

RESEARCH ARTICLE

Treated with preventive anticoagulation therapy in atrial fibrillation: The patients' perspective

Karin Olsson¹  | Åsa Hörnsten²  | Karin Hellström Ängerud² ¹Department of Public Health and Clinical Medicine, Umeå University, Umeå, Sweden²Department of Nursing, Umeå University, Umeå, Sweden**Correspondence**Karin Olsson, Cardiology, Heart Centre and Department of Public Health and Clinical Medicine, Umeå University, Umeå, Sweden.
Email: Karin.olsson@regionvasterbotten.se**Funding information**

This work was supported by the Heart Foundation of Northern Sweden.

Abstract**Aim:** The aim of this study was to explore patients' experiences of preventive anticoagulation therapy in atrial fibrillation.**Design:** This was a descriptive qualitative study based on interviews.**Methods:** Individual interviews with 15 patients, 6 women and 9 men, treated with preventive oral anticoagulant due to atrial fibrillation, were conducted. The interviews were analysed with qualitative content analysis.**Results:** Based on the analysis, the theme *Managing a necessary evil* emerged. The theme comprised the three categories: *Coping with anxiety and changes in daily life*, *Having confidence in care* and *Being a partner or only a receiver of treatment*. Patients described it like being faced with a situation where a treatment perceived as vital was weighed against undesirable consequences and risks. Patients trusted caregivers and had confidence in care, but there was a risk of being a receiver of care instead of becoming a partner.**KEYWORDS**

atrial fibrillation, oral anticoagulation therapy, patients' experiences, qualitative

1 | BACKGROUND

Atrial fibrillation (AF) is a common arrhythmia in adults, which increases the risk for stroke (Pistoia et al., 2016). The prevalence of AF in adults is 2%–4%, and the disease is expected to increase in prevalence (Hindricks et al., 2020). It is estimated that in year 2030 about 14–17 million people in Europe will have AF. One important cornerstone in the management of AF is thrombosis prophylaxis with oral anticoagulant therapy (OAC), with vitamin K antagonists (VKA) or non-VKA oral anticoagulants (NOAC). VKAs have for a long time been the only treatment for thromboembolic diseases but nowadays NOAC is an increasingly common treatment alternative (Kirchhof, Benussi, et al., 2016). Both treatments can be complicated because they increase the risk of bleeding, but one difference with

warfarin is that it requires frequent blood tests and dosage adjustments (Salmasi et al., 2019).

2 | INTRODUCTION

Oral anticoagulant treatment reduces stroke and mortality in AF patients, but despite the evidence for OACs to reduce the risk for stroke, some patients stop taking their medications (Hindricks et al., 2020; Kirchhof, Benussi, et al., 2016). Reasons for not taking OACs are reported to be lack of knowledge about the purpose of the therapy, the risk of bleeding complications or the effort required from the patient to verify or adjust the dose of VKA (Kirchhof, Benussi, et al., 2016; Pandya & Bajorek, 2017). A systematic review

This is an open access article under the terms of the [Creative Commons Attribution-NonCommercial-NoDerivs](https://creativecommons.org/licenses/by-nc-nd/4.0/) License, which permits use and distribution in any medium, provided the original work is properly cited, the use is non-commercial and no modifications or adaptations are made.

© 2021 The Authors. *Nursing Open* published by John Wiley & Sons Ltd.

found that adherence and persistence with NOAC therapy were poor among patients with AF (Shehab et al., 2019), others describe the association between low knowledge and poorer adherence to OAC medication (Rolls et al., 2017; Smet et al., 2018). In an interview study of patients on both VKA and NOAC, knowledge gaps and misconceptions of AF and its treatment were identified and a negative attitude, especially against VKA, was found (Salmasi et al., 2019). Thrysoee et al. describe uncertainty among patients with AF, and difficulties in understanding the association between AF, anticoagulation and stroke, and also that patients did not understand that AF was a lifelong disease (Thrysoee et al., 2018).

