

# Patients' knowledge of heart failure and their perception of the disease

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**Purpose:** The aim of this study was to gain a deeper insight into patients' perception of chronic heart failure (CHF) symptoms by analyzing their compliance with nonpharmacological recommendations.

**Patients and methods:** This was a prospective, single-center survey-based registry. Patients included in this study were hospitalized between December 2014 and January 2016 at the 1<sup>st</sup> Department of Cardiology, University Hospital of Lord's Transfiguration, Poznań University of Medical Sciences, and had been diagnosed with CHF at least 3 months prior to inclusion. Participants were divided according to New York Heart Association (NYHA) functional class into mild CHF (NYHA I and II) and severe CHF (NYHA III and IV), and according to age into young (<50 years), middle-aged (50–70 years) and old (>70 years). The survey included information about the patients' sex, age, education, length of the illness and 12 questions about their perception of CHF. This study included 201 patients. The mean age was 58±15 years.

**Results:** The younger the patients, the more often they thought that CHF is curable. The patients presenting with severe CHF tended to think that CHF is incurable significantly more often than those with mild CHF. Most of the patients considered loss of appetite, cough and vomiting the least alarming symptoms. Significantly more patients with severe CHF exercised less and reported reduced sexual activity more often in comparison to the mild CHF patients. Most of the young patients reported no changes to their sexual activity, body mass index (BMI) or exercise after diagnosis of CHF. Most of the old patients exercised less than before diagnosis of CHF. Significantly more middle-aged patients reduced their BMI, quit smoking and reported lower sexual activity after diagnosis of CHF in comparison to the other groups.

**Conclusion:** Patients need to be better educated about the nature of CHF and the importance of lifestyle changes.

**Keywords:** chronic heart failure, patient knowledge, patient compliance, lifestyle changes, nonpharmacological recommendations

## Introduction

Cardiovascular diseases (CVDs) are the major cause of death globally. More people die annually from CVDs than from any other cause.<sup>1</sup> Overall, it appears that chronic heart failure (CHF) affects 1%–3% of the general population and ~10% of the very elderly.<sup>2</sup> The lifetime risk of developing heart failure (CHF) is one in five.<sup>3</sup> In the developed countries, the number of patients with CHF is increasing. This trend is a result of an increasing number of the elderly and the survival improvement after acute myocardial infarction.<sup>4</sup> Although CHF is an important epidemiologic problem, the awareness of most of its aspects in the general population in Europe is low. There are clear misconceptions for the nature, severity, treatment options and costs.<sup>5</sup> In addition, the majority of studies reveal lack of knowledge of CHF among patients.<sup>6–8</sup>

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Moreover, old and very old patients with CHF often do not perceive it as a life-limiting disease.<sup>9</sup> Recent studies highlight that the patients' ability to recognize and interpret CHF symptoms is limited.<sup>10</sup> Furthermore, researchers reveal low compliance rate in following nonpharmacological regimen.<sup>7</sup> The successful management of CHF includes substantial changes in patients' everyday life, including maintaining euvolemia, smoking and alcohol cessation, proper diet and exercise training.<sup>11</sup> CHF patient self-care is thought to be cardioprotective and complementary to optimal medical management in improvement of outcomes.<sup>12</sup> However, many patients have problems with following nonpharmacological recommendations.<sup>7,13</sup> Nonconcordance with treatment regimen may increase the risk for readmissions, longer hospitalization and worsening of symptoms.<sup>14</sup> The aim of our article is to analyze CHF patients' compliance with nonpharmacological recommendations and to gain a deeper insight into their knowledge of CHF symptoms.

## Materials and methods

This was a prospective, single-center survey-based registry. The survey was designed to include information about the patients' sex, age, education, length of the illness and 12 questions about their perception of the disease. The CHF symptoms, symptoms the patients consider alarming, the effect of treatment, how patients follow pharmacological and nonpharmacological recommendations and the influence of the disease on the patients' relationships were particularly explored. The subjects were divided according to New York Heart Association (NYHA) functional class into mild CHF (NYHA I and II) and severe CHF (NYHA III and IV), and according to age into young (<50), middle-aged (50–70) and old (>70).

## Inclusion criteria

This study included consecutive patients hospitalized between December 2014 and January 2016 at the 1st Department of Cardiology at University Hospital of Lord's Transfiguration of Poznań University of Medical Sciences with CHF diagnosed at least 3 months prior to inclusion, both symptomatic and asymptomatic (NYHA functional class I–IV), who were hospitalized because of exacerbation of CHF, qualification for invasive treatment (implantable cardioverter defibrillator/ cardiac resynchronization therapy device implantation or heart transplantation) and for treatment or diagnostics of ischemic heart disease. Written consent was obtained before each interview. The study was approved by the Poznań University of Medical Sciences Bioethical Committee.

