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Management of Newly Diagnosed Atrial Fibrillation in an Outpatient

Clinic Setting - Patient's perspectives and experiences

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Conflict of interest

None to declare

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ABSTRACT

Aims: To gain in-depth knowledge on patients' experiences of the consultation processes at a multidisciplinary atrial fibrillation outpatient clinic in a university hospital in Denmark.

Background: Atrial fibrillation is the most common arrhythmia associated with morbidity and mortality if not diagnosed and treated as recommended by guidelines. Patients with newly diagnosed atrial fibrillation should be managed in an outpatient setting which includes medical examination, patient education and decision making on medical therapy.

Design: This is a qualitative study including 14 patients referred from general practitioners newly diagnosed with atrial fibrillation, ranging from being asymptomatic to patients having mild to severe symptoms.

Methods: Data was generated in 2013-2015 using participant observation during each consultation, followed by individual interviews post-consultation.

Results: Patients were referred with limited information on AF and knowledge about the management consultation procedures. The consultations were performed in a professional way by a heart rhythm specialist as well as by nurse with emphasis on the medical aspects of atrial fibrillation. The understanding that atrial fibrillation is not a fatal disease in itself was very important for patients. At the same time, visiting the clinic was overwhelming and information was difficult to understand and patients found it difficult to be involved in decision-making.

Conclusions: This study indicates that patients were uncertain on AF before as well as after consultation. The communication was concentrated on the medical aspects of atrial fibrillation and visiting the clinic was an overwhelming experience.

Patients had difficulty understanding what atrial fibrillation was and why they were treated with anticoagulation, and that it was a lifelong treatment.

Relevance for clinical practice: This study demonstrates some lack of patient-centred care and an absent of tailored patient AF-related education. Furthermore, the study highlights the need and importance of active patient involvement.

Keywords: atrial fibrillation, clinical management, multidisciplinary care, outpatient clinic, patient experiences

BACKGROUND

Atrial Fibrillation (AF) is the most common cardiac arrhythmia and is associated with increased morbidity and mortality (Camm *et al.* 2010). It is estimated that the incidence of AF will at least double by the year 2050 (Broge 2011, Naccarelli *et al.* 2009, Rich 2009, Stewart *et al.* 2004) reaching epidemic levels (Chugh *et al.* 2014) and complications will expand dramatically. Poor guideline adherence in the management of AF (Estes *et al.* 2011), will influence the patients' AF symptom burden' (Bohnen *et al.* 2011) and increase the economic burden of the health care system (Ringborg *et al.* 2008, Savelieva & Camm 2008, Stewart *et al.* 2004). There is a wide variety in the way patients experience AF symptoms ranging from completely asymptomatic patients to those with a complex burden of severe physical symptoms, and related mental and social consequences (Camm *et al.* 2010, Deaton *et al.* 2003, Kellen 2004) which is associated with increased uncertainty resulting in poor mental and general health (Kang 2005). AF symptoms include palpitations, shortness of breath, fatigue, dizziness, and syncope (January *et al.* 2014). Symptoms can be misinterpreted by patients as well as by health care providers as not disease-related and caused by other conditions such as ageing, physical deconditioning or stress, resulting in delay of diagnosis and treatment (McCabe *et al.* 2014).

Patients with AF have also been found to have a significantly lower Health-related Quality of Life (HRQOL) and more symptoms of anxiety and depression compared to the general population and to patients with other heart diseases (Thrall *et al.* 2006, Thrall *et al.* 2007). This might be caused by delayed diagnosis, lack of

caring support to cope with the emotional burden of AF and distress caused by unpredictable AF symptoms and lack of counselling regarding the nature of AF and self-management (McCabe *et al.* 2011). AF accounts for one third of all hospital admissions for arrhythmia (Fuster *et al.* 2006), which is the primary cost driver in AF management (Reynolds *et al.* 2007) in North America as well as in Europe (Chugh *et al.* 2001, Tsang *et al.* 2003). Furthermore, Reynolds *et al.* (Reynolds *et al.* 2010) compared symptom frequency and HRQOL between hospitalised AF patients versus non-hospitalised. They found that increased symptom frequency and severity as well as reduction in HRQOL were associated with hospitalisation.

An intervention to contribute to reduce hospitalisation significantly in these patients is to strengthen outpatient services for elective treatment and short-term follow-up (Conti *et al.* 2012). A nurse-coordinated outpatient clinic might contribute to this in terms of reducing waiting times and number of appointments, improving patients' experiences of arrhythmia services, and reducing healthcare costs (Wise & Annus 2013). Furthermore, a Dutch study demonstrated that a nurse-coordinated AF-clinic had a positive impact on guideline adherence (Hendriks *et al.* 2010). This effect is also shown in a subsequent study comparing a nurse-led AF-clinic with usual care (Hendriks *et al.* 2012). In this study, Hendriks *et al.* demonstrated that a nurse-led AF clinic, improved patient management, and clinical outcomes in terms of reduced cardiovascular hospitalisations and death while being a cost-effective management approach (Hendriks & Strömberg 2015). Little is known from the literature about how patients with newly detected AF are informed about AF and its treatment options in an outpatient clinic setting and

what patients' attitudes and beliefs are towards participation in treatment decisions. Thus, the purpose of this study was to describe newly referred AF patients' experiences on the consultation processes at an AF-clinic.

