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ORIGINAL RESEARCH

Patients' views on stroke prevention for atrial fibrillation after an intracerebral haemorrhage: a qualitative study

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Aim

(i) To explore the attitudes of patients with atrial fibrillation (AF) towards oral anti-coagulation (OAC) for stroke prevention post-intracerebral haemorrhage (ICH) and (ii) to explore factors that influence patients' decision-making process for stroke prevention.

Methods and results

Patients with documented diagnosis of AF and history of a non-traumatic ICH, who were eligible for long-term OAC were recruited from eight hospitals in England, using purposive sampling. Data were collected using semi-structured interviews and analysed using Framework analysis. Twelve patients (mean (SD) age 76.2 (6.6) years; 9 men) were recruited. Patients' main priority was to maintain an acceptable quality of life (QoL), reflected by the main theme '*Living my life as normal*'. When deciding to accept or decline OAC for stroke prevention, patients were influenced by the following: (i) The *individual*, meaning factors relating to individuals' personal attitudes towards health and healthcare, (ii) *Medical* factors, encompassing factors relating to patients' trust in medical expertise and patients' information-seeking behaviours, and (iii) *Social* factors, highlighting the influence of patients' social support network on patients' decision-making.

Conclusion

Patients' decision-making for stroke prevention for AF post-ICH was influenced by individual, medical, and social factors. At the heart of patients', decision-making were concerns with maintaining an acceptable QoL. The study findings help nurses and other healthcare professionals to better understand what matters to patients who are eligible for stroke prevention for AF post-ICH, thus promoting more effective shared decision making.

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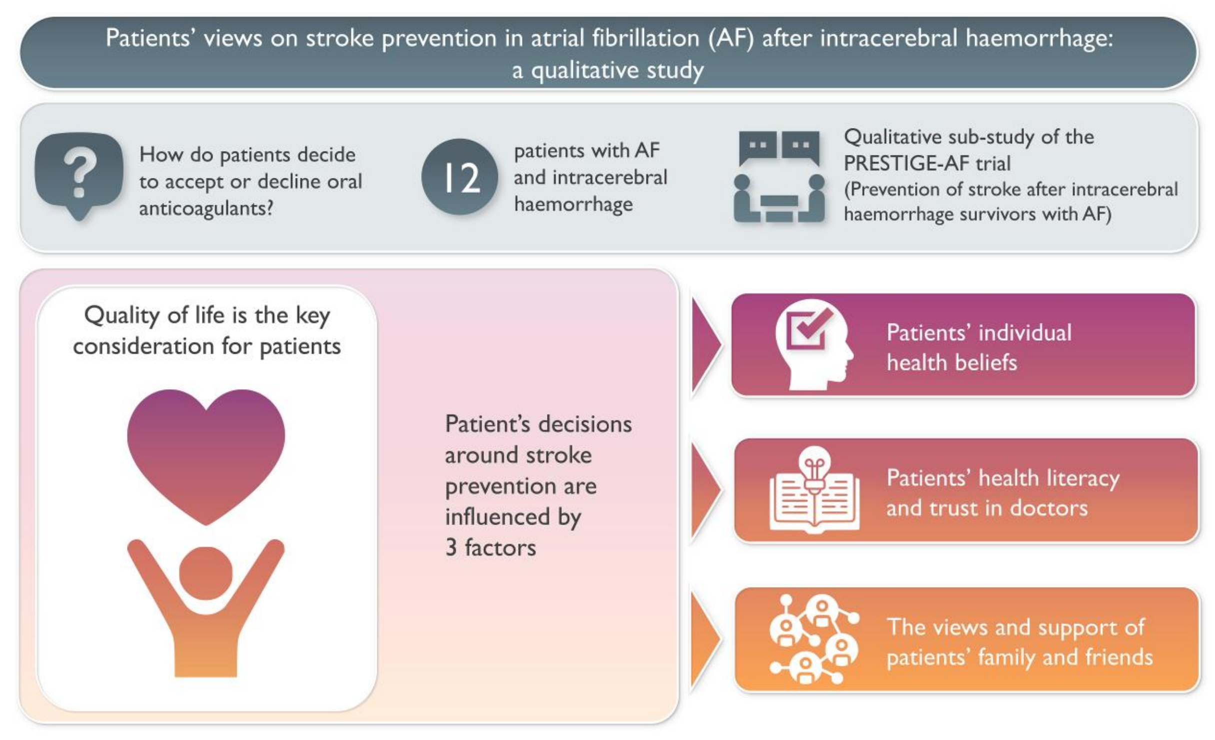
† A list of the PRESTIGE-AF Consortium members is available in the Supplementary Materials.

