ORIGINAL RESEARCH

More positive patient-reported outcomes in patients newly diagnosed with atrial fibrillation: a comparative longitudinal study

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Aims	To compare patient-reported outcomes (PROs) in patients newly (<6 months) diagnosed with atrial fibrillation (AF) with those who have had a longer diagnosis (≥6 months) and to investigate whether or not these outcomes change over a 6-month period.
Methods and results	In this longitudinal survey study, 129 patients with AF completed the Revised Illness Perception Questionnaire, the Arrhythmia-Specific questionnaire in Tachycardia and Arrhythmia, and the Hospital Anxiety and Depression Scale at baseline and after 6 months. At baseline, patients newly diagnosed with AF ($n = 53$), compared with patients with a previous diagnosis ($n = 76$), reported AF as more temporary ($P = 0.003$) and had a higher belief in personal and treatment control ($P = 0.004$ and $P = 0.041$, respectively). At a 6-month follow-up, patients newly diagnosed reported a lower symptom burden ($P = 0.004$), better health-related quality of life (HRQoL); ($P = 0.015$), and a higher personal control ($P < 0.001$) than patients previously diagnosed. Over time, in patients newly diagnosed, symptom burden and the anxiety symptom score decreased ($P = 0.001$ and $P = 0.014$, respectively) and HRQoL improved ($P = 0.002$).
Conclusion	Patients newly diagnosed with AF reported more positive PROs both at baseline and at a 6-month follow-up than patients with a previous diagnosis of AF. Therefore, it is important to quickly capture patients newly diagnosed to support their belief in their own abilities. Such support may, alongside medical treatments, help patients manage the disease, which may lead to reduced symptom burden and better HRQoL over time.

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Graphical Abstract
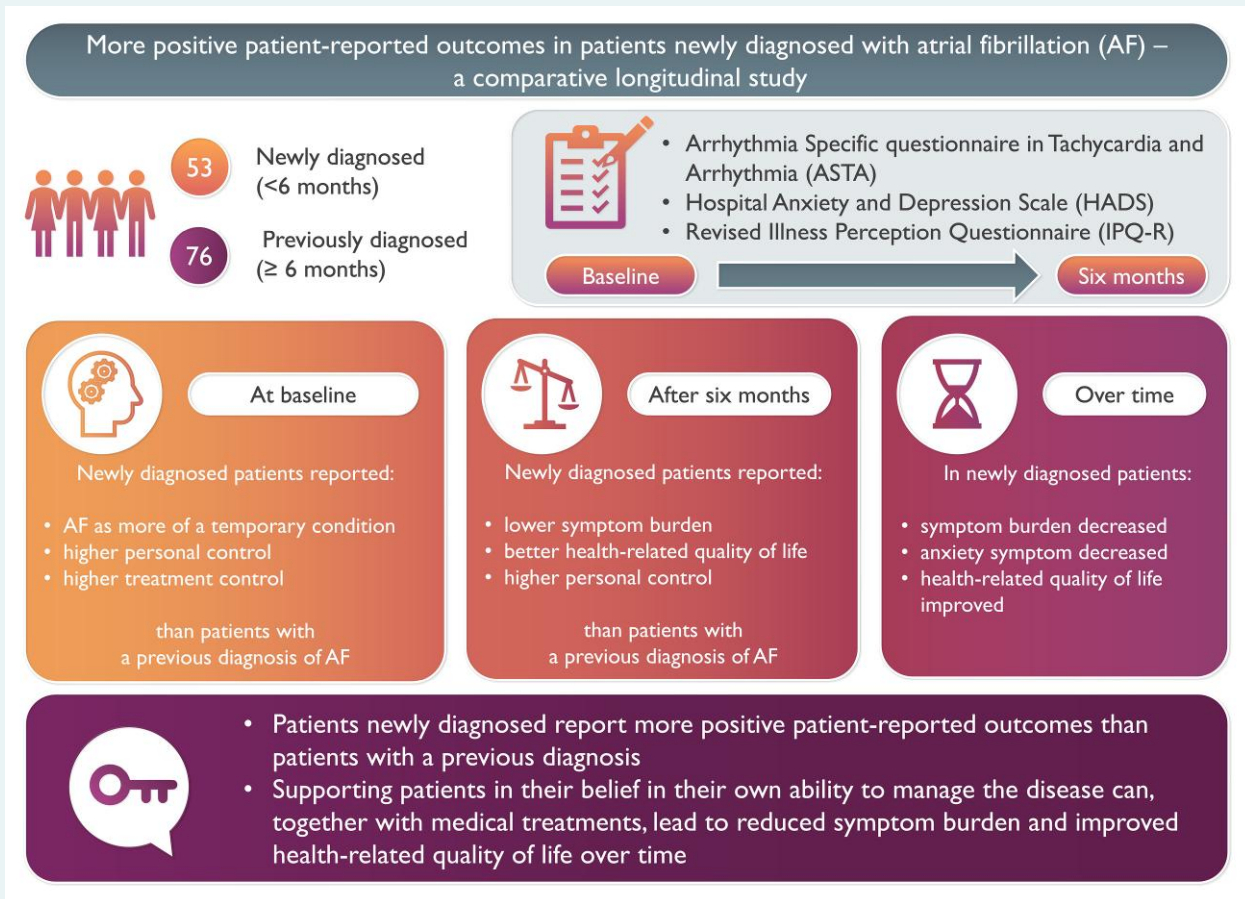
Novelty
- This study of patient-reported outcomes (PROs) provides new insights into how atrial fibrillation (AF) affects patients at different stages of the disease course.
- Patients newly diagnosed with AF report higher beliefs in personal and treatment control than patients with a previous diagnosis.
- Patients with a previous diagnosis of AF report a higher symptom burden and worse health-related quality of life after 6 months than newly diagnosed patients.
- Using PRO measurements in the care of patients with AF can create a basis for more individualized care.

