

# Illness Perceptions and Health-Related Quality of Life in Women and Men With Atrial Fibrillation

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**Background:** Health-related quality of life (HRQoL) is worse in patients with atrial fibrillation (AF) compared with other populations. Factors affecting HRQoL in patients with AF are not fully clarified. Illness perceptions are important determinants of disease management and may affect HRQoL. **Objective:** The aims of this study were to describe illness perceptions and HRQoL in women and men with AF and to explore the relationship between illness perceptions and HRQoL in patients with AF. **Methods:** This cross-sectional study included 167 patients with AF. Patients completed the Revised Illness Perception Questionnaire and HRQoL questionnaires: Arrhythmia-Specific questionnaire in Tachycardia and Arrhythmias, the three-level version of the EuroQol 5-dimensional questionnaire, and EuroQol visual analog scale. Subscales of the Revised Illness Perception Questionnaire significant in correlation analysis with the Arrhythmia-Specific questionnaire in Tachycardia and Arrhythmias HRQoL total scale were included in a multiple linear regression model. **Results:** Mean age was  $68.7 \pm 10.4$  years, and 31.1% were women. Women reported lower personal control ( $P = .039$ ) and worse HRQoL measured with the Arrhythmia-Specific questionnaire in Tachycardia and Arrhythmias physical subscale ( $P = .047$ ) and the EuroQol visual analog scale ( $P = .044$ ) compared with men. Illness identity ( $P < .001$ ), consequences ( $P = .031$ ), emotional representation ( $P = .014$ ), and timeline cyclical ( $P = .022$ ) were related to and adversely affected HRQoL. **Conclusions:** This study found a relationship between illness perceptions and HRQoL. Some subscales of illness perceptions negatively affected HRQoL in patients with AF, which indicates that efforts to change illness perceptions may be helpful in improving HRQoL. Patients should be given the opportunity to talk about the disease, their symptoms, their emotions, and the consequences of the disease to enable increased HRQoL. A challenge for healthcare will be to design support for each patient based on his/her illness perceptions.

**KEY WORDS:** atrial fibrillation, health-related quality of life, illness perceptions

Atrial fibrillation (AF) is the most common cardiac arrhythmia worldwide, with an estimated prevalence of 2% to 4%, which is expected to rise.<sup>1</sup> A prominent risk factor is advancing age, but risk is also affected by high

blood pressure, smoking, alcohol abuse, and obesity.<sup>2</sup> Atrial fibrillation is associated with increased risk of a stroke, increased risk of heart failure, and increased mortality.<sup>1</sup> Some individuals with AF can be completely

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asymptomatic during an AF episode, whereas others experience symptoms such as shortness of breath, palpitations, chest pain, and dizziness, which are symptoms that can be disabling and lead to major limitations in activities of daily living.<sup>1</sup> Age-adjusted prevalence of AF is lower in women than in men.<sup>1</sup> In addition, women report more AF symptoms, lower functional status, a higher degree of anxiety symptoms, depression, and lower health-related quality of life (HRQoL) compared with men.<sup>3</sup> Health-related quality of life is lower in patients with AF compared with the general population,<sup>4</sup> healthy controls, and patients with other heart diseases.<sup>4,5</sup> It is known that the severity of symptoms,<sup>5-7</sup> symptom frequency, and anxiety<sup>5</sup> affect HRQoL in patients with AF negatively, which also increases the risk of hospitalization.<sup>7</sup> However, there are still gaps in knowledge of factors influencing HRQoL.

Authors of previous studies have reported relationships between illness perceptions and HRQoL in patients with different kinds of diseases.<sup>8-10</sup> Illness perceptions, based on the common-sense model of self-regulation,<sup>11,12</sup> are organized cognitive representations that individuals form about their illness or a health threat. These representations can be categorized into 5 dimensions: identity, timeline, control/cure of illness, consequences, and causes.<sup>12</sup> These perceptions are important determinants of behavior and management of an illness or a health threat and are associated with a number of important outcomes, such as adherence to treatment, lifestyle changes, and functional recovery.<sup>11,13</sup> An illness perception that is negative may give poorer opportunities to recover and can lead to an increased need for care.<sup>14</sup>

Research describing illness perception in women and men with AF is sparse. The only study found shows that men attribute more symptoms to AF and have higher scores in personal control and treatment control than women.<sup>15</sup> There are also few studies describing illness perceptions and their relationship to HRQoL in patients with AF, and this is an area suggested for further research.<sup>5</sup> In the few studies found, illness perceptions negatively affected HRQoL<sup>16</sup> and contributed to psychological distress.<sup>17</sup> These studies focus on patients either with persistent AF<sup>16</sup> or with recurrent and symptomatic AF,<sup>17</sup> making it difficult to compare and translate the result to a general population of patients with AF. Because of differences in how AF affects different individuals, more studies are needed.