Graphical Abstract



Patients' views on stroke prevention in atrial fibrillation (AF) after intracerebral haemorrhage: a qualitative study

How do patients decide to accept or decline oral anticoagulants?

12 patients with AF and intracerebral haemorrhage

Qualitative sub-study of the PRESTIGE-AF trial (Prevention of stroke after intracerebral haemorrhage survivors with AF)

Quality of life is the key consideration for patients

Patient's decisions around stroke prevention are influenced by 3 factors

Patients' individual health beliefs

Patients' health literacy and trust in doctors

The views and support of patients' family and friends

Keywords Atrial fibrillation • Stroke • Anti-coagulation • Shared decision-making • Intracerebral haemorrhage • Qualitative

Novelty

- Patients who have sustained an intracerebral haemorrhage (ICH) prioritise quality of life when deciding if they would be willing to take oral anti-coagulant therapy to prevent atrial fibrillation (AF)-related stroke.
- Few patients are actively involved in deciding if they should take oral anti-coagulant therapy to prevent stroke in AF after sustaining an ICH.
- Input from informal carers is an important part of patients' decision-making process when deciding to accept or decline oral anti-coagulant therapy for stroke prevention in AF post-ICH.

Introduction

Patients with atrial fibrillation (AF) and ≥1 additional risk factor for ischaemic stroke are considered eligible to receive long-term oral anti-coagulation (OAC) for stroke prevention,[1] either a non-vitamin K antagonist oral anti-coagulant (NOAC, dabigatran, rivaroxaban, apixaban, or edoxaban) or a vitamin K antagonist, such as warfarin.[2] All OAC therapy increases the risk of bleeding but in most patients with AF the benefits of OAC for stroke prevention outweigh the risk of major bleeding.[3] However, patients who have previously sustained a major haemorrhage, such as an intracerebral haemorrhage (ICH), are at a significant risk of recurrent major bleeding.[4,5] The 2024 European Society of Cardiology guidelines on the management of AF state that there is currently insufficient evidence to determine if patients with AF and ICH should be offered OAC therapy for stroke prevention post-ICH.[6] Other clinical guidelines advise that OAC can be considered for stroke prevention in patients with AF and ICH if the cause of bleeding has been addressed.[7–9] Importantly, patients with a history of ICH or other types of major bleeding have often been excluded from studies exploring the safety and efficacy of NOAC and/or patients' preference for OAC therapy due to concerns about the increased risk of bleeding in the ICH population and to prevent over inflation of the primary safety endpoint. Excluding this important population results in a dearth of information regarding benefit vs. risk of OAC in this patient group, which is problematic because up to 31% of patients with ICH have AF[10,11] and commonly require long-term stroke prevention with OAC. Although there is currently no evidence on the attitudes of patients with AF who have also sustained an ICH towards OAC therapy for the purpose of stroke prevention, some recent evidence is available on physician attitudes, which reports that concerns about re-bleeding and patient attitudes to bleeding risk affect whether physicians prescribe OAC for stroke prevention to patients with AF and ICH.[12]

Therefore, this study, conducted by a multi-disciplinary team of nurses, physicians, and researchers working in the field of AF-related