Introduction

With an estimated 2–4% prevalence, atrial fibrillation (AF) is the most prevalent arrhythmia and is expected to increase. Increased prevalence can partly be attributable to improved detection and increased longevity in the general population since increased age is a prominent risk factor for AF.[1] Also, hypertension, diabetes mellitus, obesity, obstructive sleep apnoea, smoking, and high and long-term alcohol intake are contributing risk factors.[2] Atrial fibrillation increases the risk of stroke, heart failure, and premature death.[1] Symptoms accompanying the disease, such as palpitations, reduced physical ability, shortness of breath, and fatigue, are

common, sometimes with a large impact on life.[3,4] Initially, >50% of people are asymptomatic.[1] Even among those with symptoms, there are symptom-free periods despite their having AF.[5] Atrial fibrillation symptoms do not always appear alone but can appear in clusters, with co-occurring symptoms.[6] However, the mechanisms behind the symptomatology and the variability of AF have still not been fully understood.[5] Previous research has shown that AF is associated with worse health-related quality of life (HRQoL), often attributed to symptom severity[7,8] and symptom burden.[7] Both worse HRQoL and AF-related symptoms are associated with a higher risk of hospitalization.[7] Improvements in symptom burden and HRQoL in patients with AF have

been reported with antiarrhythmic pharmacological treatments[9] and ablation.[9,10] However, ablation has been shown to reduce symptoms and improve HRQoL to a greater extent than antiarrhythmic pharmacological treatments.[9] In a previous study, 52% of patients reported being free from symptoms 5 years after catheter ablation.[10] Medical treatments and ablation will not reduce symptom burden and improve HRQoL for all.[9,10] Patients with AF are a multifaceted group with large differences in HRQoL, and it is not only symptoms and the symptom burden of AF that have an impact.[7] Anxiety and depression symptoms related to AF,[8] gender,[1] age,[1] the patient's acceptance,[11] and perception of the illness[12] have also been shown to contribute to differences in HRQoL.

A recent study showed that a high symptom burden, anxiety and depression symptoms, and worse HRQoL as measured by patient-reported outcomes (PROs) at discharge in patients hospitalized due to arrhythmia were associated with increased healthcare costs.[13] Considering that patients with AF seek healthcare frequently[14,15] and given an expected rise in the prevalence of AF,[1] enormous pressure on an already strained healthcare system might be expected. Therefore, it is important to measure PROs and use the results to improve patient outcomes.

Patient-reported outcomes are defined as 'any report of the status of a patient's (or person's) health condition, health behavior, or experience with healthcare that comes directly from the patient, without interpretation of the patient's response by a clinician or anyone else'.[16] Patient-reported outcome findings can aid in the shared decision-making process to complement clinical objective measurements.[17] Guidelines recommend routinely measuring PROs for improving patient care and determining the effect of treatments.[1]

Living with chronic illness can be described as a journey that includes hills and valleys. Depending on whether a person has been newly diagnosed or when disease symptoms develop, the focus might change between either well-being or disease management. The shifting perspectives model describes living with chronic illness as an ongoing, continually shifting process but also as an opportunity for patients to make sense of their illness experiences.[18] To our knowledge, no study has investigated differences in outcomes as measured by PROs between patients newly diagnosed with AF and those who have lived with the disease longer. Additionally, illness perceptions in newly diagnosed patients, especially those with a chronic condition, have been suggested as an area for further research, one that could provide information on possible critical occasions during the disease when interventions are essential.[19] The same argument can be made with respect to other outcomes measured using PROs, such as symptom burden, HRQoL, and anxiety and depression. Increased knowledge about differences in PROs might lead to an increased understanding of how patients are affected by the disease at different stages of the disease course. Furthermore, increased knowledge can lead to a better understanding of how care should be adapted depending on which stage the patient is in the course of the disease. Therefore, this study aimed to compare PROs in patients newly (<6 months) diagnosed with AF with those who have had a longer diagnosis (≥6 months) and to investigate whether or not these outcomes change over a 6-month period.