This study enables investigation of the relationships between illness perceptions and HRQoL in patients, with different types of AF, with and without symptoms. Furthermore, this study also provides the opportunity to describe illness perceptions and HRQoL in women and men and investigate sex differences. With increased knowledge of the effects of illness perceptions on HRQoL, healthcare professionals can better support patients and change their illness perceptions, thereby improving their

HRQoL. Improving HRQoL is an important treatment goal in the management of AF.<sup>1</sup>

The aims of this study were to describe illness perceptions and HRQoL in women and men with AF and to explore the relationship between illness perceptions and HRQoL in patients with AF.

## Methods

### Study Participants, Design, and Setting

This study with a cross-sectional design was conducted between March 2018 and March 2020 at a cardiology clinic in a university hospital in Sweden. A total of 180 patients with paroxysmal or persistent AF who were admitted and scheduled for electrical cardioversion were consecutively recruited in the waiting room. Patients 18 years and older with a diagnosis of AF and able and willing to fill in questionnaires were asked to participate. Oral and written informed consent was obtained. Patients filled in self-reported questionnaires the same day before the electrical cardioversion. In this study, AF was divided into paroxysmal (if they had the cardioversion within 7 days of symptom onset) or persistent (if the cardioversion was performed more than 7 days after symptom onset).<sup>1</sup> Of the 180 patients who agreed to participate and were included in the study, 13 were excluded: 8 were excluded because of administrative reasons (eg, did not submit the questionnaires or submitted the questionnaires without completing them), and 5 were excluded because of no diagnosis of AF. Finally, the study consisted of 167 participants.

### Ethical Considerations

Ethical approval for this study was obtained from the Swedish Ethical Review Authority. This study follows the principles outlined in the Declaration of Helsinki.<sup>18</sup>

### Measurements

Background data and information about previous illnesses, the date when first given a diagnosis of AF, and the type of AF, paroxysmal or persistent, were retrieved from questionnaires and patients' medical records. Previously validated questionnaires were used in this study to assess patients' illness perceptions and HRQoL. Illness perceptions were assessed using the Revised Illness Perception Questionnaire.<sup>19</sup> Health-related quality of life was assessed using the Arrhythmia-Specific questionnaire in Tachycardia and Arrhythmias (ASTA)<sup>20,21</sup> and the three-level version of the EuroQol 5-dimensional questionnaire or EuroQol-5D-3L (hereafter EQ-5D) and EQ-visual analog scale (VAS).<sup>22</sup>

### Revised Illness Perception Questionnaire

The Revised Illness Perception Questionnaire is a generic questionnaire that measures individuals' perceptions and beliefs about their illness.<sup>19</sup> The questionnaire

has been validated and translated into several languages. In Sweden, the instrument has been validated among patients with myocardial infarction.<sup>23</sup> The Revised Illness Perception Questionnaire consists of 3 different areas: illness identity, illness perceptions, and causal attribution.<sup>19</sup> In this study, we used and analyzed illness identity and illness perceptions.