## Statistical analysis

Statistical analysis was performed using STATISTICA 12 Statsoft. Probability distribution of continuous variables was tested with Lillefors and Shapiro–Wilk tests. Student's *t*-test and analysis of variance (ANOVA) were used to compare continuous variables with normal distribution and Mann–Whitney *U* and Kruskal–Wallis ANOVA tests were used for continuous variables with non-normal distribution. Chi-square tests were used for categorical variables. The data are expressed as mean values with standard deviation for continuous variables and percentages for categorical variables. A *P*-value of <0.05 was considered statistically significant for all the tests.

## Survey

The survey was designed to include information about patients' sex, age and education, length of the illness and 12 questions about their perception of the disease.

1. The patients were asked to choose any number of the following items that they consider the most inconvenient: dependence on others, exercise intolerance, difficulties in performing daily activities, systematic drug intake, frequent hospitalizations and systematic follow-up medical visits.
2. The patients were asked to choose any number of the following symptoms that they consider the worst: dyspnea, nocturnal dyspnea, cough, chest pain, syncope, palpitations, edema, loss of appetite, orthopnea, vomiting, insomnia and tachycardia.
3. The patients were asked whether the pharmacological treatment relieved the symptoms.
4. The patients were asked to choose any number of the symptoms mentioned in question 2 that improved on the employed treatment.
5. The patients were asked to choose any of the symptoms mentioned in question 2 they consider alarming.
6. The patients were asked "Do you think CHF is curable?"
7. The patients were asked about their compliance with pharmacological recommendations suggested by cardiologist.
8. The patients were asked about their compliance with pharmacological recommendations suggested by GP or other specialist.
9. The patients were asked, according to their responses to 7th and 8th questions, the reason for their noncompliance with pharmacological recommendations.
10. The patients were asked how the diagnosis of CHF influenced their lifestyle: diet change, exercise, body

mass index (BMI) change, alcohol consumption, smoking and sexual activity.

11. The patients were asked how diagnosing CHF influenced their relationships with family.
12. The patients were asked how the diagnosing of CHF influenced their relationships with friends.

## Results

### Baseline characteristics

In total, 201 patients were included in this study. The mean age was  $58 \pm 15$  years (min 20, max 92). Most of them were men ( $n=152$ , 76%). Assessment at admission indicated that 67 patients had mild CHF (NYHA I and II) and 126 severe CHF (NYHA III and IV) (Table 1). There were no significant differences in age, sex and length of disease between the mild and severe CHF patients. The latter had significantly higher B-type natriuretic peptide (BNP) and N-terminal of the pro-hormone brain natriuretic peptide (pro-BNP) blood concentration (Table 2). There were 52 young (aged <50 years), 111 middle-aged (aged 50–70 years) and 37 old (aged >70 years) patients. These groups did not show any significant differences concerning severity of CHF symptoms (Table 3).

### Knowledge of CHF

Most patients with mild CHF believed their disease to be curable, and almost half of the severe CHF patients thought CHF to be incurable (Figure 1). The younger the patients, the more often they thought CHF to be curable, and most of the old patients claimed CHF incurable (Figure 2). The patients presenting with severe CHF tended to think CHF to be incurable significantly more often than those with mild CHF (Figure 1).

### Perception of symptoms of CHF

Most of the patients with mild CHF considered chest pain, palpitations and dyspnea alarming. Among the patients with

**Table 2** Characteristics by NYHA FC groups

Characteristics	NYHA FC I–II	NYHA FC III–IV	P-value
Patients (n)	67	126	
Age (years), mean $\pm$ SD	$56 \pm 14$	$59 \pm 15$	0.14
Male sex, n (%)	54 (81%)	90 (71%)	0.22
Length of disease (years), mean $\pm$ SD	$11 \pm 11$	$12 \pm 12$	0.68
BNP (pg/mL)	405	821	0.002
Pro-BNP (pg/mL)	2,061	3,991	0.01

**Abbreviations:** BNP, B-type natriuretic peptide; FC, functional class; NYHA, New York Heart Association; pro-BNP, N-terminal of the prohormone brain natriuretic peptide.

severe CHF, the most often chosen alarming symptoms were dyspnea, chest pain and palpitations. Significantly fewer patients in both groups chose loss of appetite, insomnia, vomiting and cough (Figure 3). The patients with mild CHF tended to choose palpitations as an alarming symptom significantly more often than those with severe CHF (Figure 3). Most of the young and middle-aged patients considered chest pain and dyspnea alarming (Table 4). The old patients considered tachycardia and dyspnea the most alarming. The least often chosen symptoms in all the groups were loss of appetite, cough and vomiting (Figure 4).

