Swollen neck veins: 0 - no, 1 - lying, 2 - standing

Wheezing in the lungs: 0 - no, 1 - the lower parts of the lungs (1/3), <math>2 - to the level of the scapula (2/3)

Having gallop rhythm: 0 – no, 1 – yes

Liver: 0 - not enlarged, plus 1 - 5 cm, 2 - 5 cm

Swelling: 0 – no, 1 – minor swelling, 2 – swelling, 3 – anasarca

Systolic BP: 0 - >120, 1 - 100-120, 2 - <100 mm Hg

The participants were randomized into two groups using random numbering software. The groups were matched by age, gender, functional class of CHF, and score on the SECC scale. **Patients of the 1st group** (173 people, average age  $63 \pm 8,1$ ) were trained according to a 12-hour program entitled "Self-management in CHF". The sessions were held by specialists from the Department of General Practice-Family Medicine at Kharkiv Medical Academy of Postgraduate Education.

The purpose of the training: 1) to show the importance of following the physician's advice, self-control, adequate physical activity and a balanced diet, as well as regular admission of pharmaceutical drugs, and thus motivate patients to follow all the recommendation; 2) to teach patients self-

management and ways of assessment of the adequacy of physical exercise. Patients were also given memos (on treatment, good nutrition, and physical activity).

In the 2nd group (198 people, average age  $64 \pm 8,4$ ), training was not conducted, and patients received the necessary information from the family doctor. Patients of both groups received standard treatment. After 6 months, we again conducted a survey and objective examination of the patients.

A questionnaire was developed asking a series of questions including basic demographic data, a series of questions regarding the education received, who provided it and self-perceived knowledge. For the assessment of self-management needs, 10 standardized open-ended questions were used (Table 3).

#### Table 3. Questionnaire for assessment of CHF self-management needs

- 1. What is your greatest concern or fear about your CHF?
- What things have helped you most to control your disease?
- 3. What things do you need to learn to help you live with CHF?
- 4. Describe who currently helps you manage your CHF and how they help?
- 5. What is your most important goal for helping you live better with your disease?
- 6. What may get in the way of controlling your CHF?
- 7. What have you done to help manage your CHF since being diagnosed?
- 8. What people do you have in place to help increase your physical activity?
- 9. What are some things that may prevent you from being physically active?
- 10. What types of physical activity do you enjoy?

The focus of the questions was on setting of goals, expectations, social support and individual needs with the aim of learning about individual goals for the future (e.g. overcoming losses and fears) that were used to tailor subsequent counseling using cognitive-behavioral techniques to enhance CHF self-management and physical activity.

All data was entered into a Microsoft Office Excel spreadsheet. Analysis was undertaken using an SPSS statistical package. The Kruskal–Wallis test was used to examine the difference in knowledge scores. The chi-square test was used to test the differences in the method of CHF diagnosis, education and support.

The data obtained was processed using a SPSS Statistics 17.0 package (SPSS Inc., USA). Verification of the normal distribution of the compared parameters was done according to the criterion of the Kolmogorov. The basic statistical characteristics (confidence level, for which a confidence interval of 0.05 was built) were determined. To test the hypothesis of equality of the two averages, a paired two-sample Student's t-test in samples with normal distribution was used, with a paired Kruskal–Wallis test in other cases. The chi-square test was used to learn the differences in the method of education and support. With this test, we compared the frequency of symptoms, which were expressed as a percentage, and determined statistically significant differences (in the form of error probability). Average values with normal distribution are represented as  $M \pm SD$ .

### Results

We can see from Table 4 that the principal source of education for patients diagnosed with CHF is through their general practitioner. Some topics are more likely to be cov $7.3 \pm 2.5$ 

 $6.2 \pm 2.0$ 

 $5.4 \pm 2.3$ 

68 (18%)

53 (14%)

ered by the general practitioner (general education, diet, blood glucose monitoring), whilst other topics are more likely to be covered by the cardiologist (blood pressure, reducing cholesterol and exercise).

Table 4. CHF diagnosis, CHF education and self-perceived

knowledge

All patients

By whom were you diagnosed?

By your family physician

By your local hospital

By cardiologist

Chowledge score out of 10 (mean ± SD)

Knowledge of CHF in general

Knowledge of diet and nutrition

All patients

247 (67%)

56 (15%)

68 (18%)

Chowledge score out of 10 (mean ± SD)

Knowledge of CHF in general

Knowledge of diet and nutrition

7.1 ± 2.1

Knowledge of blood pressure

Knowledge of cholesterol

Reducing blood cholesterol

Smoking cessation

Knowledge of glucose

No information received about:

CHF treatment at the time of diagnosis
Diet/healthy eating
Exercise
Monitoring blood glucose
Importance of checking blood pressure

34 (9%)
83 (22%)
79 (21%)
130 (35%)
56 (15%)

Table 5 shows the results of the survey of patients in both groups at the beginning and after 6 months. Before training, few patients kept a diary of introspection, measured body weight or followed the recommendations on nutrition and physical activity. After the training (group 1), the percent-

age of patients who kept a diary of introspection increased almost 3-fold, the percentage of patients measuring blood pressure and heart rate increased 4-fold, and those measuring body mass (BM) – 6-fold.