Within illness identity, 14 common, general symptoms are listed. The patients are asked to answer yes/no if they have experienced any of the listed symptoms during the disease and yes/no if they believe the symptom is related to the disease. The total score for yes-ranked items on symptoms related to the disease forms the patient's illness identity. Illness perceptions cover the patient's perceptions of the illness. The patients are asked to mark on a 5-point Likert scale how much they agree or disagree with 38 items with different statements about the disease. The 38 items are then divided into 7 subscales. *Timeline acute/chronic* evaluates whether the patients see the disease as an acute/temporary condition or whether they think their condition is permanent. *Consequences* includes the effect of the condition on the patients and on their everyday life. *Emotional representations* evaluates the patients' emotional response (anxiety, anger, depression, etc) to their condition. *Personal control* represents the extent to which patients perceive themselves to have control over their illness. *Treatment control* relates to whether the patient feels the disease is under control (current treatment, medication, etc). *Illness coherence* evaluated the patients' understanding of their disease. *Timeline cyclical* distinguishes between daily changes in symptoms of disease and persistent symptoms.<sup>19</sup> Higher scores on a subscale indicate a stronger perception of the subscale's concept. Scoring high on subscales of coherence, personal control, and treatment control indicates an understanding of the condition and a positive notion of controllability of the disease. High scores on the subscales of illness identity, timeline acute/chronic, consequences, and timeline cyclical indicate a strong perception of the number of symptoms caused by the disease, its chronic nature, negative consequences caused by the disease, and its cyclical nature. Finally, high scores on the emotional representation subscale indicate a strong emotional response to the disease.<sup>19</sup> In this study, Cronbach  $\alpha$  coefficient was 0.67 for illness identity and between 0.69 and 0.89 for the subscales of illness perceptions.

### **Arrhythmia-Specific Questionnaire in Tachycardia and Arrhythmias**

Arrhythmia-Specific questionnaire in Tachycardia and Arrhythmias is a Swedish, validated disease-specific questionnaire measuring symptoms, symptom burden, and HRQoL in patients with arrhythmia.<sup>20,21</sup> The questionnaire consists of 3 separate parts. In this study, we used part III, related to HRQoL.

Health-related quality of life was assessed using 13 items on a 4-point response scale: "No" (0), "Yes, to

some extent" (1), "Yes, quite a lot" (2), or "Yes, a lot" (3). The HRQoL total item scale can further be divided into 2 subscales: physical (7 items) and mental (6 items). The sum of scale scores ranged from 0 to 100, where higher scores indicate a more negative effect on HRQoL.<sup>20</sup> Cronbach  $\alpha$  coefficients in this study were between 0.78 and 0.91 for ASTA total scale and ASTA subscales.

### **EuroQol-5D and EuroQol-Visual Analog Scale**

The EQ-5D is a generic, validated instrument for assessing HRQoL. Health is defined and assessed according to 5 dimensions: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. Each question is rated on a 3-point Likert scale: no problems, some problems, and extreme problems.<sup>22</sup> After merging data, scores can be converted to a summary index, the EQ-5D index; in this study, the British index tariff was used.<sup>24</sup> The index ranges from 0 to 1, where 1 indicates perfect health and 0 indicates the worst possible condition.<sup>25</sup> The EQ-5D questionnaire also consists of a vertical, visual analog scale (EQ-VAS) that is scored from 0 to 100, where 0 is the worst imaginable state and 100 is the best imaginable state.<sup>22</sup>

### **Statistical Analysis**

Data were analyzed using SPSS version 28 (IBM SPSS Statistics for Windows; IBM Corp, Armonk, New York). Demographic and clinical data were analyzed using descriptive statistics. Categorical data were presented as counts and percentages, and continuous data were presented as medians with quartiles [Q1, Q3] or interquartile range and means with SDs. The  $\chi^2$  test or Fisher exact test for categorical variables was used to compare proportions between groups. Missing items in the Revised Illness Perception Questionnaire and ASTA were handled according to instructions from developers of the instruments and were imputed based on the individual participant's mean value for the various subscales. Cronbach  $\alpha$  coefficients were used to measure internal consistency. Before analysis, all data were screened for normality with Shapiro-Wilk tests and Q-Q plots. Because of skewness in the data, the Mann-Whitney *U* test was used in the univariate analyses when comparing women and men, and Spearman correlation analysis was used to determine direction and power of associations between ASTA HRQoL total scale and the subscales of the Revised Illness Perception Questionnaire, and age. The strength of the association is described as weak (small),  $r = 0.10$  to  $0.29$ ; moderate (medium),  $r = 0.30$  to  $0.49$ ; or strong (large),  $r = 0.50$  to  $1.0$ .<sup>26</sup> To examine whether subscales of the Revised Illness Perception Questionnaire significant in correlation analysis were independently associated with the ASTA HRQoL total scale, a multiple linear regression analysis was performed. Illness identity, consequences, emotional representations, and timeline cyclical were included in the multiple linear regression model based on significant correlations to the ASTA HRQoL total scale. Sex was

included in the model because sex is an important demographic variable. To mitigate issues due to nonnormal data, a square root transformation of the ASTA HRQoL total scale was used. No multicollinearity issues were observed among the independent variables in the multiple linear regression model. A 2-tailed  $P$  value of  $<.05$  was considered to be indicative of statistical significance.