Methods

Design

This comparative longitudinal survey study was conducted between March 2018 and September 2020. Patients completed questionnaires at baseline and 6 months. The Strengthening the Reporting of Observational Studies in Epidemiology guidelines were followed.[20]

Participants and setting

Patients with AF for whom electrical conversion was planned at a university hospital cardiology clinic in Northern Sweden were consecutively recruited

in the waiting room. Inclusion criteria were a diagnosis of AF, 18 years or older, and the ability and willingness to fill in questionnaires. Patients were divided into two groups: newly diagnosed and previously diagnosed. Based on guidelines[1] and the design of two previous studies,[21,22] we have chosen to define newly diagnosed for those with a new (first time) AF diagnosis <6 months and previously diagnosed for those with a diagnosis of AF ≥6 months. In this study, the type of AF was divided into paroxysmal (if their planned cardioversion was within 7 days of symptom onset) or persistent (if the planned cardioversion was >7 days after symptom onset).

Data collection

Sociodemographic and clinical characteristics were retrieved from the questionnaires and the patients' medical records. Patient-reported outcomes were collected twice, at baseline and after 6 months. Six-month follow-up questionnaires were mailed to patients, followed by one reminder. Symptoms, symptom burden, and HRQoL were measured using the Arrhythmia-Specific questionnaire in Tachycardia and Arrhythmia (ASTA).[23,24] Anxiety and depression were measured using the Hospital Anxiety and Depression Scale (HADS).[25] The Revised Illness Perception Questionnaire (IPQ-R)[26] was used to measure patients' perceptions of their illness. Cronbach's α coefficients for all instruments were used in this study, and an explanation of how to interpret the different scales can be found in Table 1.

Arrhythmia-Specific questionnaire in Tachycardia and Arrhythmias

The Arrhythmia-Specific questionnaire in Tachycardia and Arrhythmia is a validated disease-specific questionnaire[23,24] containing three separate parts. The first part covers medication and the latest episode of arrhythmia. The second part covers symptom burden with a nine-item symptom scale with four response alternatives ranging from 'no', 'yes, to some extent', 'yes, quite a lot', and 'yes, a lot' (0–3). The second part also contains seven questions regarding their arrhythmia. The third part covers HRQoL and consists of 13 items (ASTA HRQoL total scale) with the same response alternatives as those of the symptom scale. The ASTA HRQoL total scale is divided into a physical and a mental subscale with seven and six items, respectively. The symptoms and HRQoL items can be presented separately or with sum scale scores. The sum scale scores are calculated and range from 0 to 100; higher scores indicate a higher symptom burden and worse HRQoL. This study used the ASTA HRQoL total scale, the two HRQoL subscales, and the nine items of the symptom burden scale both separately and as a total sum scale score. Cronbach's α was between 0.79 and 0.91 for the different scales.[23,24]

The Hospital Anxiety and Depression Scale

The Hospital Anxiety and Depression Scale[25] is a validated, 14-item scale designed to assess symptoms of anxiety and depression in patients in somatic care. Each item consists of four response categories with scores from 0 to 3. The scale is divided into two subscales, HADS-A and HADS-D, with seven items for each subscale. Subscale scores range from 0 to 21, with higher scores representing higher anxiety and depression symptoms. Scores 8–10 indicate doubtful cases, and those ≥11 suggest cases.[25] The Hospital Anxiety and Depression Scale has been validated in the Swedish population. Cronbach's α was between 0.81 and 0.92.[27,28]

The Revised Illness Perception Questionnaire

The Revised Illness Perception Questionnaire is a validated, generic questionnaire containing questions or statements about the patient's illness perceptions and covers nine subscales.[26] In this study, seven subscales were used: timeline acute/chronic, timeline cyclical, consequences, emotional representations, treatment control, personal control, and illness coherence. For these subscales, the patient answers 38 statements on a 5-point Likert-type scale ranging from '1: strongly disagree' to '5: strongly agree'. Higher scores on each subscale indicate a stronger perception or greater degree of agreement concerning the subscale concept. Cronbach's α for the subscales varied between 0.79 and 0.89.[26]

Table 1 Interpretation of the scale score and Cronbach's α

Scales	Score range	Meaning of higher scores	Cronbach's α
ASTA			
Symptoms	0–100	Higher symptom burden	0.762
HRQoL total	0–100	Worse HRQoL	0.897
HRQoL physical	0–100	Worse physical HRQoL	0.886
HRQoL mental	0–100	Worse mental HRQoL	0.750
HADS			
Anxiety	0–21	Higher degree of anxiety	0.833
Depression	0–21	Higher degree of depression	0.791
IPQ-R			
Timeline acute/chronic	6–30	Negative perception of the illness as lasting/chronic	0.877
Consequences	6–30	Negative consequences attributed to the illness	0.791
Personal control	6–30	Positive believes in managing/controlling the illness by themselves	0.668
Treatment control	5–25	Positive believes that treatment can control/cure the illness	0.698
Illness coherence	5–25	A greater personal understanding of the illness	0.826
Emotional representations	6–30	Negative emotions attributed to the illness	0.843
Timeline cyclical	4–20	A negative perception of the illness as cyclical	0.781

ASTA, Arrhythmia-Specific questionnaire in Tachycardia and Arrhythmia; HADS, Hospital Anxiety and Depression Scale; HRQoL, health-related quality of life; IPQ-R, Revised Illness Perception Questionnaire.