European Guidelines recommend a patient-centred approach in the management of patients with AF, and patients should be empowered to participate in their own care (Hindricks et al., 2020). Shared decision-making is recommended in the decision-making process, including anticoagulant therapy, but it requires the active involvement of patients and that they are thoroughly aware of the potential benefits and risks and the different alternatives for OAC (Kirchhof, Benussi, et al., 2016; Kirchhof, Breithardt, et al., 2016). Patients' preferences for OAC were investigated in a systematic literature review (Wilke et al., 2017), which showed that patients are willing to accept a higher bleeding risk if the stroke risk can be significantly reduced. The study also showed that patients' preferences towards OACs often differ from the perspective of the physicians, where physicians evaluate bleeding risk as more important than patients do (Wilke et al., 2017). Differences in preferences regarding OAC therapy between patients and physicians are also described by others (Slavenburg et al., 2020). A study aimed at examining patients' choices showed that patients prefer treatment that does not require periprocedural interruption (bridging), which is not associated with regular INR checks and dose adjustments, which has minor interactions with food and can be taken once daily (Böttger et al., 2015).

In summary, OAC therapy is challenging and places great demands on patients. In order to be able to support patients, both in deciding on treatment and in compliance, we need knowledge about patients' perceptions and experiences of OAC therapy. Updated research describing patients' perspectives of OAC therapy remains sparse, and further studies are needed. Therefore, the aim of this study was to explore patients' experiences of preventive anticoagulation therapy in atrial fibrillation.

3 | METHODS

3.1 | Design and context

To enable a deeper understanding of the participants' experiences, an inductive qualitative design with individual interviews was chosen. The method makes it possible to gain an insight into patients' life world (Polit & Beck, 2016). This was a sub-study in a study about atrial fibrillation patients' experiences, quality of life and illness perceptions in atrial fibrillation. The main study included 180 patients

TABLE 1 Description of participants and their oral anticoagulant therapy

Participant	Age	OAC treatment	Prior experience with VKA
1	70	NOAC	X
2	56	NOAC	
3	79	NOAC	X
4	65	NOAC	X
5	75	VKA	
6	71	VKA	
7	65	NOAC	
8	70	VKA	
9	81	NOAC	
10	81	VKA	
11	74	NOAC	
12	58	NOAC	X
13	81	VKA	
14	69	NOAC	X
15	59	NOAC	X

Abbreviations: NOAC, non-VKA oral anticoagulants; OAC, oral anticoagulant therapy; VKA, vitamin K antagonists.

with atrial fibrillation, recruited at a university hospital in Sweden and hospitalized for electrical cardioversion.

3.2 | Participants

To answer the aim of this study, 15 participants, 6 women and 9 men, ages 56–81 years (median 70 years), were included through purposive sampling. Men and women with different ages, different levels of education, different marital statuses and included in the main study were contacted by telephone. They were all treated with preventive OAC due to AF, 5 with VKA and 10 with NOAC. Six of those treated with NOAC had prior experience with VKA (Table 1). Inclusion criteria for the study were AF diagnosis, treated with OAC, and willing to participate in interviews.

3.3 | Data collection

The semi-structured interviews followed a short interview guide with a focus on experiences of OAC, medications affecting daily living, and knowledge about treatment. Examples of questions were as follows: What is your experience of being treated with OAC? Has the treatment affected your life or lifestyle? What information did you receive before starting treatment? Probing questions were asked to clarify and further develop the participants' answers. The interviews were conducted between June 2018 and April 2019 and took place in the participants' homes or at the hospital according to their wishes. They were done by first (KO) and last (KHÄ) author and

two nurses undergoing specialist training; none was involved in the care of the participants. The interviews were digitally recorded and transcribed verbatim.

3.4 | Analysis

Qualitative content analysis, according to Graneheim and Lundman, was used for the analysis. This method, which covers both descriptions of the manifest content as well as interpretations of the latent content and close to the participants' lived experiences (Graneheim et al., 2017; Graneheim & Lundman, 2004) was considered appropriate according to the aim. All authors, with extensive experience of qualitative method, were involved in the analysis. The transcribed interviews were read through several times and meaning units corresponding to the aim were condensed and labelled with codes. The codes were then sorted by similarities and differences and grouped into subcategories and categories, and furthermore, the underlying meaning of the categories was identified and formulated into a theme. Throughout the analysis process, we continually reflected upon and discussed our pre-understandings. The analysis was performed and discussed by all authors until consensus was achieved.