## Results

### Background, Clinical Characteristics, Health-Related Quality of Life, and Illness Perceptions

Background and clinical characteristics for the whole group of patients with AF are shown in Table 1. The participants consisted predominantly of men (68.9%). The women were, on average, nearly 2 years older than the men were and more often lived alone. More than 83% had a degree of secondary school or higher education (university/college), and almost 72% were retired. There was a large spread in the number of months since the diagnosis was made (0–400 months; median, 19), and a larger proportion had persistent AF (65%). The most prevalent comorbidity was hypertension (59.9%), followed by heart failure (23.8%) and diabetes (18.3%) (Table 1).

The mean EQ-5D index for the whole group was  $0.786 \pm 0.177$ , and for EQ-VAS, it was  $67.4 \pm 18.2$ .

The mean for ASTA HRQoL total scale was  $26.8 \pm 18.8$ . Means for ASTA HRQoL physical and mental subscales and the subscales of IPQ-R are described in Table 2.

### Differences Between Women and Men in Illness Perceptions and Health-Related Quality of Life

Women rated lower scores in the Revised Illness Perception Questionnaire personal control subscale compared with men ( $P = .039$ ) (Table 2), indicating that women have lower confidence in their ability to control AF than men. Women rated worse HRQoL in EQ-VAS ( $P = .044$ ) and the ASTA physical subscale ( $P = .047$ ) than men (Table 2). However, there were no significant differences between sex in HRQoL measured with EQ-5D index, the HRQoL total scale, and the mental subscale of ASTA, nor with the other subscales of Revised Illness Perception Questionnaire. Regarding the illness identity scale, there were no differences between sexes: women and men, on average, scored between 4 and 5 symptoms (out of 14) as caused by AF (Table 2). Common symptoms that were scored were reduced physical ability ( $n = 120$ ), shortness of breath ( $n = 110$ ), and fatigue ( $n = 103$ ). Some patients answered “yes” to symptoms that usually are not considered to be symptoms of AF, such as stiff joints ( $n = 14$ ), red eyes ( $n = 5$ ), and sore throat ( $n = 3$ ).

**TABLE 1** Sociodemographic and Clinical Characteristics of Patients With Atrial Fibrillation (N = 167)

Variable	Range	Total	Women	Men	$P$
Sex, n (%)			52 (31.1)	115 (68.9)	
Age, mean (SD), y	22–86	68.7 (10.4)	69.9 (9.2)	68.2 (11.0)	.540
Accommodation, n (%)					.004
Cohabiting		129 (77.2)	33 (63.5)	96 (83.5)	
Living alone		38 (22.8)	19 (36.5)	19 (16.5)	
Education, n (%)					.456
Elementary school		28 (16.8)	6 (11.5)	22 (19.1)	
Secondary school		75 (44.9)	24 (46.2)	51 (44.3)	
University/college		64 (38.3)	22 (42.3)	42 (36.5)	
Occupation (employment), n (%)					
Working		47 (28.1)	13 (25.0)	34 (29.6)	.544
Retired		120 (71.9)	39 (75.0)	81 (70.4)	
Type of atrial fibrillation, <sup>a</sup> n (%)					.652
Paroxysmal		57 (34.8)	19 (37.3)	38 (33.6)	
Persistent		107 (65.2)	32 (62.7)	75 (66.4)	
History of comorbidity, <sup>a</sup> n (%)					
Diabetes		30 (18.3)	11 (21.2)	19 (17.0)	.518
Heart failure		39 (23.8)	14 (28.0)	25 (21.9)	.401
Hypertension		100 (59.9)	29 (55.8)	71 (61.7)	.466
Stroke/TIA		12 (7.2)	2 (3.8)	10 (8.8)	.344
CABG		12 (7.2)	1 (1.9)	11 (9.6)	.107
Myocardial infarction		19 (11.4)	5 (9.6)	14 (12.2)	.630
PCI		14 (8.4)	4 (7.7)	10 (8.7)	1.000
Time since atrial fibrillation diagnosis, Md [Q1,Q3], mo	0–400	19 [1, 74]	15.5 [1, 65]	20 [1, 81]	.733

<sup>a</sup>“Paroxysmal AF” refers to cardioversion within 7 days of symptom onset. “Persistent AF” refers to cardioversion performed more than 7 days after symptom onset. Abbreviations: CABG, coronary artery bypass graft; Md, median; n, number; PCI, percutaneous coronary intervention; TIA, transient ischemic attack.