Statistical analyses

Continuous variables were presented as means with standard deviation (SD) or medians with quartiles (Q1, Q3) and categorical data as counts with percentages (%). The four response options in ASTA symptoms were dichotomized into either 'No' if they had no symptoms or 'Yes' if they had symptoms. The data were screened for normality with the Shapiro–Wilk test and Q–Q plots. Because of the presence of non-normal data, the Mann–Whitney U test was used for continuous variables to assess the two groups' differences and the Wilcoxon signed-rank test for paired and repeated measures between baseline and at 6 months. The χ^2 test or Fisher's exact test for categorical data was used as appropriate, and McNemar's test was used to measure differences in categorical data between the two occasions, baseline and at 6 months. Missing items in ASTA and IPQ-R were imputed based on instructions from the developers of respective instruments and were based on the individual participant's mean value for the various subscales. To measure internal consistency in the different scales, Cronbach's α coefficients were used. A value ≥0.70 demonstrates good reliability[29]; thus, all scales are believed to be reliable in measuring the constructs. All calculations were performed using the Statistical Packages for the Social Sciences version 28 (IBM SPSS Statistics for Windows, IBM Corp., Armonk, NY, USA). A *P*-value <0.05 was considered significant.

Ethical considerations

This study was conducted in accordance with the ethical principles in the World Medical Association Declaration of Helsinki.[30] Patients received verbal and written information from one of the research team members and gave written consent before inclusion in the study. Ethical approvals was obtained from the regional Ethical Review Board, Umeå, Sweden (Dnr 2018-24-31M, Dnr 2018/151-32) and the Swedish Ethical Review Authority (Dnr 2021-06734-02).

Results

Study flow

The study flow is shown in *Figure 1*. At baseline, 180 patients completed the questionnaires, and 134 (75%) returned the follow-up questionnaire. Of these, five were excluded because of wrong diagnosis or for not completing the questionnaires. Finally, 129 patients participated in this study.

Background characteristics at baseline

The mean age was 71 (SD: 8.5) years, 33% were women, 78% were cohabiting, 81% were retired, and 82% had secondary school or higher education. There were no statistically significant differences between the two groups regarding age, sex, accommodation, employment, or level of education. However, in patients previously diagnosed compared with patients newly diagnosed, a majority of them had a secondary school or higher education (88 vs. 74%). The median time since diagnosis for patients newly diagnosed with AF was 1 month. For those with a previous diagnosis of AF, the median time was 70 months. Patients newly diagnosed more often had persistent AF (*P* < 0.001), and patients previously diagnosed more often had coronary artery disease (*P* = 0.037; *Table 2*).

Differences in patient-reported outcomes between groups at baseline and at 6-months' follow-up

At baseline, patients with a previous diagnosis reported AF as chronic (*P* = 0.003) and cyclical (*P* = 0.019) to a greater extent than patients newly diagnosed. Further, patients newly diagnosed compared with patients with a previous diagnosis reported a greater belief in treatment control (*P* = 0.041) and personal control (*P* = 0.004). More newly diagnosed patients had ≥8 in HADS-A than previously diagnosed (*P* = 0.021). The most common symptoms reported in both groups were breathlessness during activity, weakness/fatigue, and tiredness. Weakness/fatigue and chest pain were reported to a greater extent in patients previously diagnosed (*Table 3*).

At a 6-month follow-up, patients with a previous diagnosis reported a higher symptom burden (*P* = 0.004), a lower personal control
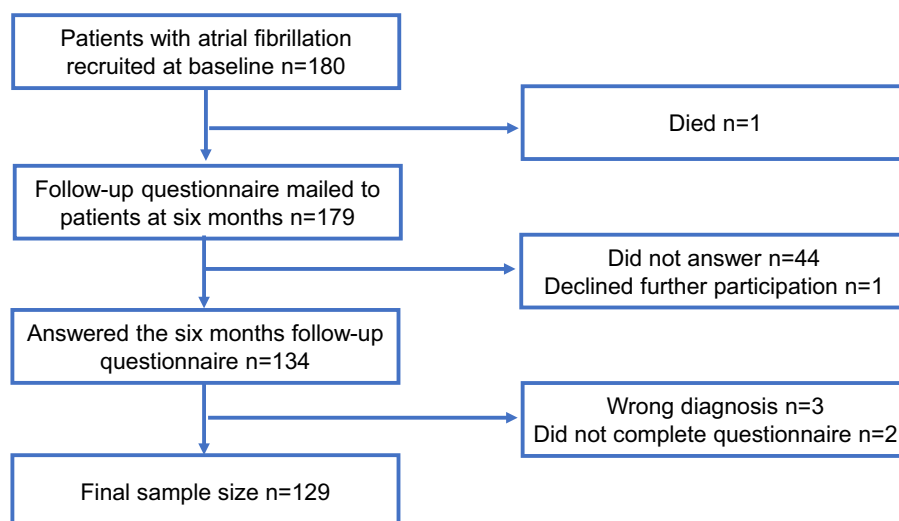
Figure 1 A flow chart of study.