### Lifestyle changes

Most of the mild CHF patients reported reducing alcohol consumption and BMI decrease. About one third of them quit smoking, changed their diet and exercised regularly. Among the severe CHF patients, more than half reported less exercise, more than one third quit smoking, changed their diet and reduced BMI and alcohol consumption. In both groups, the patients reported significantly lower sexual activity (Table 5). Significantly more patients with mild CHF exercised regularly compared to the severe CHF patients. Significantly more patients with severe CHF exercised less compared to those with mild CHF. Significantly more patients with severe CHF reported reduced sexual activity in comparison to the patients with mild CHF (Figure 5). Most of the young patients reported no changes to their sexual activity, BMI or exercise. Most of the middle-aged patients reported lower sexual activity, quitting smoking and reducing their BMI. Most of the old patients reported no changes to their sexual activity and BMI, but they exercised less (Table 5). Significantly more middle-aged patients reduced their BMI, quit smoking and reported lower sexual activity in comparison to the other groups. Significantly more young patients reduced alcohol consumption in comparison to the other groups. Significantly more old patients reported no

**Table 1** Baseline characteristics of study population (N=201)

Characteristics	
Age (years), mean $\pm$ SD	$58 \pm 15$
Male sex, n (%)	152 (76%)
Length of disease (years), mean $\pm$ SD	$12 \pm 11$
NYHA functional class	
I–II, n (%)	67 (33%)
III–IV, n (%)	126 (63%)
BNP (pg/mL)	667
Pro-BNP (pg/mL)	3,294

**Abbreviations:** BNP, B-type natriuretic peptide; NYHA, New York Heart Association; pro-BNP, N-terminal of the prohormone brain natriuretic peptide.

**Table 3** Characteristics by age groups

Characteristics	Age <50 years	Age 50–70 years	Age >70 years	P-value
Patients (n)	52	111	37	
Age (years), mean ± SD	38±8	61±5	78±5	
Length of disease (years), mean ± SD	9±11	12±12	13±10	<0.001
NYHA	1.588	1.66	1.743	0.33
BNP (pg/mL)	1,058	502	583	0.19
Pro-BNP (pg/mL)	4,191	2,621	3,817	0.76

**Abbreviations:** BNP, B-type natriuretic peptide; NYHA, New York Heart Association; pro-BNP, N-terminal of the prohormone brain natriuretic peptide.

changes to their sexual activity in comparison to the other groups (Figure 6).

## Discussion

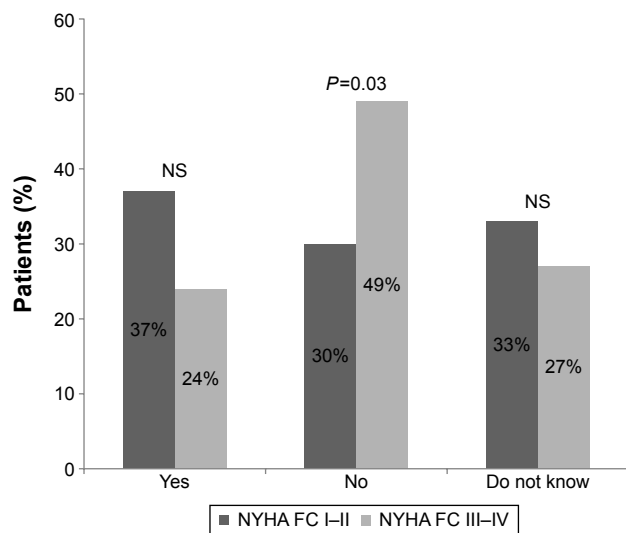
In our study, we analyzed the knowledge of a patient about his disease, which influences compliance with medical instructions and perception of the quality of life (QOL). These factors, although very subjective, can strongly affect a physician's cooperation with a CHF patient. CHF decreases QOL and survival prognosis similar to cancer.<sup>15</sup> Thus, we decided to design a nonstandardized survey, instead of using already existing standardized questionnaires, in such a way that the patients could freely choose which part of the treatment and communication should be improved.

The young and the mild CHF patients tend to believe CHF to be curable, while the old and those with severe CHF were more skeptical. It is comparable to the data obtained

by van der Wal et al – the older patients, with frequent rehospitalizations, tended to perceive their disease more negatively.<sup>16</sup> Surprisingly, in our study, 37% patients with I–II NYHA class and 24% patients classified as III–IV NYHA class perceived CHF as curable, in comparison with 9% among the van der Wal subjects.