<sup>a</sup>Missing data in 1–3 patients.

**TABLE 2** Scores for Revised Illness Perception Questionnaire Subscales, EQ-5D-3L, EuroQol Visual Analog Scale, Arrhythmia-Specific questionnaire in Tachycardia and Arrhythmias Health-Related Quality of Life Total Scale, and Arrhythmia-Specific questionnaire in Tachycardia and Arrhythmias Health-Related Quality of Life Subscales, and Comparisons Between Sex

Scales (Score Range)	n	Total Group		Women		Men		P <sup>a</sup>
		Median (IQR)	Mean (SD)	Median (IQR)	Mean (SD)	Median (IQR)	Mean (SD)	
Illness identity (0–14)	142	4 (3)	4.5 (2.3)	5 (2.5)	4.9 (2.0)	4 (3)	4.3 (2.4)	.121
Timeline (acute/chronic) (6–30)	155	21 (8)	20.9 (5.4)	21 (8)	21.4 (4.7)	21 (8)	20.6 (5.6)	.472
Consequences (6–30)	161	17 (6)	16.7 (4.5)	16.5 (7.7)	16.7 (4.4)	17 (6)	16.7 (4.5)	.852
Personal control (6–30)	162	18 (5)	18.3 (3.8)	18 (5.5)	17.5 (3.7)	19 (5)	18.7 (3.8)	.039
Treatment control (5–25)	161	19 (4)	18.2 (2.9)	19 (4.5)	18.1 (3.1)	19 (3)	18.3 (2.8)	.556
Illness coherence (5–25)	161	18 (5)	17.6 (4.2)	18 (5)	17.4 (4.4)	18 (5)	17.7 (4.1)	.865
Emotional representations (6–30)	162	15 (5)	15.6 (4.3)	16 (4.5)	16.0 (5.1)	15 (5)	15.4 (4.0)	.413
Timeline (cyclical) (4–20)	162	12 (6)	12.0 (3.4)	13 (6)	12.0 (3.6)	12 (5.5)	12.0 (3.3)	.853
EQ-5D-3L index (0.0–1.0)	166	0.796 (0.162)	0.786 (0.177)	0.727 (0.071)	0.736 (0.208)	0.796 (0.275)	0.808 (0.156)	.079
EQ-5D-VAS (0–100)	162	70 (25)	67.4 (18.2)	65 (30)	63.1 (18.5)	70 (20)	69.5 (17.8)	.044
ASTA HRQoL total (0–100)	159	23.1 (28.6)	26.8 (18.8)	30.8 (26.3)	30.7 (17.7)	22.6 (28.2)	25.1 (19.0)	.050
ASTA HRQoL physical (0–100)	162	28.6 (28.6)	31.9 (23.3)	33.3 (24.2)	37.1 (23.6)	28.6 (33.3)	29.6 (22.9)	.047
ASTA HRQoL mental (0–100)	160	16.7 (27.5)	21.4 (17.3)	22.2 (25.6)	24.5 (17.2)	16.7 (27.8)	20.0 (17.3)	.101

Data are presented as median and interquartile range (IQR), and mean and SD.

Abbreviations: ASTA, Arrhythmia-Specific questionnaire in Tachycardia and Arrhythmias; EQ-5D-3L, three-level version of the EuroQol 5-dimensional questionnaire; HRQoL, health-related quality of life; IQR, interquartile range; VAS, visual analog scale.

<sup>a</sup>Differences between women and men, measured using the Mann-Whitney *U* test.