($P < 0.001$), and a more cyclical illness ($P = 0.006$) than patients newly diagnosed. Patients with a previous diagnosis reported higher illness coherence ($P = 0.043$) compared with those newly diagnosed (Table 3).

At the 6-month follow-up, patients newly diagnosed reported AF as chronic to the same extent as those with a previous diagnosis ($P = 0.190$). Patients newly diagnosed reported better HRQoL within the ASTA total scale ($P = 0.015$) and physical subscale ($P = 0.002$) compared with those with a previous diagnosis. More patients with a previous diagnosis reported AF/episodes of AF from baseline to the 6-month follow-up ($P = 0.006$) and at 6 months, they reported more symptoms of weakness/fatigue, cold sweats, chest, and discomfort in the chest, compared with patients newly diagnosed (Table 3).

Within-group comparisons of patient-reported outcomes between baseline and 6-months' follow-up

Over time (6 months), patients newly diagnosed reported a lower symptom burden ($P = 0.001$) and lower scores in anxiety symptoms measured with HADS ($P = 0.014$). In addition, HRQoL showed an improved total scale ($P = 0.002$) and physical and mental subscale scores ($P = 0.001$ and $P = 0.014$, respectively). However, at this time, patients newly diagnosed reported the illness to be chronic to a greater extent than at baseline ($P < 0.001$), and their beliefs in treatment control decreased ($P = 0.035$; Table 4).

Discussion

Our findings show that patients newly diagnosed, compared with patients with a previous diagnosis, to a greater extent, reported AF as temporary and had a stronger belief that the illness was controllable by their efforts and through treatments. Further, patients with a previous diagnosis reported the illness as chronic and recurrent to a greater extent than patients newly diagnosed with AF. Over time, patients newly diagnosed reported AF as chronic to the same extent as patients with a previous diagnosis. In addition, their belief that AF could be controlled by treatment decreased. However, their belief in their ability to control AF remained, their symptom burden and level of anxiety symptoms decreased, and their HRQoL improved.

In our study, patients previously diagnosed with AF reported better HRQoL (27.6) at baseline as measured with the ASTA HRQoL total scale compared with what patients reported in the study by Walfridsson et al.,[10] while waiting for ablation (36.5) but worse HRQoL than what patients reported 5 years after ablation (14.2). Our results showed that HRQoL did not differ at baseline between patients newly diagnosed and those with a previous diagnosis. At the 6-month follow-up, HRQoL improved in newly diagnosed patients but not in patients with a previous diagnosis. Explanations for that could be that more patients reported recurrent episodes of AF and had a higher AF symptom burden at the 6-month follow-up than did patients newly diagnosed with AF. Another explanation might be a greater belief in the illness as recurrent and unpredictable (timeline cyclical), combined with lower confidence in their ability to control the illness (personal control). Perceptions of AF as recurrent have been shown to affect HRQoL negatively.[12] The unpredictability of symptoms in AF has further been reported to cause emotional distress and a loss of control from not knowing when the next episode of AF will appear, leading to limitations in planning social activities.[3,31]

Patients newly diagnosed reported higher personal control at baseline and at the 6-month follow-up than patients with a previous diagnosis, indicating a greater belief in their ability to manage and control AF. The results also indicate that patients' beliefs about managing and controlling the illness may decrease over time. However, it is difficult to predict when this will occur and why. In interviews, patients have reported that they lack knowledge and support from healthcare professionals and have learned to manage AF themselves.[3,4] One explanation for a decrease in personal control may be that constant recurrences of AF lead to disappointment and reduced self-confidence in managing the illness. A patient newly diagnosed may not have experienced recurrences to the same extent as previously diagnosed patients and, therefore, may believe more strongly in their ability to manage the disease. Patients newly diagnosed with AF in our study reported lower personal control at baseline (19.7) and at 6 months (19.9) compared with patients during the first week (22.3) and 4 months after a myocardial infarction (21.3).[32] This result indicates that patients newly diagnosed with AF have lower beliefs in themself in controlling the illness than patients with myocardial infarction. According to the shifting perspectives model,[18] people newly diagnosed are more keen on focusing on the disease and its control and are more open to advice regarding lifestyle