3.5 | Trustworthiness

We followed the recommendations from Graneheim and Lundman (2004) to ensure trustworthiness. Men and women with different ages, different levels of education, different marital statuses with different backgrounds and experiences were included for credibility. In all interviews, focus was on the same area for dependability. Transferability was achieved by giving a clear description of the data collection, settings and characteristics of participants and process of analysis. Quotations were used to illustrate findings.

3.6 | Ethical considerations

This study conformed to the principles outlined in the Declaration of Helsinki and was approved by the Swedish Ethical Review Authority (Dnr 2018-24-31M). All participants received written and oral

information from the researchers and gave their written informed consent.

4 | RESULTS

The result of this study revealed the theme *Managing a necessary evil*, and the three categories connected to the theme were *Coping with anxiety and changes in daily life*, *Having confidence in care* and *Being a partner or only a receiver of treatment*. An overview of the theme, categories and subcategories is given in Table 2 and is explained more in detail in the following text.

4.1 | Managing a necessary evil

The theme in this study of patients being treated with preventive OAC condensed the experiences of being faced with a situation where a treatment that was perceived as vital, was weighed against undesirable consequences and risks. Patients trusted caregivers and had confidence in care, but there was a risk of being a receiver of care instead of becoming a partner. The following categories describe the participants' experiences and handling of the situation.

4.2 | Coping with anxiety and changes in daily life

This category encompassed how OAC influenced daily life and coping with the changes. The treatment affected daily life in varying degrees depending on former lifestyle and situation in life, the treatment they received, and how participants tolerated the medication. The treatment also had an emotional impact on the participants that they had to deal with.

4.2.1 | Accepting the treatment affecting life and lifestyle

Participants expressed that treatment with anticoagulants had a significant impact on their daily life, and that it was something they had to accept. Some were dissatisfied with the medication and felt that it was impossible to exercise or to live their lives the

TABLE 2 Subcategories, categories and theme

Subcategories	Categories	Theme
<ul style="list-style-type: none"> • Accepting that the treatment affects life and lifestyle • Handling dose adjustments and side effects • Dealing with anxiety 	Coping with anxiety and changes in daily life	Managing a necessary evil
<ul style="list-style-type: none"> • Trusting caregivers • Feeling cared for 	Having confidence in care	
<ul style="list-style-type: none"> • Lacking insights and involvement • Searching for more knowledge • Becoming a partner 	Being a partner or only a receiver of treatment	

way they wanted. "Then, I said, I don't want it like this. I was tired of having the medication; it didn't work exercising and living the way I wanted." (12)

Participants stated that they had to be careful not to hurt themselves and avoided situations when there was a risk of injury. This was to some extent linked to the lack of antidote to NOAC. Travelling was a stress factor for those who needed to take a prothrombin time test (PT/INR) when travelling abroad. Those treated with VKA described that they had to reflect on their diet and sometimes adjust it due to recommendations from care.

With the Waran, there are certain things that are inappropriate to eat too much of, it applies to salad and to strawberries for example. I eat salad quite regularly so it's like the same all the time and then it does not matter, but strawberries are a bit difficult because they are seasonal.

(10)

4.2.2 | Handling dose adjustments and side effects

Most participants with experience with VKA reported that frequent testing was troublesome. VKA was perceived as difficult to adjust, with fluctuating test values or missing times for tests, and interactions with other drugs resulting in confused and irregular dosing. Some also reported experiencing extended hospital stays related to treatment with VKA. Participants who performed self-tests adapted dosage and sampling times based on the current PT/INR and expressed becoming more independent.

After taking a course, I got the equipment. So, last night for example, I took a quick check, 2.3, it is quite okay, I have the knowledge and I am so experienced with Waran. I can change the dose myself and I can control the medication. It should be between 2 and 3.

(13)

Some participants reported that their skin was so sensitive that it was injured even without an identified explanation and it was difficult to stop the bleeding. Others stated that they were bleeding less than expected and had no discomfort from side effects. It became a routine to take their anticoagulants, and, although it was sometimes forgotten, there was an opinion that forgetting a single tablet did not have consequences. It was described as "just one tablet" (8) out of several. Participants stated that they accepted side effects as being easy bleeding and did not think much about them, as they felt forced to take the medication.

I have to take this medicine. Therefore, I have tried not to read too much about it. I thought, I should not frighten myself by reading about side effects.