Table 1 Baseline characteristics of patients who participated in an interview

Patient ID	Gender	Age range[a]	Time since index ICH	Receiving OAC or anti-platelets at time of ICH	Receiving OAC after ICH
1	Male	65–74	<1 year	Yes	Yes
2	Male	75–84	<1 year	Yes	Yes
3	Male	65–74	<6 months	Yes	Yes
4	Female	75–84	<6 months	Yes	Yes
5	Male	75–84	<6 months	Yes	No
6	Male	75–84	<6 months	Yes	No
7	Male	85–94	<6 months	Yes	Yes
8	Male	65–74	<6 months	No	No
9	Male	65–74	<6 months	Yes	Yes
10	Male	65–74	>1 year	No	No
11	Female	75–84	<1 year	Yes	No
12	Female	75–84	<1 year	Yes	No

ICH, intracerebral haemorrhage; ID, identification; OAC, oral anti-coagulants.
[a]At time of recruitment into study.

stroke prevention, explored patients' attitudes towards commencing or restarting OAC for stroke prevention post-ICH and the factors that influence their decision-making process for stroke prevention. To our knowledge, this is the first study to address patient views on stroke prevention for AF post-ICH and factors affecting their decision making.

Methods

This is a sub-study of the PRESTIGE-AF trial (NCT03996772); ethical approval was granted by the South Central—Oxford A Research Ethics Committee (REC reference 19/SC/0435). The inclusion and exclusion criteria for this qualitative study were: age ≥18 years, a documented diagnosis of AF and history of a non-traumatic ICH, and eligible for long-term OAC for the purpose of preventing AF-related stroke. Those unable to independently consent to the study and/or unable to complete a data collection interview in English were excluded. The target sample size was 14 participants who were eligible for the PRESTIGE-AF study; this was determined based on similar qualitative studies in the field.[13,14] Data saturation[15] was reached within the existing sample.

Participants were recruited from eight NHS Trusts in England using purposive sampling between 24 November 2021 and 8 June 2023. Data were collected using individual semi-structured interviews, which were facilitated by a topic guide (see Supplementary material online, *Table S1*). The patient topic guide was developed by DL based on existing literature on patient-centred outcomes in AF-related stroke prevention and OAC therapy and on the findings from a focus group with five survivors of ICH. The resulting topic guides contains different questions for patients with and without experience of OAC (see Supplementary material online, *Table S1*). Participants had the option of being accompanied by a family member during the interview. Interviews were undertaken in-person or via the telephone, audio recorded, and transcribed verbatim. Interviews ranged from 12 to 60 min, lasting on average 25 min and were conducted by E.I., a doctoral qualitative researcher. Data were analysed using Framework analysis, with the aid of NVivo (version 12) software. The analysis was performed in five stages: familiarization, identifying a thematic framework, indexing, charting, mapping, and interpretation.[16] This process generated a matrix that allowed the research team to structure the data by theme, code, or participant. The matrix also promotes rigour by facilitating transparency and scrutiny as it reflects the researchers' decision-making process during coding and theme generation. The initial coding and framework design was performed by E.I. and reviewed by R.R.L. and D.A.L.; the final themes were confirmed over several discussions between the research team. E.I., a doctoral researcher with experience of working in cardiac nursing, kept a reflexive diary over the course of the study to record any queries or uncertainties about the research process, and reflected on how her experience of caring for patients with AF may have impacted her response to the study participants. The consolidated criteria for reporting qualitative research checklist[17] was used to report the study results. This provides a robust mechanism to increase transparency and therefore trustworthiness of the findings. Triangulation of data with previously collated data of interviews with clinicians caring for this cohort of patients, allows for added depth.[12]

Results

Participants

Twelve patients with a confirmed diagnosis of AF and non-traumatic ICH participated in an interview (*Table 1*). The mean age of patients at the time of recruitment was 76.2 (SD 6.6) years and three (25%) were female. Ten participants were receiving OAC at the time of their ICH, of whom six were restarted on OAC post-ICH. No participants were newly initiated on OAC post-index ICH. Four patients were accompanied by their relative during the interview, but all patients were able to provide written informed consent and participate in the study independently.

Themes and sub-themes

The overarching theme from the data is *'Living my life as normal'*. This theme reflects patients' desire to maintain an acceptable quality of life (QoL) and is influenced by the following factors: (i) the *individual*, which highlights factors relating to individuals' personal attitudes towards health and healthcare, (ii) the *medical*, which highlights factors relating to patients' trust in medical expertise and patients' information-seeking behaviours, and (iii) the *social*, which highlights the influence of their social support network on patients' decision-making (*Figure 1*).