Table 2   Sociodemographic and clinical characteristics of patients with atrial fibrillation

	Total group (n = 129)	Newly diagnosed (n = 53)	Previously diagnosed (n = 76)	P
Age, year, mean (SD)	70.8 (8.5)	70.2 (7.8)	71.2 (8.9)	0.354
Minimum–maximum	44–86	49–84	44–86	
Sex, n (%)				
Female	43 (33.3)	15 (28.3)	28 (36.8)	0.311
Male	86 (66.7)	38 (71.7)	48 (63.2)	
Accommodation, n (%)				
Living alone	28 (21.7)	10 (18.9)	18 (23.7)	0.514
Cohabiting	101 (78.3)	43 (81.1)	58 (76.3)	
Education, n (%)				
Elementary school	23 (17.8)	14 (26.4)	9 (11.8)	0.070
Secondary school	55 (42.6)	18 (34.0)	37 (48.7)	
University/college	51 (39.5)	21 (39.6)	30 (39.5)	
Employment, n (%)				
Working	25 (19.4)	10 (18.9)	15 (19.7)	0.902
Retired	104 (80.6)	43 (81.1)	61 (80.3)	
Time since AF diagnosis, months, median (Q1, Q3)	14 (1, 74)	1 (0, 1)	70 (25, 101)	
Type of AF[a], n (%)				
Paroxysmal AF	46 (36.2)	7 (13.5)	39 (52.0)	**<0.001**
Persistent AF	81 (63.8)	45 (86.5)	36 (48.0)	
Comorbidity[a], yes, n (%)				
Diabetes	27 (21.1)	13 (25.0)	14 (18.4)	0.370
Heart failure	31 (24.6)	15 (28.3)	16 (21.9)	0.411
TIA/stroke	11 (8.5)	3 (5.7)	8 (10.5)	0.524
Coronary artery disease	23 (17.8)	5 (9.4)	18 (23.7)	**0.037**
OSA	22 (17.1)	9 (17.0)	13 (17.1)	0.985

The bold figures denote statistically significant *P*-values; newly diagnosed, a diagnosis of AF <6 months; previously diagnosed, a diagnosis of AF ≥6 months; *P*, differences between newly diagnosed and previously diagnosed patients with AF.
AF, atrial fibrillation; OSA, obstructive sleep apnoea; SD, standard deviation; TIA, transient ischaemic attack.
[a]Missing data in 1–3 patients.

change and self-management support. This process is, however, continually shifting, suggesting that some people with a long disease duration may also benefit from self-management support.[18]

At baseline, the mean score for HADS-A and HADS-D was <8 in both groups, not indicating symptoms of anxiety or depression. However, 25% of patients newly diagnosed scored ≥8 in HADS-A at baseline, indicating symptoms of anxiety and is a higher score than for a normal population in Sweden (11–12%)[27,28] and higher than for patients 1 year after ablation for AF (19%).[33] The baseline questionnaire was completed shortly before the scheduled cardioversion, which may partially explain the high percentage. However, the result points to the importance of making individual assessments and where PRO measurements can be of help.

In this study, patients, both newly and previously diagnosed, reported lower symptom burden at baseline compared with patients waiting for ablation.[10] At the 6-month follow-up, newly diagnosed patients reported a decreased symptom burden, while patients previously diagnosed did not. Two goals of patient care in AF are to reduce symptom burden and improve HRQoL. Since symptoms and symptom burden affect HRQoL,[8,31] great emphasis is placed on reducing symptoms and symptom burden with medical treatments and ablation. However, it is also

essential to consider risk factor management to reduce the risk of AF and/or reduce symptom burden. It is clear from our results that some patients lacked knowledge about AF as a chronic condition and did not understand that AF cannot be cured. This is also described in a previous study, where patients believed that an AF ablation would eliminate the need for anticoagulation (43%), improve survival (58%), and decrease stroke rates (89%). Remarkably, referring physicians reported equivalent results.[34] Since patients' knowledge about AF can be deficient,[35–37] we cannot assume that all patients understand the impact of risk factors for developing and worsening AF. It is of great importance that care is based on the individual patient's situation, so that the necessary changes are possible to implement. Lane *et al.*[38] emphasized the importance of patients receiving tailored education and integrated care. This requires a knowledge of the patient's well-being and beliefs about the disease. Patient-reported outcome measurement can be helpful, and its use is highlighted and recommended in the guidelines.[1,17]

In the future, a support programme for patients during the course of the disease, including increased counselling and education in AF with risk factor management, may contribute to improved illness perception, reduced recurrence of AF, reduced symptom burden, and increased HRQoL. However, as patients with AF are a multi-faceted group, the

Table 3 Differences in patient-reported outcome measures between patients newly diagnosed with atrial fibrillation (<6 months) and patients previously diagnosed with atrial fibrillation (≥6 months), at baseline and at 6 months