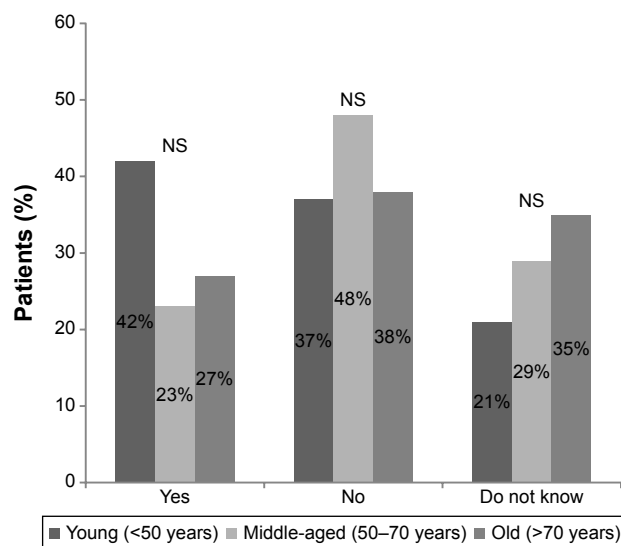
In general, we observed similar QOL decrease with increasing NYHA class as Juenger et al among the Heidelberg population 14 years ago, who used the SF-36 survey.<sup>17</sup> The same result was obtained in a study of Turkish population in a smaller group of only 35 patients.<sup>18</sup> It seems that QOL-improving drugs still do not meet the patients' expectations. Physical symptoms like shortness of breath or chest pain were associated with severe CHF, comparable to the survey-based study of Heo et al dated 2010.<sup>19</sup>

The level of knowledge about alarming symptoms lays a shadow on the communication between doctors and



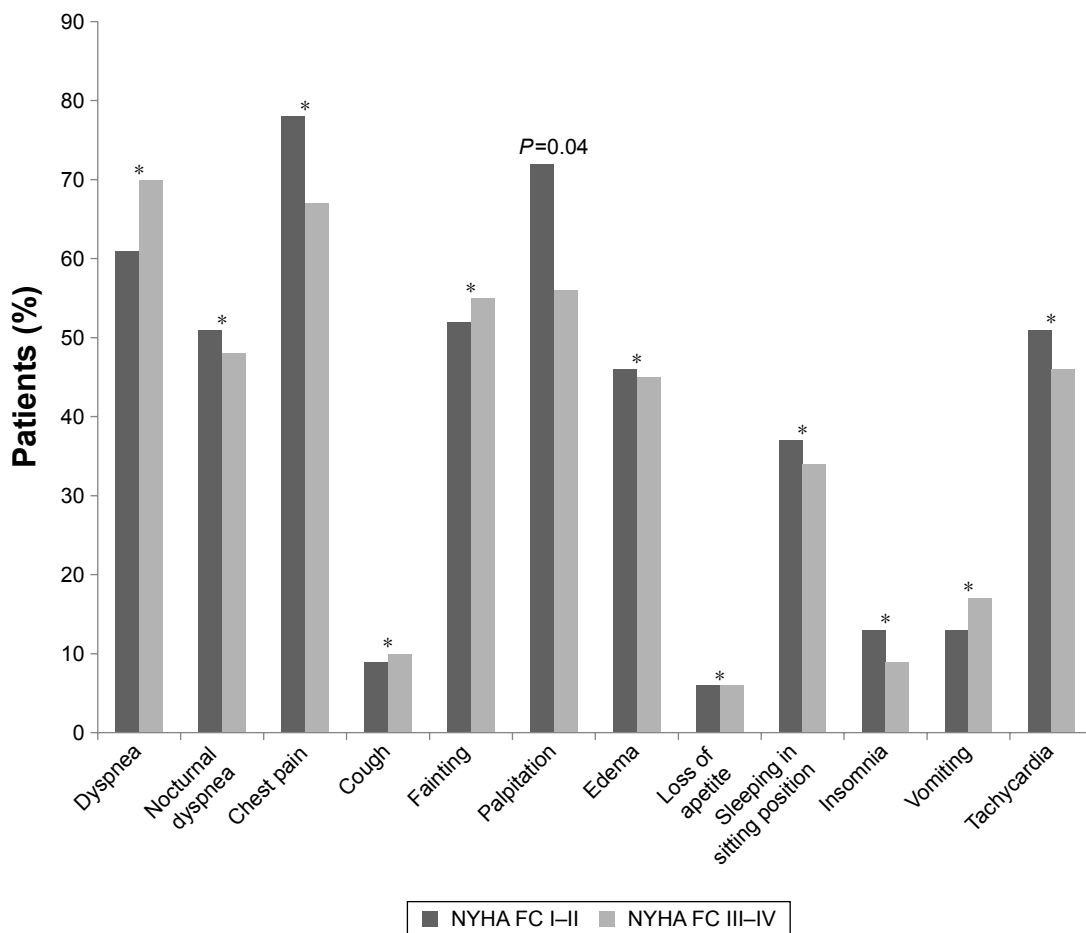
**Figure 1** Response to question: "Do you think HF is curable?", sorted by NYHA FC group.