### Correlations Between Illness Perceptions and Health-Related Quality of Life

There was a strong positive correlation between worse HRQoL measured with the ASTA total scale and the Revised Illness Perception Questionnaire subscales regarding illness identity ( $r = 0.658$ ) and consequences ( $r = 0.509$ ). In other words, the more symptoms and consequences the patient attributed to the disease, the worse the HRQoL. There was a moderate positive correlation between worse HRQoL and emotional representations ( $r = 0.449$ ) and timeline cyclical ( $r = 0.302$ ) (Table 3), indicating that an emotional response (eg, anger, anxiety) to AF and the experience that AF is constantly recurrent are associated with worse HRQoL. A multiple linear regression model (Table 4) was performed to determine factors associated with ASTA HRQoL. Stronger illness identity ( $P < .001$ ), higher consequences ( $P = .031$ ), greater emotional representations ( $P = .014$ ), and higher timeline cyclical ( $P = .022$ ) were associated with worse HRQoL. Meaning that attributing more symptoms and consequences to AF, having higher emotional representations (eg, anxiety, anger) to AF, and the conviction that the illness is recurrent were associated with worse HRQoL.

### Discussion

The main findings of this study showed that higher scores on subscales of illness perceptions, namely, illness identity, consequences, emotional representation, and timeline cyclical, negatively affected HRQoL in patients with AF. This result is supported by a previous study in patients with persistent AF,<sup>16</sup> where the same subscales of the

Revised Illness Perception Questionnaire were associated with worse HRQoL as in this study. However, compared with their study, our study included both patients with persistent and paroxysmal AF, indicating that the illness perceptions associated with worse HRQoL also apply to patients with paroxysmal AF. Their result also showed that patients with beliefs of high personal control were associated with worse HRQoL.<sup>16</sup> Because high personal control is usually associated with positive outcomes, the

**TABLE 3** Correlation Between Health-Related Quality of Life Measured With Arrhythmia-Specific questionnaire in Tachycardia and Arrhythmias Health-Related Quality of Life Total Scale and Subscales of the Revised Illness Perception Questionnaire, and Age

Variables	ASTA HRQoL		
	$\rho$	95% CI	P
IPQ-R scales			
Illness identity	0.658	0.547–0.747	<.001
Timeline (acute/chronic)	0.130	–0.036 to 0.289	.113
Consequences	0.509	0.378–0.620	<.001
Personal control	–0.035	–0.196 to 0.127	.661
Treatment control	–0.070	–0.230 to 0.093	.387
Illness coherence	–0.055	–0.215 to 0.108	.496
Emotional representation	0.449	0.310–0.570	<.001
Timeline (cyclical)	0.302	0.148–0.442	<.001
Age	0.003	–0.157 to 0.163	.972

Abbreviations: ASTA, Arrhythmia-Specific questionnaire in Tachycardia and Arrhythmias; CI, confidence interval; HRQoL, health-related quality of life; IPQ-R, Revised Illness Perception Questionnaire;  $\rho$ , Spearman rank correlation coefficient.

**TABLE 4** Multiple Linear Regression Model of Factors Associated With Health-Related Quality of Life Measured With Arrhythmia-Specific questionnaire in Tachycardia and Arrhythmias Health-Related Quality of Life Total Scale, in Patients With Atrial Fibrillation

Variables	B	95% CI	P
(Constant)	-1.413	-2.789 to -0.038	.044
Illness identity	0.495	0.378-0.613	<.001
Consequences	0.071	0.007-0.135	.031
Emotional representations	0.079	0.016-0.142	.014
Timeline (cyclical)	0.087	0.013-0.162	.022
Sex	0.360	-0.162 to 0.881	.175

$F = 34.819$ ,  $R^2 = 0.574$ , and adjusted  $R^2 = 0.558$ .

Abbreviation: CI, confidence interval.

authors argue that worse HRQoL may be because patients who constantly control the disease may experience that the disease leads to major consequences in everyday life. In our study, there was no association between personal control and HRQoL. The difference between these results may be due to factors such as different inclusion and exclusion criteria. However, an important aspect is that Taylor et al further developed the Revised Illness Perception Questionnaire instrument from a generic version to a disease-specific instrument for patients with AF, and some items related to the personal control subscale were changed from the generic questionnaire.