Overall, participants viewed OAC as 'yet another drug' [P5] that they took to keep themselves physically well. Rather than AF-related stroke prevention or OAC-associated bleeding risk, participants' main concern was the desire to regain their QoL post-ICH. Thus, much of participants' decision-making refers to more general factors such as attitude to preventative medication and the support of family members,

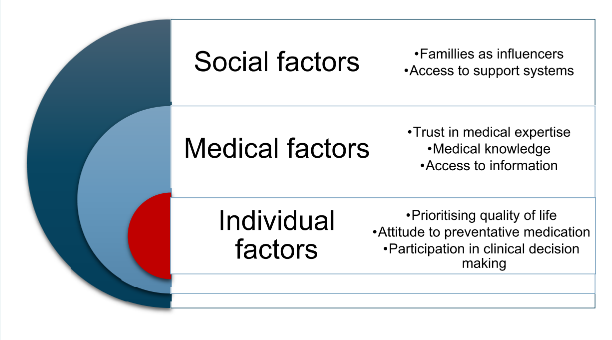


Figure 1 Sub-themes—individual, medical, and social, that influence patients' decision-making process, encompassing the overarching theme of 'living my life as normal'.

which are inherently interlinked with issues associated with AF, stroke prevention, and OAC.

The results below are supported with quotations from study participants. An asterisk (*) denotes participants who re-started OAC post-ICH for stroke prevention in AF.

Individual factors

The first sub-theme, '*Individual factors*' explores the influence that each participants' personal attitude to health and healthcare had on their individual decision-making process.

Prioritising quality of life

All participants viewed healthcare more generally, and OAC use more specifically, through the lens of their QoL:

> *'Well, they* [OAC] *seem to keep me alive, so that's what it is.'* [P3*]

As a group, participants struggled to verbalize the impact that OAC were having on their QoL, either positive or negative, instead viewing them as one of several healthcare interventions that maintained their physical health:

> *'I had no problems with it* [NOAC]*, it was … yet another of the drugs that I was told to take. So, I took them.'* [P5]

Of those who sustained an ICH on OAC, a minority verbalized the risks and benefits of accepting OAC therapy post-ICH, although all were aware of the risks of bleeding associated with OAC.

> *'Obviously, the fact is that the blood thinners made it* [the ICH] *worse. But I don't know how much.'* [P9*]

Attitude to preventative medication

The desire to be physically well was the main reason why participants agreed to take preventative medications such as OAC:

> *'It's supposed to help me out so that's it…I'm interested in staying alive.'* [P1*]

However, some participants described that the perceived treatment burden associated with certain medications outweighed any benefit. For example, one patient explained that his warfarin had been switched to apixaban post-ICH, which he preferred as it reduced the treatment burden of taking long-term OAC.

One patient had initially agreed to take OAC post-ICH but changed their mind, stating that the associated risks of recurrent ICH or other major bleeding outweighed any possible benefits for them.

> *'I've decided not to take it* [apixaban]*… Because it was a known risk* [for bleeding]*, and I didn't think it was responsible… of me to take it.'* [P7*]

Participation in clinical decision-making

Most patients described limited participation in decision-making and their narratives often positioned themselves as a passive recipient of medical care.

> *'But when it comes to medication, I don't question…I follow what they* [the doctors] *say.'* [P8]

When asked if they initiated discussions about diagnoses or treatments with health professionals, most participants said that they did not. Instead, there was an expectation that the health professional would steer the conversation.

> *'If people* [health professionals] *tell me to take things, I take them and if I don't like what they're doing to me, I stop taking them. And then I probably won't tell them that I stopped. Because they didn't ask!'* [P6]

For many participants, following the recommendations of their medical team with limited involvement from themselves was the 'normal' thing to do, although a minority of patients in this study felt that they were willing to query clinicians' decisions.