**Abbreviations:** FC, functional class; HF, heart failure; NS, not significant; NYHA, New York Heart Association.



**Figure 2** Response to question: "Do you think HF is curable?", sorted by age group.

**Abbreviations:** HF, heart failure; NS, not significant.



**Figure 3** Positive response to question: "Do you consider this symptom alarming?", sorted by NYHA FC group.

**Note:** \*Not significant.

**Abbreviations:** FC, functional class; NYHA, New York Heart Association.

patients showing either doctors as ineffective teachers, being expected to provide patients with all the necessary information, or incapable of gaining patients' trust to correct their inaccurate knowledge from other sources. In Poland,

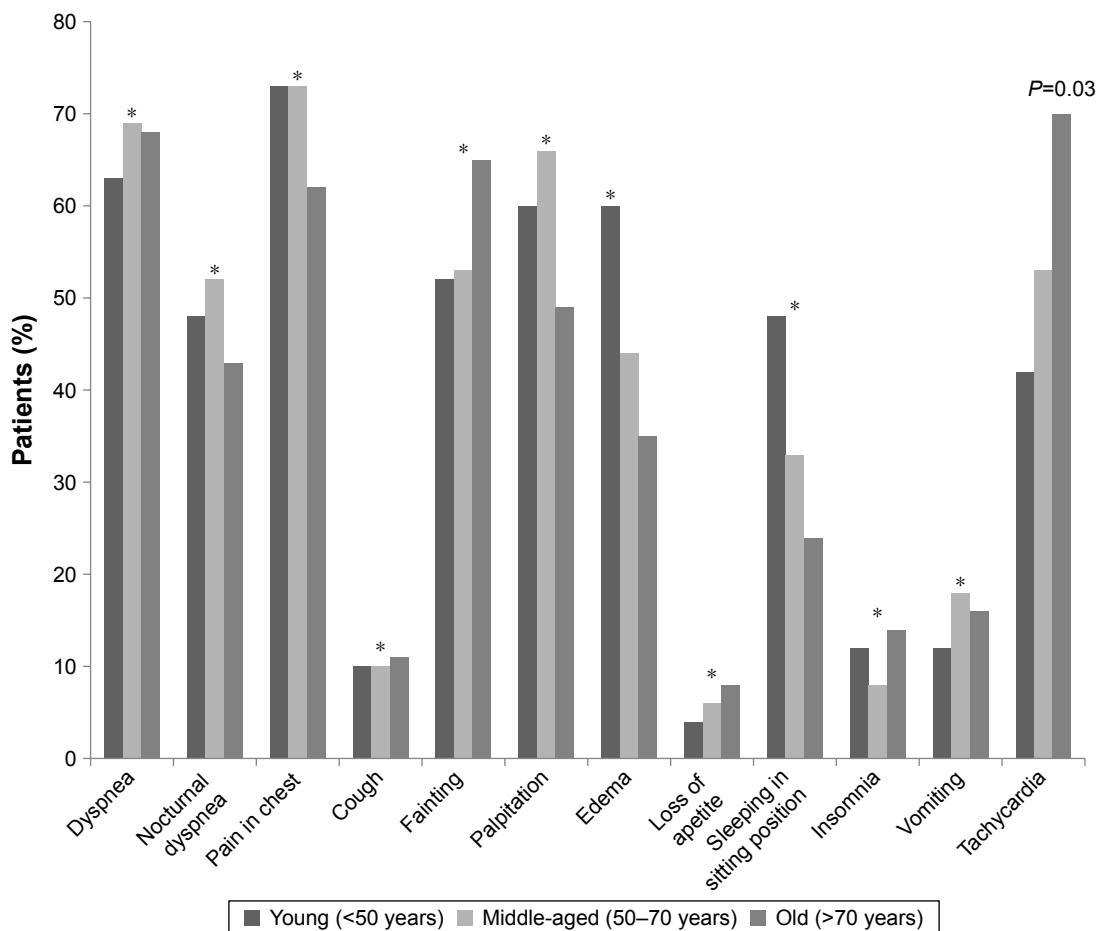
there is no other professional source of medical knowledge to educate patients, so doctors sometimes present paternal attitude regarding this matter. CHF multidisciplinary programs and informative initiatives are still novel ideas and