(2)

Participants who switched from VKA to NOAC were pleased and experienced relief when tests decreased. Change of medication led to a sense of freedom. It simplified everyday life and made it easier for those who wanted to travel. Participants who reported former side effects of nosebleeds experienced great improvement.

4.2.3 | Dealing with anxiety

Having AF and being treated with antithrombotic medication sometimes caused anxiety, both the diagnosis itself and its treatment. Most worries were experienced at the beginning of the treatment. As the experiences with the treatment increased and time passed, the anxiety was less noticeable.

The first time I was treated with Elequis I was extremely scared. It was in the fall and slippery and I thought, if I slip and get hurt and as medicating with NOAC, I will get a brain haemorrhage. Which is better, preventing a thrombosis or getting brain haemorrhage?

(7)

To handle anxiety, some stated that taking the drug led to a feeling of safety because they relied on the treatment to prevent unwanted events related to the disease.

I know that it is to prevent stroke, so the medication makes me feel safe. If I don't take it, I can't get electric conversion.

(9)

4.3 | Having confidence in care

Having confidence in care was reported as important. Confidence was built on trust in caregivers, in the knowledge of the professionals and in the feeling of being care for.

4.3.1 | Trusting caregivers

Trusting caregivers was described and seen as important, and the participants perceived doctors and nurses as educated and professional and therefore they complied with the treatment. "I trust the doctors and if they say I should take medicine, then I will take it. They have the knowledge about this". (8)

Trust was also based on continuity and the relationship created between the patient and the caregiver. Continuity was important as well as when the conversation between caregivers and participants was straightforward and honest. It created a sense of calm.

... My wife and I had been thinking about changing medication. I brought it up with my doctor, whom I have seen for years, at my last visit in March, but added: If you say I should take the medicine, then I will continue. It feels safe that he didn't transfer my check-ups to a health care centre.

(4)

4.3.2 | Feeling cared for

The care process generally worked well with continuous visits. The caregiver checked if participants were able to manage their medication, handled the anticoagulant setting carefully and planned with close controls, which led to a feeling of being well cared for.

I have been so well taken care of. It works well with doctor visits and they check if I can manage the medication. I feel surrounded by care that really works well.

(2)

Participants treated with VKA felt that they received feedback quickly in connection with blood sampling and they felt safe with the continuous contact. Those treated with NOAC were grateful to receive such expensive medicines, which was interpreted as being respected and important to care for.

Yes, I am grateful that I received Eliquis, it is an expensive medicine. It is nice that they think I am worth it, but it is lucky that there is high-cost protection.

(3)

4.4 | Being a partner or only a receiver of treatment

This category concerns patients' involvement in their own treatment. Some participants considered themselves as partners in the decision about OAC treatment, but most accepted the doctors' decisions, regardless of whether information about different treatment options was given or not, and became only a receiver of care. The reason for that was often respect for the professional knowledge of the doctors, and that they had never reflected on the possibility of being involved in the decision-making process.

4.4.1 | Lacking insights and involvement

Some patients expressed that they had not received any information about OAC before being put on treatment. On the other hand, some described that they avoided making decisions with the given information. The reasons for this were that they did not want to scare themselves or that they trusted the doctor.

When there was a lack of understanding of the consequences of the treatment, problems arose, such as in the following quotation when medication had to be adjusted prior to examination.

I was told to take the tablet every day, it was important, but I never understood that I could not pause the medication in any way. As when I did the colonoscopy, I received written information that I should pause it. I thought there was coordination between those who would do a colonoscopy and the cardiologist but that was not the case so my electrical conversion could not be done as planned.

(11)

Participants did not question the doctor's prescription. When lacking knowledge, one cannot participate in decision-making, so they were obedient and compliant.

I have not really been involved in decisions, but I have done as they told me. When you do not have knowledge yourself, you do as others say.

(6)

4.4.2 | Searching for more knowledge

Several participants described that they searched for information on Internet, despite having received information from the healthcare provider, to compare with the given information. Some participants talked to other people with experience with anticoagulants and thus gained new knowledge.

It's doubtless a problem for us as patients. We don't really know what's best for us unless they tell us and then you go home and look at what's written online.

(1)

4.4.3 | Becoming a partner

The imbalance between the professional doctor and the needing patient was obvious in the interviews, and the expectations from the patient were that the doctor decides. Some stated that the doctor had informed them about the alternatives and their advantages, disadvantages and risks, but they blamed themselves for not being more active and asking questions.