The same situation is seen when keeping to a diet and physical activity. The significance of differences between the frequency of symptoms at the baseline and after 6 months was determined by the chi-square test. All the differences among patients of the 1st group were statistically significant (error probability is p < 0.0008).

Among patients who did not undergo training, the situation did not improve after 6 months, and according to some parameters, it became even worse (differences are not statistically significant).

**The 1st group:** the average systolic blood pressure (SBP) during the observation period (6 months) decreased by 7.2 mm (5% of the original, p = 0.0000139), heart rate – by 3% (p = 0.0004), scores on the SECC scale – by 15% (p = 0.0001). Mid-values of body mass (BM) and diastolic blood pressure (DBP) have not changed.

**In the 2nd group**, all the parameters changed insignificantly (Table 6).

The coding of the interviews yielded three major topics, including loss, fear and desire for improved care. These major topics were composed of seven sub-topics, including four associated with loss, two with fear and one with desire for improved care.

The topic of loss comprised four sub-topics, including loss of normal functioning, loss of independence, loss associated with other medical conditions and loss of social contacts (social isolation). Among the patients, the frequency with which the various sub-themes of loss were expressed ranged from 37% to 92% (Table 3). The two most frequent-

Table 5. Compliance with recommendations on lifestyle and self-control (percentage of complaints)												
	Initial state				After 6 months							
	Group 1		Group 2		Group 1		Group 2					
	Pers.	%	Pers.	%	Pers.	%	Pers.	%				
Diary of self-control	29	17	43	22	153	88	38	19				
Monitoring of BP is not less than 1 time in 2 days	38	22	49	25	151	87	51	26				
Monitoring of HR is not less than 1 time in 2 days	38	22	49	25	140	81	68	34				
Measurement of BM is 2 times per week	11	6	9	5	103	60	9	5				
Compliance with the recommendations of BD	22	13	24	12	87	50	38	19				
Compliance with the recommendations of FA		10	19	10	106	61	40	20				

BP – blood pressure, HR – heart rate, BM – body mass, BD – balanced diet, FA – physical activity. Recommendations for BD: fluid restriction and salt restriction, 4 meals, not to use sugar. Recommendations for FA: daily walks, therapeutic exercises.

Table 6. Some indicators of the general condition of patients in the groups											
	Initial state		After 6 months								
	Group 1	Group 2	Group 1		Group 2	Group 2					
	Average ± SD	Average ± SD	Average ± SD	p	Average ± SD	р					
ВМ	89.9 ± 15.12	88.1 ± 14.81	89.7 ± 15.72	*	90.6 ± 15.04	*					
SBP	140.1 ± 16.67	138.7 ± 15.99	132.9 ± 10.13	0.0000139	138.1 ± 14.35	*					
DBP	91.2 ± 17.31	90.2 ± 15.33	90.4 ± 17.01	*	92.4 ± 14.89	*					
HR	82.2 ± 6.15	79.0 ± 5.86	79.6 ± 3.86	0.0004	79.3 ± 5.67	*					
SECC	5.89 ± 1.39	5.74 ± 1.42	4.99 ± 1.38	0.0001	6.69 ± 1.41	*					

BM – body mass, SBP – systolic blood pressure, DBP – diastolic blood pressure, HR – heart rate, SECC – scale of evaluation of clinical condition; p – the probability of error in the determination of statistically significant differences between the baseline and after 6 months; \* – not significant.

ly voiced concerns concerned loss of normal functioning (92%) and loss associated with other medical impairments (74%)

Concern about loss of normal functioning was characterized by a loss of normal activities not necessarily essential to survival, such as performing recreational activities and hobbies or the inability to complete tasks in a normal fashion or at a normal pace. This loss was often attributed to breathlessness and fatigue.

Loss of normal functioning associated with symptoms from CHF also contributed to concerns about loss of independence characterized by the inability to perform tasks necessary for daily living, such as shopping, bathing and maintaining the household.

Symptoms associated with CHF and other chronic conditions contributed to a reduction in social activities and feelings of social isolation. Moreover, the patients expressed concern about lack of, or inadequate, social support.