**Table 4** Positive response to question: "Do you consider this symptom alarming?"

Symptoms	Age 20–50 years	Age 50–70 years	Age >70 years	P-value	NYHA FC I-II	NYHA FC III-IV	P-value
Dyspnea	63% (33)	69% (77)	68% (25)	0.75	61% (41)	70% (88)	0.29
Nocturnal dyspnea	48% (25)	52% (58)	43% (16)	0.62	51% (34)	48% (61)	0.87
Chest pain	73% (38)	73% (81)	62% (23)	0.42	78% (52)	67% (85)	0.19
Cough	10% (5)	10% (11)	11% (4)	0.98	9% (6)	10% (13)	0.96
Fainting	52% (27)	53% (59)	65% (24)	0.41	52% (35)	55% (69)	0.85
Palpitation	60% (31)	66% (73)	49% (18)	0.18	<b>72% (48)</b>	<b>56% (70)</b>	<b>0.04</b>
Edema	60% (31)	44% (49)	35% (13)	0.06	46% (31)	45% (57)	0.99
Loss of appetite	4% (2)	6% (7)	8% (3)	0.69	6% (4)	6% (8)	0.83
Sleeping in sitting position	48% (25)	33% (37)	24% (9)	0.05	37% (25)	34% (43)	0.78
Insomnia	12% (6)	8% (9)	14% (5)	0.58	13% (9)	9% (11)	0.44
Vomiting	12% (6)	18% (20)	16% (6)	0.57	13% (9)	17% (22)	0.60
Tachycardia	<b>42% (22)</b>	<b>53% (59)</b>	<b>70% (26)</b>	<b>0.03</b>	51% (34)	46% (58)	0.64

**Notes:** Data shown as percentage (n). Data shown in bold indicate significant associations with palpitations and NYHA functional class and tachycardia and age of patients, respectively.

**Abbreviations:** FC, functional class; NYHA, New York Heart Association.



**Figure 4** Positive response to question: "Do you consider this symptom alarming?", sorted by age group.

**Note:** \*Not significant.

not very common in Poland. Nurses specialized in CHF could very well fill this gap. The patients in general know which symptoms are the most alarming, but the majority do not recognize particular symptoms as CHF symptoms

or do not link them with one another, that is, sleeping in sitting position with dyspnea or insomnia. It leads to the assumption that a presenting patient will report only the most urgent symptoms of his disease. It is rather because

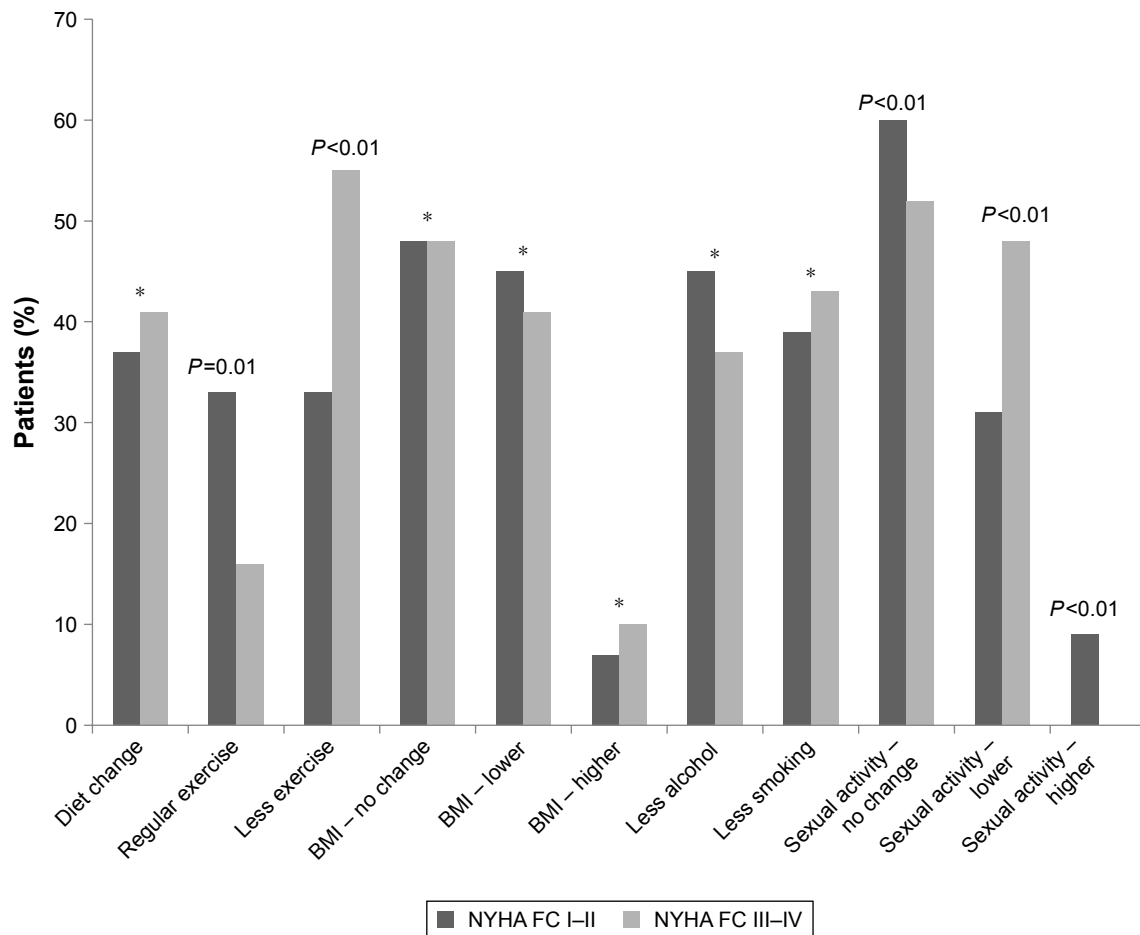
**Table 5** Lifestyle changes among patients