She told me about 3 different medicines, but I should have written down what she said There was one that you only need to take once a day, there was one that you take twice, one in the morning on one in the evening. Then there are some that were quite new, as I understood, and not so well known. I should have

written down their names and then read about them.

But I trust the doctor very much...

(5)

However, there were also indications that those participants who had become more experienced, and when they also experienced continuity in care, they dared to question the doctors' suggestions. They eventually became more involved and active in discussions about for example benefits and negative side effects of medication and discussed until agreement was achieved between two partners, one on medical treatment and one on coping with the illness in daily life.

I was on my annual check with my doctor, whom I have met with for years after my heart attack, and complained about all the tests. It was a stress factor, and we agreed to change medication.

(3)

5 | DISCUSSION

In this study, aiming to explore experiences of preventive anticoagulation therapy in patients with atrial fibrillation, the theme *Managing a necessary evil* and the three categories:

Coping with anxiety and changes in daily life, having confidence in care and being a partner or only a receiver of treatment emerged and will be discussed below.

The results in this study showed that OAC treatment affected life and lifestyle, and this is similar to previous results (Clarkesmith et al., 2017; Mas Dalmau et al., 2017). An interview study exploring patients' experiences of OAC treatment found that there were challenges related to OAC, and the challenges included lifestyle restrictions and problems related to maintaining INR (Clarkesmith et al., 2017). Patients' narratives in this study revealed a feeling of not being able to live the life they wanted, and the restrictions were experienced as limiting and thus affecting quality of life in a negative way.

This study showed that for some participants, the OAC treatment caused anxiety, and most worries were experienced at the beginning of the treatment. Previous studies have found that patients who had been on OAC therapy less than one year had more negative perceptions about the treatment (Casais et al., 2005) and more worries about the treatment than those who have had the OAC treatment longer (Bajorek et al., 2009). The feelings of anxiety seem to decrease over time, although it may take a while. This points out the importance of paying special attention to patients at the beginning of the treatment, and to be aware that some of them need extra support to prevent anxiety and negative impacts on their quality of life.

Participants in this study expressed that they had confidence in care and trusted the caregivers when they suggested treatment with OAC. They perceived that the doctors had great knowledge.

In our study, all participants were included from a university hospital, which may have contributed to the respect for the caregiver's knowledge.

Trust in caregivers was also found in a study by Pokorney et al., which interviewed patients and providers about decision-making regarding OAC use for stroke prevention in atrial fibrillation. A major theme emerged from patients' narratives, "trust in provider recommendations". Patients trusted their providers and tended to defer decision-making to their providers. The authors discuss that patients' "trust in providers' recommendations does not eliminate the need for patient involvement in decision-making" (Pokorney et al., 2019).

Crucial for patient involvement and shared decision-making is a clear communication of risk and treatment benefits, side effects, as well as available treatment options, and not just information. If patients are invited to be involved in OAC treatment decisions, it will also put greater demands on them. Involved patients cannot expect someone else to make decisions for them (Hargraves et al., 2016). It is important, from a patient safety point of view, that patients be involved in the decision about OAC and take their own responsibility over the treatment. If the patient does not know why the decision about OAC is made, the health care does the patient a disservice. By being involved, they also have knowledge about how and why the treatment is crucial, and therefore the ability to prevent errors that may occur. Healthcare organization tends to be fragmented, divided into different specialties, and missing a holistic view of the patients' illness and treatments. Therefore, it is important that the patient understand the importance of questioning changes or interruptions in treatment. Our study showed that the process of involvement was easier if there was an established relationship between patients and caregivers. An established relationship requires in turn continuity in care. In clinical guidelines, there are clear recommendations that patients should be involved in their care, but the recommendations are not always implemented (Ali-Ahmed et al., 2020), as this result also showed. Involvement is a process that develops over time, and it is important that caregivers can support that process.

