

# Patient-reported outcomes in atrial fibrillation: is it worthwhile systematically evaluating?

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**This invited commentary refers to ‘More positive patient-reported outcomes in patients newly diagnosed with atrial fibrillation: a comparative longitudinal study’ by L. Holmlund *et al.*, <https://doi.org/10.1093/eurjcn/zvad139>.**

Atrial fibrillation (AF) is a common cardiac arrhythmia associated with various negative effects, on patients’ quality of life (QOL) and psychological well-being. This longitudinal study highlighted key findings focusing on patients newly diagnosed with AF, compared with those with longer-existing AF, and their perceptions and outcomes over time, using patient-reported outcomes (PROs).<sup>1</sup> Notably, a significant proportion of patients newly diagnosed with AF considered the arrhythmia as a transient condition rather than a chronic ailment, potentially mitigating associated anxiety and distress. Furthermore, there was a noticeable increase in patients’ perception of personal control over their condition and the efficacy of treatment modalities, fostering a sense of empowerment and optimism.

At the 6-month mark, newly diagnosed AF patients reported a lower symptom burden. Additionally, these patients experienced a reduction in the severity and frequency of AF-related symptoms, contributing to an overall improvement in well-being. This contrasts with findings in individuals with established AF diagnoses. For instance, analysis of the EAST-AFNET 4 trial, comparing early rhythm control vs. standard care, revealed no significant disparity in the overall European Heart Rhythm Association (EHRA) symptom score or EQ-5D score between the early rhythm control group and the usual care cohort.<sup>2</sup> Further, it is also important to acknowledge AF pattern as a factor in patients’ symptoms and QOL. In a sub-analysis of the EAST trial, early rhythm control led to an improvement in QOL, as measured by EQ-5D, in patients with paroxysmal and persistent AF but not in those recently diagnosed, defined as within 7 days of trial enrolment.<sup>3</sup>

Early diagnosis and education are crucial to helping patients with the knowledge of their condition which could improve their overall QOL. A previous qualitative study highlighted the cognitive and emotional responses that were exhibited in patients following their onset of symptoms and subsequent diagnosis of AF. This is largely influenced by the lack of knowledge of the condition and the interaction with healthcare providers.<sup>4</sup> Additionally, prior research has demonstrated the deleterious impact of depression and anxiety symptoms on QOL in AF

patients.<sup>5</sup> However, in the current study of Holmlund *et al.*, patients reported marked improvements in various facets of their QOL, indicative of a positive trajectory in overall health status. This was accompanied by a heightened perception of personal control over their condition, suggestive of adaptive coping mechanisms and proactive engagement in AF management. Over time, patients with newly diagnosed AF exhibited a consistent decline in symptom burden, suggestive of potential adaptation to the condition and/or effectiveness of treatment interventions. Gradual reductions in anxiety levels reflected a stabilization of psychological well-being and adjustment to the diagnosis, while progressive improvements in health-related QOL (HRQOL) underscored the potential for positive adaptation and managing AF. These stabilization trends in QOL echo the findings from the previous IMPACT-AF study, which observed similar patterns over a year across various intervention modalities.<sup>6</sup>

As people become older, keeping a high HRQOL is important for all, not only in patients with AF. Insights into patients’ perceptions about their health and condition are instrumental in this respect, as recently shown by a statement on behalf of the European Society of Cardiology concerning the use of PROs.<sup>7</sup> Despite the quality of the present study and analysis, various factors could have impacted the results. Firstly, it would have been interesting to have more information on how patients received education and are followed up at the University Hospital Cardiology Clinic in Northern Sweden and if this has changed over time, as we know that patients’ beliefs about the arrhythmia can possibly impact their QOL and psychological distress.<sup>8</sup> Questions can be raised as follows: Was a standardized education programme in place? Were educational materials used? Was an integrated care approach used tackling topics such as self-management and risk factor management? Is education about the arrhythmia reinforced during follow-up visits? Secondly, there was a large difference in the median time since diagnosis, which was only 1 month in the newly diagnosed group and around 6 years in the group of patients with a longer diagnosis. It can be postulated that patients in the early phase of their disease still do not identify AF as a chronic condition but think that it is easily controllable by medication or procedures. Conversely, patients with a longer diagnosis may have already experienced the cyclical effect of AF, having undergone more interventions, such as direct current

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cardioversions and pulmonary vein isolations, which could have failed, impacting their confidence in effective management of the arrhythmia. Therefore, it would also have been interesting to know the baseline information and if there were any arrhythmia recurrences during the study follow-up in both groups. Thirdly, the fact that the baseline measurement was taken at the hospital, at the time an electrical cardioversion was planned, where patients were recruited in the waiting room, while after 6 months they completed the questionnaire at home without a healthcare provider nearby, could have impacted the within-group comparisons between baseline and follow-up. This is important to consider as it is known that various factors related to the source, mode, method, and setting of data collection of PROs can impact patients' responses.<sup>9</sup> Finally, various instruments can be used to follow up on the well-being of AF patients.<sup>10</sup> In this study, the investigators chose to use the Arrhythmia-Specific questionnaire in Tachycardia and Arrhythmia (ASTA),<sup>11</sup> the Hospital Anxiety and Depression Scale (HADS),<sup>12</sup> and the Revised Illness Perception Questionnaire (IPQ-R).<sup>13</sup> It is not clear why more AF-specific PROs were not utilized. The International Consortium for Health Outcomes Measurement (ICHOM) also formulated a standard set of outcome measures for patients with AF including still other PROs (e.g. SF-12, PROMIS, AFEQT, and AFSS).<sup>14</sup> More research is needed on the use of these instruments in the follow-up of AF patients to determine the ideal PRO measure for a particular study.

In summary, the study by Holmlund and colleagues highlights that it is of pivotal importance to measure PROs in AF patients over time to evaluate how the arrhythmia impacts their symptom burden, QOL, and anxiety. The findings underscore the importance of promptly engaging and supporting patients newly diagnosed with AF to encourage their confidence and belief in their own capabilities. Early intervention and tailored support have the potential to significantly impact patients' perceptions, symptom experiences, and overall well-being, fostering a more positive trajectory in their journey with AF. Future research should explore tailored interventions aimed at further enhancing patient empowerment and optimizing long-term outcomes in AF management.

**Conflict of interest:** None declared.

## Data availability

No new data have been used in this commentary.

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