Lifestyle changes	NYHA FC I-II	NYHA FC III-IV	P-value	Age 20-50 years	Age 50-70 years	Age >70 years	P-value
Diet change	37% (25)	41% (51)	0.78	40% (21)	43% (48)	32% (12)	0.51
Regular exercise	<b>33% (22)</b>	<b>16% (20)</b>	<b>0.01</b>	25% (13)	23% (25)	11% (4)	0.23
Less exercise	<b>33% (22)</b>	<b>55% (69)</b>	<b>&lt;0.01</b>	50% (26)	48% (53)	41% (15)	0.66
BMI							
No change	48% (32)	48% (61)	0.77	<b>58% (30)</b>	<b>41% (45)</b>	<b>57% (21)</b>	<b>0.04</b>
Lower	45% (30)	41% (52)	0.77	<b>27% (14)</b>	<b>50% (56)</b>	<b>38% (14)</b>	<b>0.04</b>
Higher	7% (5)	10% (13)	0.77	<b>15% (8)</b>	<b>9% (10)</b>	<b>5% (2)</b>	<b>0.04</b>
Less alcohol	45% (30)	37% (46)	0.37	<b>46% (24)</b>	<b>44% (49)</b>	<b>16% (6)</b>	<b>0.02</b>
Less smoking	39% (26)	43% (54)	0.7	<b>44% (23)</b>	<b>50% (56)</b>	<b>16% (6)</b>	<b>&lt;0.01</b>
Sexual activity							
No change	<b>60% (40)</b>	<b>52% (66)</b>	<b>&lt;0.01</b>	<b>67% (35)</b>	<b>41% (46)</b>	<b>78% (23)</b>	<b>&lt;0.01</b>
Lower	<b>31% (21)</b>	<b>48% (60)</b>	<b>&lt;0.01</b>	<b>31% (16)</b>	<b>55% (61)</b>	<b>19% (7)</b>	<b>&lt;0.01</b>
Higher	<b>9% (6)</b>	<b>0% (0)</b>	<b>&lt;0.01</b>	<b>2% (1)</b>	<b>4% (4)</b>	<b>3% (1)</b>	<b>&lt;0.01</b>

**Notes:** Data shown as percentage (n). Data shown in bold indicated lifestyle changes that were significantly associated with either NYHA functional class or age.