> *'And I said to* [the cardiologist]*, Look, I've got this heart operation coming up… so if you could contact the neurologist, I'd like to know what their opinion is.'* [P10]

Few individuals discussed any element of uncertainty regarding clinical decision-making. Of those who did, all chose to adhere to their physician's advice.

> *'Like I said, surely they wouldn't have suggested me going on apixaban if it was going to really put me at risk?! I mean, I realise there is a risk.'* [P4*]

Being able to exercise some degree of choice regarding medical treatments was important to some participants. Most often, those who valued choice also appreciated therapies or medications that were associated with minimal treatment burden. Nonetheless, the importance of being able to choose only led to active participation in clinical decision-making for a minority of patients.

> *'I normally let them tell me what they… what the advice is and what they're going to do, and then… I probably wouldn't make an on-the-spot decision, I'd probably go away and think about it.'* [P10]

Generally, patients stated that, since they were happy with clinicians' decision-making, there was no need for them to exercise their right to make an active choice in healthcare.

Medical factors

This sub-theme explores the influence that the medical team and patients' understanding of their condition had on their decision-making.

Trust in medical expertise

Overall, there was a sense of trust in medical professionals. Participants perceived doctors to be experts in their field, equipped with the knowledge to make clinical decisions on behalf of patients.

> *'We're talking about people whose life and careers are invested in this, who am I to answer!'* [P9*]

The belief that doctors are well-placed to make the 'right' clinical decisions was further enhanced by participants' belief that clinicians generally acted in patients' best interest. Two patients described situations in which miscommunication between themselves and health professionals had led to the administration of incorrect medication. Nonetheless, such events did not seem to negatively affect participants' overall positive perception of health professionals.

> *'Well, I suppose that they are so busy. But that was the only thing, really, and I misunderstood some of the explanations.'* [P3*]

Health literacy

Most participants stated that they had unanswered questions at the end of medical consultations, which led to some confusion about which medications patients were meant to be taking and which medication they had to stop.

> *'Well, I was told this morning that I ought to be taking something else, but I haven't been taking that for quite some time.'* [P6]

A varying level of knowledge of AF, stroke, and OAC was demonstrated by participants. They were all aware that they had had an ICH, rather than an ischaemic stroke, and some were able to explain the likely cause of their ICH.

> *'Apparently it was very high blood pressure, I believe. I still can't believe it!'* [P4*]

Most participants had sustained an ICH whilst on OAC and a minority were able to verbalize any perceived possible association between long-term OAC therapy and bleeding risk.

> *'Obviously the fact that I was on blood thinners didn't help! It might've helped that I didn't have a clot, but it didn't help with not having a bleed!'* [P9*]

Participants also showed varying understanding of why they had been commenced on an OAC.

> *'I wasn't sure why I was taking a blood thinner, I just presumed that because of the stroke.'* [P8]

When asked directly, some patients were unsure if they still had AF, partly because they attributed symptoms that can be associated with AF to other causes.

> *'I sometimes get a bit out of breath now, but I think in all honestly it's because I can't exercise the same as I used to be able to.'* [P4*]

Access to information

Health professionals were patients' most trusted source of information and few participants described looking for information about AF, OAC, or stroke from other sources. For some participants, this was because they felt that health professionals were well-placed to offer personalized healthcare advice.

> *'The consultant will say, Ah, wait a minute, well we can do that but it will affect this. So, I tend to trust the consultant more.'* [P10]

Some patients expressed a preference for specific and practical information rather than more general knowledge about their conditions.

> *'But nobody ever sat me down and said, Well, you have this and we're now going to do this with you. It was all sort of… a bit vague.'* [P6]

However, some doubts were expressed about the benefits of obtaining more information about AF, stroke, or OAC.

> *'Nah, I haven't bothered asking anybody else about it cause… I just can't be bothered with it, it's not necessary.'* [P1*]

A minority of participants commented that they struggled with knowing what to ask clinicians or that there was little time during medical consultations for patients to process information.