Within the illness identity subscale, those patients who attributed several symptoms to AF had worse HRQoL than those who did not. This is concordant with a previous study.<sup>16</sup> Petrie and Weinman<sup>14</sup> state that patients may attribute symptoms that are not associated with the disease. This phenomenon is probably due to the fact that they develop beliefs about symptoms caused by the disease. Furthermore, the authors point out that an important aspect of this attribution is that the patient's view of symptoms linked to the disease can differ from the views of healthcare staff.<sup>14</sup> Some patients in our study reported that AF caused symptoms such as stiff joints, red eyes, and sore throat. These symptoms are not included in symptoms usually associated with AF.<sup>1</sup> Listening to and finding out which symptoms patients believe are caused by AF may help to clarify misunderstandings. A previous study showed that patients who understand the disease better control AF and report fewer symptoms.<sup>27</sup> Education about the disease and management of self-care in AF (managing of risk factors, triggers, controlling symptoms, etc) may help patients better understand the symptoms that may accompany the disease, avoid a new episode of AF, and reduce symptoms. A reduced symptom burden can affect HRQoL in a positive way.

In this study, the Revised Illness Perception Questionnaire subscale for consequences had a strong correlation to and affected HRQoL negatively. Consequences include

how the condition impacts the patient's everyday life, for example, family life, work, and lifestyle, but it can also include finances. Consequences reflect the patient's subjective experiences of the difficulty that the disease entails and not always the clinical, objective picture of the severity of the disease.<sup>14</sup> Problems might arise when healthcare professionals' views differ significantly from the patient's view of consequences caused by AF. Healthcare has a medical focus, and patients are often informed that AF is not a dangerous illness, at least as long as their prescribed medication is taken. However, although the illness is not dangerous, patients can experience negative consequences of the illness in their daily life. In a mixed method study, Stridsman et al<sup>28</sup> found that the consequences of living with AF that most affected HRQoL negatively were impaired physical ability, not being able to perform daily activities, and planning leisure activities. Studies also showed that patients avoided planning social activities, their exercise habits were influenced, and their work situations suffered because of disabling symptoms and unpredictable episodes of AF.<sup>28,29</sup> Although European Society of Cardiology guidelines recommend multidisciplinary care for the management of AF, multidisciplinary care is mostly based on a medical and structured approach, based on the "Atrial fibrillation Better Care" pathway (A, avoid stroke; B, better symptom control; and C, cardiovascular risk factors and comorbid condition management).<sup>1</sup> Care of patients with AF would benefit from a more person-centered approach based on the patients' perspectives and needs. Finding out the patients' perspective on consequences and needs can enable healthcare to help the individuals understand and manage their illness and get a better everyday life.

Emotional representations, such as being worried, scared, and depressed when thinking of AF, negatively affected HRQoL in patients in this study. In a review by Son et al,<sup>5</sup> AF-related anxiety was the factor that most affected HRQoL. In addition to anxiety, depression is also well known to affect HRQoL.<sup>30</sup> Not being able to deal with emotions that are triggered by a health threat can reduce self-management activities and negatively affect health.<sup>31</sup> The patient's emotions toward AF must therefore be taken into account by healthcare professionals in the meeting and education on self-management of the disease.

Women reported lower scores than men in the Revised Illness Perception Questionnaire subscale for personal control, indicating that women experience lower confidence in their ability to take control of the disease compared with men. This result is supported by a previous study.<sup>15</sup> Reasons why women experience lower personal control are unclear. Study authors suggest that women have a lower sense of personal control than men do, and the difference becomes greater with age.<sup>32,33</sup> Sex differences can be explained by education,

### What's New and Important

- Patients' views of symptoms they associate with the disease may differ from symptoms associated with AF from a medical perspective.
- Measuring illness perceptions in patients with AF can be a useful tool for healthcare professionals. Increased knowledge about individuals' perceptions of their illness is helpful in the design of care and can lead to increased HRQoL.

physical health, and living together with someone.<sup>33</sup> In this study, there were no significant differences in age, education, and comorbidity; however, women more often lived alone. Early intervention with information about and management of the disease can strengthen confidence in self-management in a positive direction and thus increase HRQoL and may therefore be particularly important in women. However, the level of information should be based on each patient's ability to absorb and translate information.