Achieving shared decision-making is not an easy task (Noseworthy et al., 2018). One problem is that patients, like in our study, do not feel that they have enough knowledge. Another problem is how to deal with those who do not want to or are not able to be involved in their care. To overcome these and other difficulties, decision aids have been developed. A Cochrane review of studies aimed at evaluating the effectiveness of decision aids showed that when participants' knowledge increased, decisional conflict related to feeling uninformed decreased, and so did also the proportion of participants who were passive in decision-making (Stacey et al., 2017). In a study of the effect of a decision-making tool for thromboprophylaxis in atrial fibrillation, Eckman et al. showed similar results as in the review above, but also that satisfaction with providers increased and medication adherence improved (Eckman et al., 2018).

The theme "Managing a necessary evil" summarizes the results of this study. Managing is related to how much impact the medicine has on your life, if you feel confidence in the care and how involved you are in the process. All participants in our study

perceived their medication as necessary. In a study aimed at investigating the first associations, patients had with taking their medication and whether these associations were related to adherence behaviour, the highest mean adherence rates were found for participants reporting "necessity" followed by "routine". Their study found that negative associations reported were mostly of an emotional nature, whereas positive associations were mostly of a cognitive nature (Kleppe et al., 2017). This confirms the necessity of involving the patient in their own care, for us to listen to their feelings regarding medication and for patients to process what the treatment entails.

6 | CONCLUSION

By considering patient's needs and the phase they are in, the opportunities to participate in decisions about OAC treatment increase. The process of getting involved takes time and presupposes continuity in care. Increased participation enables safer OAC treatment, and decision aids may improve participation.

6.1 | Study limitation

This study is a single-centre study, performed at a university hospital in Sweden, and this may have affected the results. Healthcare systems are organized differently in different countries, which must be considered when assessing transferability of the results to other contexts.

ACKNOWLEDGEMENT

Thanks to Gisela Vikström and Sara Salomonsson for contributing to the data collection and for providing input to the analysis. We also would like to thank all the participants in this study.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