Scales (score range)	Baseline			6-month follow-up		
	Newly diagnosed (n = 53)	Previously diagnosed (n = 76)	P^a	Newly diagnosed (n = 53)	Previously diagnosed (n = 76)	P^a
ASTA, mean (SD)						
Symptoms (0–100)	26.1 (15.1)	31.9 (15.4)	0.065	21.7 (16.1)	30.6 (17.2)	**0.004**
HRQoL total (0–100)	24.1 (17.1)	27.6 (17.7)	0.386	18.2 (16.7)	26.0 (20.2)	**0.015**
HRQoL physical (0–100)	28.1 (21.2)	32.4 (22.4)	0.424	20.5 (20.3)	32.8 (25.2)	**0.002**
HRQoL mental (0–100)	19.2 (15.6)	22.0 (16.5)	0.427	15.5 (15.0)	19.4 (18.7)	0.304
HADS, mean (SD)						
Anxiety (0–21)	4.7 (3.4)	3.8 (2.9)	0.093	3.8 (3.5)	3.6 (3.2)	0.929
Depression (0–21)	3.0 (2.8)	3.0 (2.7)	0.986	2.8 (2.6)	2.8 (2.6)	0.935
HADS, ≥8, %						
Anxiety	25.0	9.6	**0.021**[b]	17.0	9.6	0.219[b]
Depression	7.5	8.1	1.000[b]	3.8	2.7	1.000[b]
IPQ-R, mean (SD)						
Timeline acute/chronic (6–30)	19.5 (4.6)	22.4 (5.0)	**0.003**	22.3 (4.5)	23.1 (5.5)	0.190
Consequences (6–30)	15.7 (3.6)	17.1 (4.7)	0.101	16.0 (3.8)	17.0 (4.6)	0.093
Personal control (6–30)	19.7 (3.1)	17.9 (3.8)	**0.004**	19.9 (3.2)	17.4 (4.2)	**<0.001**
Treatment control (5–25)	18.6 (2.3)	17.6 (2.9)	**0.041**	17.7 (2.7)	17.1 (3.3)	0.213
Illness coherence (5–25)	17.4 (3.5)	17.9 (4.3)	0.422	17.3 (4.3)	19.0 (4.1)	**0.043**
Emotional representations (6–30)	15.9 (4.5)	15.0 (4.2)	0.283	15.3 (4.1)	15.0 (4.6)	0.890
Timeline cyclical (4–20)	11.2 (3.2)	12.6 (3.1)	**0.019**	10.9 (3.7)	12.6 (2.9)	**0.006**
AF/episodes of AF, yes %				59.6	81.6	**0.006**[b]
Symptoms, yes %			P^b			P^b
Breathlessness during activity	82.4	91.7	0.120	83.7	89.3	0.358
Breathlessness even at rest	41.2	41.9	0.936	30.6	39.2	0.331
Dizziness	51.0	63.5	0.162	38.8	55.6	0.070
Cold sweats	25.5	40.5	0.082	18.4	44.0	**0.003**
Weakness/fatigue	80.4	93.1	**0.034**	68.8	90.7	**0.002**
Tiredness	80.4	92.0	0.055	69.4	84.0	0.054
Chest pain	15.7	33.3	**0.027**	12.5	30.7	**0.021**
Pressure/discomfort in chest	37.3	48.0	0.233	22.9	48.0	**0.005**
Worry, anxiety	54.9	47.3	0.403	50.0	53.3	0.715

The bold figures denote statistically significant *P*-values.
ASTA, Arrhythmia-Specific questionnaire in Tachycardia and Arrhythmia; IPQ-R, Revised Illness Perception Questionnaire; HADS, Hospital Anxiety and Depression Scale; HRQoL, health-related quality of life.
[a]The Mann–Whitney *U* test.
[b]The χ^2 test.

measurement of PROs confers an advantage of making more individualized care possible.

Strengths and limitations

To our knowledge, this is the first study exploring differences in outcomes reported using PRO measurements between patients newly diagnosed with AF and those who have lived with the diagnosis longer. We obtained survey responses from 75% at the 6-month follow-up, which is a high response rate. Validated PROs were used, which increases the validity of the results. These also had high Cronbach's α values, which

increases the reliability of the results. As with most studies, there are also some limitations that must be considered. This study was conducted at a single centre, which may reduce its generalizability. The two groups were not equal in size. In addition, newly diagnosed patients tend to be very observant of their symptoms, which may have led to differences in responses between groups. We also do not have data on those who choose not to participate in the study. There was a large variation in the number of months that previously diagnosed patients had lived with AF. Further, they also had other cardiovascular diseases to a greater extent than those newly diagnosed, which is a factor that should be

Table 4 Within-group comparisons of patient-reported outcomes between baseline and 6-month follow-up