Health-related quality of life was worse in women compared with men measured with the ASTA physical subscale and EQ-VAS. The fact that HRQoL is worse in women with AF is consistent with previous studies.<sup>3,6,34,35</sup> For comparison, Walfridsson et al showed that women have worse HRQoL in the ASTA total scale and the physical and mental subscales compared with men. Compared with patients in this study, the patients in the Walfridsson et al<sup>35</sup> study scored HRQoL worse on all scales for both women and men. An explanation may be that their study included patients referred for ablation. Patients referred for ablations are often symptomatic, which might affect HRQoL negatively.

In this study, patients with AF reported similar scores in the Revised Illness Perception Questionnaire subscales of timeline acute/chronic ( $20.9 \pm 5.4$ ) and higher scores in timeline cyclical ( $12.0 \pm 3.4$ ) compared with patients 4 months after a myocardial infarction<sup>9</sup> ( $20.01 \pm 5.39$  and  $10.80 \pm 2.89$ , respectively). Furthermore, patients with AF scored lower in the Revised Illness Perception Questionnaire subscales of consequences ( $16.7 \pm 4.5$ ) and emotional representations ( $15.6 \pm 4.3$ ) compared with patients with myocardial infarction ( $18.18 \pm 4.61$  and  $16.65 \pm 4.80$ , respectively).<sup>9</sup> These results indicate that patients in our study experienced the illness more recurrently but experienced fewer consequences and less emotional impact due to AF compared with patients 4 months after myocardial infarction. Finally, patients with AF reported similar scores on the Revised Illness Perception Questionnaire illness coherence subscale ( $17.6 \pm 4.2$ ) and lower scores on the personal control subscale ( $18.3 \pm 3.8$ ) compared with patients with myocardial infarction ( $17.12 \pm 3.92$  and  $21.26 \pm 3.94$ , respectively).<sup>9</sup> These results indicate that patients with AF had lower confidence in being able to control the disease themselves compared with patients 4 months after myocardial infarction.

Patients with AF, in this study, reported slightly lower HRQoL scores compared with patients with acute myocardial infarction measured with EQ-VAS ( $67.4 \pm 18.2$  vs  $70.6 \pm 19.9$ , respectively)<sup>36</sup> but higher scores measured with the EQ-5D index compared with those waiting for coronary artery bypass graft surgery ( $0.796$  vs  $0.76$ ). However, 1 and 3 to 5 years after surgery, the patients who underwent coronary artery bypass graft reported better HRQoL ( $0.86$  and  $0.84$ , respectively)<sup>37</sup> than patients with AF. This might indicate that patients with AF have worse HRQoL than patients with other heart diseases, but conclusions must be drawn with caution.

The results of this study highlight the importance of healthcare professionals having a broader focus that is complementary to the purely medical approach and that they see the person behind the disease. As the experiences of AF differ among individuals, person-centered care may suit patients with AF. Person-centered care has a wider perspective where the patient is in focus and co-creators in their own care.<sup>38</sup> This form of care has positively affected several factors in patients with heart failure, including HRQoL,<sup>39</sup> but more research is needed in patients with AF.

### Clinical Implications

It is important to ask the patient about the perception of illness at an early stage of the disease and listen to what the patient thinks is important. Increased knowledge about the individuals' perception of their illness is helpful in the design of care and can lead to increased HRQoL. Measuring illness perception in patients with AF can be a useful tool for healthcare professionals.

### Conclusion

Atrial fibrillation can negatively affect some patients' HRQoL through emotional representations such as anger, anxiety, depression, and the consequences that patients experience as a result of the condition. Health-related quality of life can also be negatively affected by recurrent symptoms and the number of symptoms related to AF. The relationship between illness perceptions and HRQoL indicates that efforts to change illness perceptions could be useful in improving HRQoL. Information is a common strategy to support people in their self-management; however, being given the opportunity to talk about the disease, their symptoms, their emotions, and the consequences of the disease for daily life is a broader way to support people to live a better life with their illness. A challenge for healthcare will be to design support for each patient based on his/her illness perceptions.

### Study Limitations

The limitations of this study were that it had a cross-sectional design and was performed at a single center, which limits the generalizability of the results. We did

not include comorbidities in the multiple linear regression, which could have influenced the results, because these factors also may negatively affect HRQoL. The strengths are that there was a mixture of different ages, patients with and without symptoms, and both persistent and paroxysmal AF, which makes the variation richer, because it is in a real population of patients with AF. Fewer women than men were included in this study, but this was expected because more men are affected by AF and at earlier ages.

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