ORCID

Karin Olsson  <https://orcid.org/0000-0003-1877-4381>

Åsa Hörnsten  <https://orcid.org/0000-0003-1543-6512>

Karin Hellström Ängerud  <https://orcid.org/0000-0002-7918-6121>

REFERENCES

- Ali-Ahmed, F., Pieper, K., North, R., Allen, L. A., Chan, P. S., Ezekowitz, M. D., Fonarow, G. C., Freeman, J. V., Go, A. S., Gersh, B. J., Kowey, P. R., Mahaffey, K. W., Naccarelli, G. V., Pokorney, S. D., Reiffel, J. A., Singer, D. E., Steinberg, B. A., Peterson, E. D., Piccini, J. P., ... & O'Brien, E. C. (2020). Shared decision-making in atrial fibrillation: Patient-reported involvement in treatment decisions. *European Heart Journal - Quality of Care and Clinical Outcomes*, 6(4), 263–272. <https://doi.org/10.1093/ehjqcco/qcaa040>
- Bajorek, B. V., Ogle, S. J., Duguid, M. J., Shenfield, G. M., & Krass, I. (2009). Balancing risk versus benefit: The elderly patient's perspective on warfarin therapy. *Pharmacy Practice*, 7(2), 113–123. <https://doi.org/10.4321/S1886-36552009000200008>
- Böttger, B., Thate-Waschke, I. M., Bauersachs, R., Kohlmann, T., & Wilke, T. (2015). Preferences for anticoagulation therapy in atrial fibrillation: The patients' view. *Journal of Thrombosis and Thrombolysis*, 40(4), 406–415.
- Casais, P., Meschengieser, S. S., Sanchez-Luceros, A., & Lazzari, M. A. (2005). Patients' perceptions regarding oral anticoagulation therapy and its effect on quality of life. *Current Medical Research and Opinion*, 21(7), 1085–1090. <https://doi.org/10.1185/030079905X50624>
- Clarksmeith, D. E., Lip, G. Y. H., & Lane, D. A. (2017). Patients' experiences of atrial fibrillation and non-vitamin K antagonist oral anticoagulants (NOACs), and their educational needs: A qualitative study. *Thrombosis Research*, 153, 19–27. <https://doi.org/10.1016/j.thromres.2017.03.002>
- Eckman, M. H., Costea, A., Attari, M., Munjal, J., Wise, R. E., Knochele, C., Flaherty, M. L., Baker, P., Ireton, R., Harnett, B. M., Leonard, A. C., Steen, D., Rose, A., & Kues, J. (2018). Shared decision-making tool for thromboprophylaxis in atrial fibrillation – A feasibility study. *American Heart Journal*, 199, 13–21. <https://doi.org/10.1016/j.ahj.2018.01.003>
- Graneheim, U. H., Lindgren, B. M., & Lundman, B. (2017). Methodological challenges in qualitative content analysis: A discussion paper. *Nurse Education Today*, 56, 29–34. <https://doi.org/10.1016/j.nedt.2017.06.002>
- Graneheim, U. H., & Lundman, B. (2004). Qualitative content analysis in nursing research: Concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today*, 24(2), 105–112. <https://doi.org/10.1016/j.nedt.2003.10.001>
- Hargraves, I., LeBlanc, A., Shah, N. D., & Montori, V. M. (2016). Shared decision making: The need for patient-clinician conversation, Not Just Information. *Health Affairs*, 35(4), 627–629. <https://doi.org/10.1377/hlthaff.2015.1354>
- Hindricks, G., Potpara, T., Dagres, N., Arbelo, E., Bax, J. J., Blomström-Lundqvist, C., Boriani, G., Castella, M., Dan, G.-A., Dilaveris, P., Fauchier, L., Filipatos, G., Kalman, J. M., La Meir, M., Lane, D. A., Lebeau, J.-P., Lettino, M., Lip, G. Y. H., Pinto, F. J., ... ESC Scientific group. (2020). 2020 ESC Guidelines for the diagnosis and management of atrial fibrillation developed in collaboration with the European Association of Cardio-Thoracic Surgery (EACTS). *European Heart Journal*, 42(5), 541–543.
- Kirchhof, P., Benussi, S., Kotecha, D., Ahlsson, A., Atar, D., Casadei, B., Castella, M., Diener, H.-C., Heidbuchel, H., Hendriks, J., Hindricks, G., Manolis, A. S., Oldgren, J., Popescu, B. A., Schotten, U., Van Putte, B., Vardas, P., Agewall, S., Camm, J., ... Zeppenfeld, K. (2016). 2016 ESC Guidelines for the management of atrial fibrillation developed in collaboration with EACTS. *Europace*, 18(11), 1609–1678. <https://doi.org/10.1093/europace/euw295>
- Kirchhof, P., Breithardt, G., Bax, J., Benninger, G., Blomstrom-Lundqvist, C., Boriani, G., Brandes, A., Brown, H., Brueckmann, M., Calkins, H., Calvert, M., Christoffels, V., Crijns, H., Dobrev, D., Ellinor, P., Fabritz, L., Fetsch, T., Freedman, S. B., Gerth, A., ... Camm, A. J. (2016). A roadmap to improve the quality of atrial fibrillation management: Proceedings from the fifth Atrial Fibrillation Network/European Heart Rhythm Association consensus conference. *Europace*, 18(1), 37–50. <https://doi.org/10.1093/europace/euv304>
- Kleppe, M., Lacroix, J., Ham, J., & Midden, C. (2017). 'A necessary evil': Associations with taking medication and their relationship with medication adherence. *Psychology, Health & Medicine*, 22(10), 1217–1223. <https://doi.org/10.1080/13548506.2017.1316412>
- Mas Dalmau, G., Sant Arderiu, E., Enfedaque Montes, M. B., Solà, I., Pequeño Saco, S., & Alonso Coello, P. (2017). Patients' and physicians'