Scales (score range)	Patients newly diagnosed (*n* = 53)			Patients previously diagnosed (*n* = 76)		
	Baseline	6 months	*P*ᵃ	Baseline	6 months	*P*ᵃ
ASTA, mean (SD)						
Symptoms (0–100)	26.1 (15.1)	21.7 (16.1)	**0.001**	31.9 (15.4)	30.6 (17.2)	0.708
HRQoL total (0–100)	24.1 (17.1)	18.2 (16.7)	**0.002**	27.6 (17.7)	26.0 (20.2)	0.791
HRQoL physical (0–100)	28.1 (21.2)	20.5 (20.3)	**0.001**	32.4 (22.4)	32.8 (25.2)	0.480
HRQoL mental (0–100)	19.2 (15.6)	15.5 (15.0)	**0.014**	22.0 (16.5)	19.4 (18.7)	0.111
HADS, mean (SD)						
Anxiety (0–21)	4.7 (3.4)	3.8 (3.5)	**0.014**	3.8 (2.9)	3.6 (3.2)	0.633
Depression (0–21)	3.0 (2.8)	2.8 (2.6)	0.310	3.0 (2.7)	2.8 (2.6)	0.146
HADS, ≥8%						
Anxiety	25.0	17.0	0.289ᵇ	9.6	9.6	1.000ᵇ
Depression	7.5	3.8	0.625ᵇ	8.1	2.7	0.219ᵇ
IPQ-R, mean (SD)						
Timeline acute/chronic (6–30)	19.5 (4.6)	22.3 (4.5)	**<0.001**	22.4 (5.0)	23.1 (5.5)	0.156
Consequences (6–30)	15.7 (3.6)	16.0 (3.8)	0.663	17.1 (4.7)	17.0 (4.6)	0.731
Personal control (6–30)	19.7 (3.1)	19.9 (3.2)	0.855	17.9 (3.8)	17.4 (4.2)	0.174
Treatment control (5–25)	18.6 (2.3)	17.7 (2.7)	**0.035**	17.6 (2.9)	17.1 (3.3)	0.220
Illness coherence (5–25)	17.4 (3.5)	17.3 (4.3)	0.627	17.9 (4.3)	19.0 (4.1)	0.159
Emotional representations (6–30)	15.9 (4.5)	15.3 (4.1)	0.203	15.0 (4.2)	15.0 (4.6)	0.852
Timeline cyclical (4–20)	11.2 (3.2)	10.9 (3.7)	0.634	12.6 (3.1)	12.6 (2.9)	0.460
Symptoms, yes %			*P*ᵇ			*P*ᵇ
Breathlessness during activity	82.4	83.7	1.000	91.7	89.3	1.000
Breathlessness even at rest	41.2	30.6	0.109	41.9	39.2	0.815
Dizziness	51.0	38.8	0.227	63.5	55.6	0.189
Cold sweats	25.5	18.4	0.508	40.5	44.0	0.648
Weakness/fatigue	80.4	68.8	0.125	93.1	90.7	1.000
Tiredness	80.4	69.4	0.180	92.0	84.0	0.227
Chest pain	15.7	12.5	1.000	33.3	30.7	0.791
Pressure/discomfort in chest	37.3	22.9	0.146	48.0	48.0	1.000
Worry anxiety	54.9	50.0	1.000	47.3	53.3	0.454

The bold figures denote statistically significant *P*-values; newly diagnosed, diagnosed with AF ≥6 months; previously diagnosed, diagnosed with AF ≥6 months.

AF, atrial fibrillation; ASTA, Arrhythmia-Specific questionnaire in Tachycardia and Arrhythmia; HRQoL, health-related quality of life; HADS, Hospital Anxiety and Depression Scale; IPQ-R, Revised Illness Perception Questionnaire ≥6 months.

ᵃWilcoxon signed-rank test.

ᵇMcNemar's test.

considered in the interpretation of the results. To the best of our knowledge, no cut-off values are available in the different scales for IPQ-R and ASTA, which would have made the results easier to interpret.

anxiety and depression, and their HRQoL at different stages during the course of the disease. This information can increase the knowledge of how the healthcare system should handle each patient based on individual assessments.

Conclusions

We found that patients newly diagnosed with AF reported more positive outcomes, as measured via PROs, both at baseline and at the 6-month follow-up, than patients with a previous diagnosis of AF. Therefore, it is important to quickly capture patients newly diagnosed with AF to support their belief in their own abilities. Along with medical treatments, such support may help patients manage the disease, which may lead to reduced symptom burden and better HRQoL over time. Measuring PROs in patients with AF can provide data on how these patients perceive their illness, their symptoms and symptom burden, their

Author contributions

L.H., C.H., Å.H., K.O., F.V., and K.H.Ä.: conceptualization, validation, writing—review and editing, and visualization. L.H., C.H., K.O., and K.H.Ä.: resources and investigation. L.H., C.H., and K.H.Ä.: formal analysis. L.H.: writing—original draft. K.H.Ä.: supervision and project administration. L.H. and K.H.Ä.: data curation and funding acquisition.

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Data availability

The data underlying this article will be shared on reasonable request to the corresponding author.

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