The topic of fear was frequently expressed and comprised fear about disease progression (67%) and suffocation (44%). Fear of disease progression was characterized by concerns about the future of one's illness and uncertainty as to how to prevent progression of the disease. Patients frequently reported experiences of severe breathlessness associated with intense panic and fear. Moreover, these episodes contributed to fear about dying in respiratory distress. The desire to avoid breathlessness was poignantly clear.

The topic of desire for improved care was frequently expressed by patients (59%) and focused on lack of self-management support and a general lack of understanding of their condition, including how to care for themselves. Patients were confused, frustrated and wanted to learn more about their illness. They had difficulty knowing how to get their informational and medical needs met.

### **Discussion**

While a number of qualitative and quantitative studies have been conducted to examine various aspects of patients' knowledge and perceptions about CHF, few have specifically examined patients' perspectives concerning barriers, facilitators and personal goals for self-management in representative samples of patients [9]. By focusing on patients' perceptions of their needs, we hoped to guide development of cognitive-behavioral intervention for self-management support. The goal of self-management support is to 'change patient' behavior by increasing patient 'self-efficacy and knowledge' [10].

Gaps in patients' knowledge and health literacy – i.e. the ability to obtain, understand and act on health care information – have been described in a number of qualitative studies and surveys. This lack of association between improved knowledge and health outcomes is a consequence of the fact that health-related behaviors are affected by a number of factors other than knowledge, including emotional adjustment to illness, self-efficacy, motivation, self-management skills, social support, environmental obstacles and ongoing support [11, 12].

The potential influence of these factors on patient behaviors and health outcomes has been examined previously in qualitative studies and in a smaller number of surveys. From these earlier studies, major factors that may affect living with CHF and self-care include lack of knowledge, inadequate communication with providers, loss of social support, multiple co-morbidities, medication issues, physical limitations, loss of control, loss of meaningful activities, fear of getting worse, daily uncertainty, helplessness and the emotional impact of illness [13, 14].

Much still needs to be learned about the impact of education on self-efficacy in patients with heart failure, as there are a limited number of studies that have been conducted. Even though the authors did not specify which components of their intervention should affect self-efficacy, results suggest that several educational intervention approaches appear to be effective in increasing self-efficacy, e.g. one-to-one or group education. Both individual education and group education may improve the self-efficacy of self-care behaviors among patients with heart failure.

Schreurs et al. reported that self-efficacy improved using group education, but did not report the statistics of self-efficacy [15]. Flynn et al. reported a statistically significant improvement in self-efficacy at 52 weeks with group education, but only reported a p-value (p < 0.001) for the total self-efficacy score [16]. The group education and support Yehle et al. provided did not improve self-efficacy in self-care [17]. Definitive conclusions about the impact of group education on self-efficacy cannot be made from these three studies. Additionally, it is difficult to draw conclusions about what factors in the educational interventions most influenced self-efficacy, because the studies did not report on patient responses to specific aspects of each intervention.

While the ultimate goal of self-management support is improved functional and health outcomes through patients' health-related behaviors (e.g. medical management adherence, smoking cessation, physical activity, diet), there remain a number of questions about specific content and how to deliver self-management support in general, and for CHF in particular [18]. For clinicians, a consistent area of concern is the desire among patients for improved care, which is consistent with the findings from previous investigations stating that quality of communication and duration of the relationship between physician and patient affect the health literacy and self-efficacy of patients.

Moreover, poor physician communication is a barrier to self-management, and communication style has a major influence on one making a commitment to specific goals and plans for behavioral change. Further research is needed to determine the best cognitive-behavioral methods for encouraging CHF patients to become motivated to overcome losses and fears and convert their need for information into actual behavioral change that will help them manage their illness better.

### **Conclusions**

Teaching self-management for patients with heart failure is vital. CHF education was mainly delivered through primary care by family physicians. Only a few patients said they had received education from hospital consultants.

While there have been a growing number of efficacious pharmacological and non-pharmacological interventions for patients with CHF, their effectiveness will be limited without self-management support to assist patients in adopting behaviors that contribute to improved health.

Our findings show the significant role of self-management and patient education in the treatment of CHF. Considering the fact that only through self-management can we achieved a significant reduction of arterial blood pressure, heart rate and improvement of the general state, we expect an increase in life expectancy due to patient education.

Our results suggest that the content of self-management support for patients with CHF needs to focus on addressing patients' needs for improved health literacy, fears associated with uncertainty, disease progression and suffering; and expectations about overcoming or replacing losses and desire for improved care. Attention to these topics may enhance patient self-efficacy and their motivation to engage in more comprehensive self-management.

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Tables: 6 Figures: 0 References: 18

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