> *'In the hospital, when they explain things, there's a lot of medical terms or information so you don't take it all in at that time.'* [P10]

Social factors

The sub-theme, '*Social factors*' describe the influence that participants' families and social networks had on their decision-making process and included the involvement of informal carers and family members in clinical decision-making, and participants' need to access practical support.

Families as influencers

Most participants stated that their families had some impact on clinical decision-making, although the exact form of familial involvement in decision-making varied from person to person. Generally, families acted as advisors, whereby they gave their opinion on issues relating to OAC or other general matters, but the final decision rested with the patients themselves. A few patients felt that they did not want to make decisions that went against the wishes of their family members. For example, one participant said the following about participating in the PRESTIGE-AF trial:

> *'My family knew, and they did research cause my daughter said, No, dad, you don't go on this trial till I've done my…! And so she asked around a lot, too.'* [P9*]

In some instances, informal carers took on the role of patient advocates, often through practical need, such as a language barrier or a patient's reduced cognitive function.

> *'She* [patient's partner] *knows better than I do because one of the destructive effects is loss of memory.'* [P5]

In such situations, family members described a variety of information-seeking behaviours to increase their knowledge of OAC.

> *'I must look it up and see, you know. I want to compare that with the rivaroxaban… and, you know, learn the same as you do.'* [partner of P2*]

Families as support systems

All participants relied on their families or wider extended network for practical support. This was most often due to the functional or neurological symptoms directly related to the index ICH.

> *'Anything that involves the telephone, she* [patient's wife] *deals with really. And also any correspondence regarding medical things, she deals with.'* [P7*]

Some patients were keen to reduce their support on family members and regain their independence, whilst others appeared to accept that they would require support long-term. For some, families and friends were a source of emotional as well as practical support.

> *'I go out with my daughter… to forget these things.'* [P11]

In some cases, participants relied on their families for medical information.

> *'I'd ask my wife first… She knows all.'* [P2*]

Discussion

The overarching theme from this study exploring patients' decision-making for stroke prevention was '*Living my life as normal*', which reflects patients' focus on maintaining an acceptable lifestyle post-ICH. Patients' overall attitude to pharmacological stroke prevention for AF post-ICH was largely dictated by individuals' trust in medical expertise as well as personalized perceptions of the value of preventative medicine and the burden of the proposed treatment.

This study suggests that patients' attitude to OAC is influenced by factors that directly relate to their perception of QoL. Of the studies that have explored the views of patients with AF on anti-thrombotic therapy, most have focused on OAC and have investigated patients' attitudes to stroke and bleeding risks,[18] although some lifestyle factors, such as interactions with food have also been explored.[19,20] However, in this study, few participants discussed stroke prevention in the context of stroke and bleeding risks, and few patients could elaborate on the risks and benefits of OAC post-ICH. Patients focused predominantly on QoL-related issues such as medication regimens, medication-related side-effects, and personal views on the value of preventative medication. Most study participants were willing to take preventative medication because they believed that medication would help them live longer. Thus, clinicians who advise individuals with AF and ICH on stroke prevention therapy should explore patients' perception of QoL and attitudes towards preventative medication as a way of delivering patient-centred care, in addition to discussing the risks and benefits of OAC and acknowledging patient preferences in treatment decisions.

Few patients reported having active involvement in clinical decision-making and most participants expressed implicit trust in physicians' ability to make the correct clinical decision on behalf of patients. Most patients who sustained their ICH whilst on OAC agreed to be restarted and only one disagreed with their physician's advice to restart OAC post-ICH. In a multi-national survey of AF patients' attitude to shared decision-making regarding OAC therapy, 45% of participants stated that they preferred physicians to make the decision.[21] Stroke physicians who make decisions about stroke prevention in patients with AF and ICH also state that many patients favour physician-led decision-making.[12] Additionally, patients' real or perceived limited knowledge of their condition(s) has been cited as a barrier to shared decision-making across clinical specialties.[22,23] Thus, interventions that aim to increase AF patients' involvement in decision-making often incorporate educational or informational elements.[24]

Informal carers influenced patients' clinical decision-making. Given that both AF and ICH are associated with decreased neurological function,[25,26] some patients may face challenges understanding medical information and communicating their treatment preferences. Many participants relied on family and friends for accessing medical information and carers who contributed within the interview described a desire to learn more about the patients' medical condition and treatment. Whilst patients' information needs are being increasingly addressed by educational interventions, few of these interventions are also open to informal carers. Given that carers' informational needs may differ from patients' needs,[27] it may be pertinent to examine and co-produce educational and informational tools targeted specifically at informal carers.