- perceptions and attitudes about oral anticoagulation and atrial fibrillation: A qualitative systematic review. *BMC Family Practice*, 18(1), 3. <https://doi.org/10.1186/s12875-016-0574-0>
- Noseworthy, P. A., Brito, J. P., Kunneman, M., Hargraves, I. G., Zeballos-Palacios, C., Montori, V. M., & Ting, H. H. (2018). Shared decision-making in atrial fibrillation: Navigating complex issues in partnership with the patient. *Journal of Interventional Cardiac Electrophysiology*, 56(2), 159–163.
- Pandya, E. Y., & Bajorek, B. (2017). Factors affecting patients' perception on, and adherence to, anticoagulant therapy: Anticipating the role of direct oral anticoagulants. *Patient*, 10(2), 163–185. <https://doi.org/10.1007/s40271-016-0180-1>
- Pistoia, F., Sacco, S., Tiseo, C., Degan, D., Ornello, R., & Carolei, A. (2016). The epidemiology of atrial fibrillation and stroke. *Cardiology Clinics*, 34(2), 255–268. <https://doi.org/10.1016/j.ccl.2015.12.002>
- Pokorney, S. D., Bloom, D., Granger, C. B., Thomas, K. L., Al-Khatib, S. M., Roettig, M. L., Anderson, J., Heflin, M. T., & Granger, B. B. (2019). Exploring patient-provider decision-making for use of anticoagulation for stroke prevention in atrial fibrillation: Results of the INFORM-AF study. *European Journal of Cardiovascular Nursing*, 18(4), 280–288. <https://doi.org/10.1177/1474515118812252>
- Polit, D., & Beck, C. (2016). *Nursing research : Generating and assessing evidence for nursing practice* (10th ed.). Wolters Kluwer.
- Rolls, C. A., Obamiro, K. O., Chalmers, L., & Bereznicki, L. R. E. (2017). The relationship between knowledge, health literacy, and adherence among patients taking oral anticoagulants for stroke thromboprophylaxis in atrial fibrillation. *Cardiovascular Therapeutics*, 35(6), e12304. <https://doi.org/10.1111/1755-5922.12304>
- Salmasi, S., Kwan, L., MacGillivray, J., Bansback, N., De Vera, M. A., Barry, A. R., Harrison, M. J., Andrade, J., Lynd, L. D., & Loewen, P. (2019). Assessment of atrial fibrillation patients' education needs from patient and clinician perspectives: A qualitative descriptive study. *Thrombosis Research*, 173, 109–116. <https://doi.org/10.1016/j.thromres.2018.11.015>
- Shehab, A., Bhagavathula, A. S., Abebe, T. B., Abegaz, T. M., Elnour, A. A., Sabbour, H. M., Uzzafer, M., Hersi, A., & Hamad, A. K. (2019). Patient adherence to Novel Oral Anticoagulants (NOACs) for the treatment of atrial fibrillation and occurrence of associated bleeding events: A systematic review and meta-analysis. *Current Vascular Pharmacology*, 17(4), 341–349. <https://doi.org/10.2174/1570161116666180123111949>
- Slavenburg, M., van den Bent, J. H., Barten, T., Reijts-Scheijgrond, M., & de Koning, C. (2020). Perceptions and experiences of atrial fibrillation patients on their condition and oral anticoagulant treatment. *Cardiology and Therapy*, 9(2), 409–420. <https://doi.org/10.1007/s40119-020-00173-8>
- Smet, L., Heggermont, W. A., Goossens, E., Eeckloo, K., Vander Stichele, R., De Potter, T., & De Backer, T. (2018). Adherence, knowledge, and perception about oral anticoagulants in patients with atrial fibrillation at high risk for thromboembolic events after radiofrequency ablation. *Journal of Advanced Nursing*, 74(11), 2577–2587. <https://doi.org/10.1111/jan.13780>
- Stacey, D., Légaré, F., Lewis, K., Barry, M. J., Bennett, C. L., Eden, K. B., Holmes-Rovner, M., Llewellyn-Thomas, H., Lyddiatt, A., Thomson, R., & Trevena, L. (2017). Decision aids for people facing health treatment or screening decisions. *Cochrane Database Systematic Review*, 4(4), Cd001431. <https://doi.org/10.1002/14651858.CD001431.pub5>
- Thrysoee, L., Stromberg, A., Brandes, A., & Hendriks, J. M. (2018). Management of newly diagnosed atrial fibrillation in an outpatient clinic setting-patient's perspectives and experiences. *Journal of Clinical Nursing*, 27(3–4), 601–611. <https://doi.org/10.1111/jocn.13951>
- Wilke, T., Bauer, S., Mueller, S., Kohlmann, T., & Bauersachs, R. (2017). Patient preferences for oral anticoagulation therapy in atrial fibrillation: A systematic literature review. *Patient*, 10(1), 17–37. <https://doi.org/10.1007/s40271-016-0185-9>

How to cite this article: Olsson, K., Hörnsten, Å., & Hellström Ångerud, K. Treated with preventive anticoagulation therapy in atrial fibrillation: The patients' perspective. *Nursing Open*. 2022; 9: 2657–2664. <https://doi.org/10.1002/nop2.964>