**Abbreviations:** BMI, body mass index; FC, functional class; NYHA, New York Heart Association.





**Figure 5** Lifestyle changes among patients, sorted by NYHA FC I-II and NYHA FC III-IV.

**Note:** \*Not significant.

**Abbreviations:** BMI, body mass index; FC, functional class; NYHA, New York Heart Association.

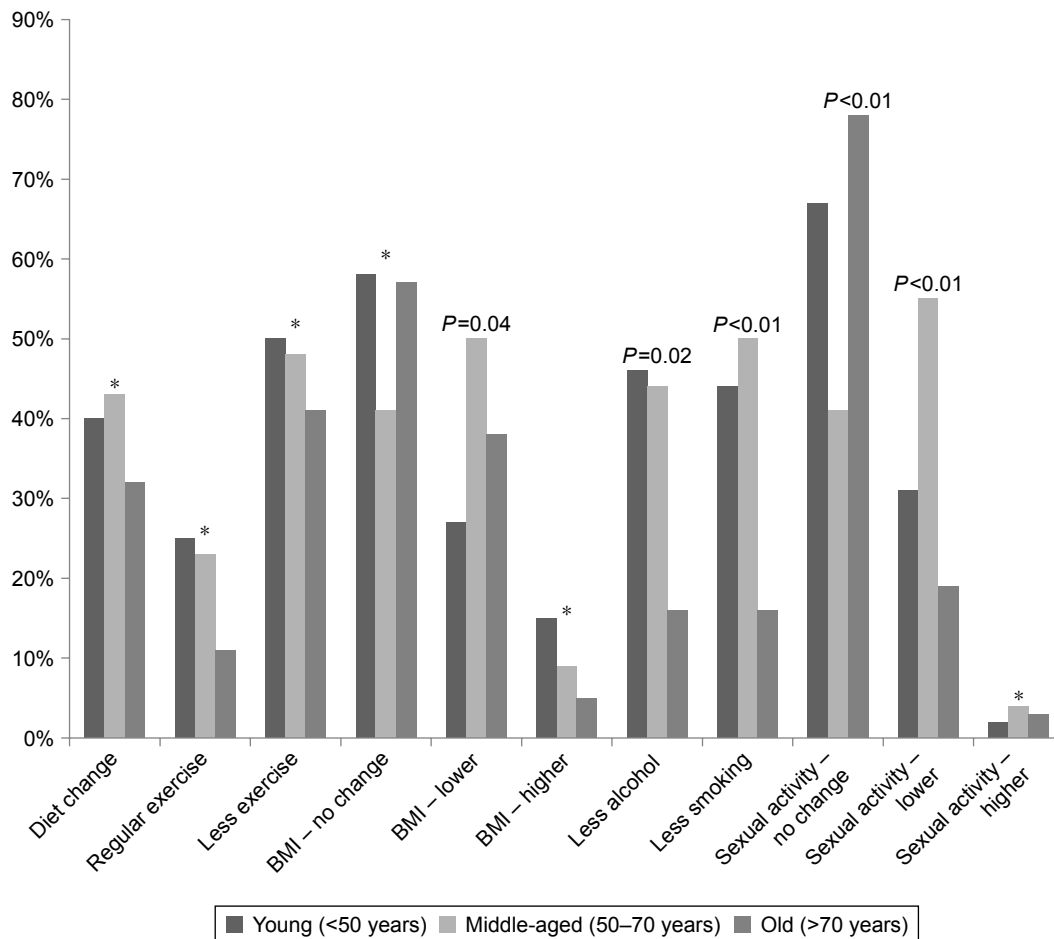
of their significance for the patient, and not because the patient was instructed about their importance by medical professionals. Perhaps specialized nurses could work as educators in lifestyle and symptoms of CHF as shown among the US population. The more educated a patient is, the fewer readmissions, as proved in a very similar population to ours.<sup>20</sup> On discharge, it is recommended not just to provide a regular hospital discharge record, but a one-on-one educational session with a medical professional seems necessary. Such attitude seems crucial especially among the elderly patients.<sup>21</sup>

It seems that the most compliant group is the middle-aged, who already raised families, have a rather stable professional situation and are able to follow medical instructions. However, suffering patients generally prefer not to follow lifestyle changes, as observed in simple salt intake restrictions.<sup>22</sup> Generally patients tend to exercise less when diagnosed with HF, some lose weight but rather as a result of

the disease because of cachexia and muscle mass reduction, but their sexual activity remains normal for age. It is never enough stressed to exercise in CHF – the proper activity level of CHF patient training sessions is still researched.<sup>23</sup> Just 3 months of regular training improves outcomes among CHF patients.<sup>24</sup> Proper self-management in this case seems to lower readmissions rate, but it is still not supported by scientific evidence.<sup>25</sup>

## Conclusion

Patients' education seems crucial in treatment of CHF. It needs to be clarified during the first medical visits that CHF cannot be cured. Patients should be educated about the symptoms of CHF, even though the majority indicates correct signs and symptoms as most alarming. It seems important to encourage positive lifestyle changes, like proper diet and exercise as prognosis-improving, lowering readmission rate and reducing CHF care costs.



**Figure 6** Lifestyle changes among patients, sorted by various age groups.

**Note:** \*Not significant.

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## Disclosure

The authors report no conflicts of interest in this work.

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