Strengths and limitations

To date, this is the only study to have explored the attitudes of patients with AF following an ICH towards pharmacological stroke prevention. It incorporates views of patients with a diverse personal experience of anti-thrombotic therapy, as not all patients were receiving OAC at the time of their index ICH or went on to restart or initiate OAC post-ICH. This variety of patient experience adds to the richness of the data because it represents a myriad of patient views regarding use of OAC post-ICH and strengthens the main finding that patients' priority for decision-making is their overall QoL, rather than specific stroke prevention therapies. Most participants were men and the average age was 76 years, therefore the findings may not reflect the views of women and younger people. Most participants were taking OAC at the time of their index ICH, and therefore the findings may not be reflective of the opinions of OAC-naïve patients. Additionally, none of the study participants had significant clinical deficits post-index ICH, which may not be representative of the wider ICH patient cohort. It does, however, represent the cohort of patients who are likely to be prescribed OAC for AF-related stroke prevention post-ICH, since 70% of participants who sustained an ICH on OAC were re-prescribed an OAC post-stroke. Finally, four of the 12 participants were accompanied by their relative during the data collection interview. Whilst this may result in some individuals being less forthcoming with personal views,[28] it must not be assumed that all individuals are reticent to speak freely about their views in the presence of others.[29] In this study, patients did not show any outward signs of moral discomfort or distress about discussing their views on OAC therapy in the presence of their family members. Transparency in reporting of findings provides the opportunity for readers to consider transferability of findings to other populations. However, the increased risk associated with this particular cohort of patients is likely to be influential in the findings presented and therefore transferability to other cohorts may be difficult.

Suggestions for practice and future research

This study has highlighted that QoL is central to patients' decision-making. Future research could explore specific aspects associated with lifestyle and health related QoL that matter to patients with AF who have survived a stroke, either ischaemic or haemorrhagic. Additionally, this study demonstrated that informal carers play an important role in patients' decision-making. Thus, health professionals involved in formal and informal education of patients should consider involving informal carers in any discussions about proposed treatments or therapies, where appropriate and where the patient wishes this. Finally, the study findings support healthcare professionals to better understand what matters to patients who are eligible for stroke prevention in AF post-ICH. This knowledge can be used to facilitate effective shared decision-making in practice that incorporates discussion of patient values regarding the risks and benefits of long-term OAC in patients with AF and ICH.

Conclusions

Patients' decision-making for stroke prevention in AF post-ICH was influenced by individual, medical, and social factors. At the heart of patients' decision-making was a concern with maintaining an acceptable QoL, which influenced their willingness to engage with preventative medical treatment. Few patients described being active participants in decision-making, and most believed that physicians were better placed to decide on stroke prevention therapy post-ICH on their behalf. Patients were supported in their decision-making by informal carers (typically a partner), who often took on the role of patient advisor and lay sources of medical information. However, both patients and their informal carers had varied and often limited understanding of AF, OAC, and stroke.

Supplementary material

Supplementary material is available at *European Journal of Cardiovascular Nursing* online.

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Author contributions

E.I.: data curation, formal analysis, investigation, methodology, project administration, validation, visualisation, writing—original draft; R.R.L.: formal analysis, methodology, project administration, supervision, validation, visualisation, Writing—review & editing; G.Y.H.L.: conceptualization, funding acquisition, supervision, Writing—review & editing; D.A.L.: conceptualization, formal analysis, funding acquisition, methodology, project administration, supervision, validation, visualisation, writing—review & editing.

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Data availability

The data used for this article cannot be shared publicly due to the need to maintain the anonymity of individuals that participated in the study. The data will be shared on reasonable request to the corresponding author.

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