METHODS

This is a qualitative study with a descriptive design following an ethnography approach which is exceptional for studying processes and relationships among people and events during time (Jorgensen 1989). The researcher was an observing participant by following the patients in the AF-clinic and in that way, the researcher gained insight in what took place pre-consultations as well as during the consultations and after-consultations. The researcher made fieldnotes (Spradley 1980) on who were involved and how they reacted, when and where activities happen and how activities influence on the patients (Jorgensen 1989). Furthermore, semi-structured individual interviews (Kvale 2007, Körner 2010) with patients were performed post-consultations.

Study participants

Participants were recruited between 2013 – 2015 and were eligible for the study if AF was documented on ECG, they were referred from a GP practice for the first time due to newly detected AF, were 18 years of age or older, and were able to understand and speak Danish. Patients were recruited prior to their first consultation in the outpatient clinic. Patients were excluded if they had any comorbidity which was unsatisfactorily treated, if they had a pacemaker within

three months before the consultations or if they were discharged after the first visit in the AF-clinic.

Setting

The study took place in an AF outpatient clinic at a large university hospital in Denmark. The multidisciplinary team (Fridlund *et al.* 2015, Körner 2010) at this clinic consists of a cardiologist who is a specialist in heart rhythm diseases (HRS) and two AF-specialized nurses, who have a wealth of experience in AF and have worked with AF-patients for several years. Nurses and cardiologist form the AF treatment team, each with specific tasks and responsibilities. The organisation of care in the AF-clinic was as follows: at the first patients had an appointment with the HRS. The HRS performed physical and medical examinations (ECG, echocardiography and medical history), questioned the patients for their signs and symptoms, informed the patients about AF and initiated medical treatment. At follow-up consultations, patients were seen by the specialized AF nurse. The nurse has more time talking with the patients, focusing on ECG control, burden of AF-symptoms, the patients' response to treatment and how patients were handling their symptoms and treatment. The nurse explained medications, and changed medical treatment if necessary after consultation with the HRS. The nurse coordinated the care, decided for how long patients were followed in the AF-clinic and when patients were discharged to follow- up by GP. If the patient had more than one consultation with a nurse, patients did not always consult the same nurse than previous. Each consultation took approximately 30 to 45 minutes.

Data collection

Data was collected by following patients pre-consultation in the waiting area as well as during every consultation at the AF-clinic as well as by semi-structured individual interviews post-consultations.

The researcher followed each patient during every consultation in the clinic from arrival to leaving the hospital after consultation. Fieldnotes in terms of condensed notes (Spradley 1980) were taken as close to the situation as possible. The following variables were recorded: time of patient arrival to the waiting area, time when consultation started, time for procedures and activities (i.e. echocardiography, ECG, information about AF and treatment) during consultation and time when consultation ended.

Fieldnotes were taking in the waiting area before each consultation regarding the patients' expectations on the consultation and thoughts about his / her illness.

During each consultation, the researcher was passively observing and taking fieldnotes on how related activities were performed, on how the patient was placed in the room, how the patient and the HRS / nurse reacted on each other and how the verbal as well as the nonverbal communication between the patient and the HRS or the nurse proceed. After the consultation, the researcher questioned the patients on their experiences during the consultations. Afterwards, the condensed notes were expanded with missing information, as recommended in the literature (Spradley 1980).

At final follow-up of consultation periods in the AF-clinic, a semi-structured digitally recorded interview (Kvale 2007) took place in a quiet room at the hospital or in the home of the patient. The interview focussed on patients' experiences of

consultations in the AF-clinic and how it affects their way of handling AF. Data collection was performed by the first author, who was not involved in the delivery of care to patients that participated in the study.

Analysis

The transcribed fieldnotes and interviews appeared as text which were analysed and interpreted in a phenomenological-hermeneutical approach based on Paul Ricoeur's interpretation theory (Ricoeur 1976). The analysis took place in a backwards and forwards process between understanding and explanation of the meaning of the text. The analysis was carried out at three analytical steps: 1) naïve reading, 2) structural analysis and 3) critical interpretation and discussion. Thus, the text was opened up for a possible understanding of what the meaning in the transcribed interviews and fieldnotes refer to in the consultation situation (Ricoeur 1973).

Naive reading is the first conjecture of the analysis (Dreyer & Pedersen 2009, Ricoeur 1976). The transcribed fieldnotes and interviews were read several times in a non-judgemental way in order to grasp the meaning of the text as a whole. What did the text say at first glance about how participants experienced the consultation processes and how they handled their illness?

Structural analysis intends to clarify the dialectics between the naïve reading and the interpretation of what the text is about, moving from units of meaning (what the text is saying) to units of significance (what is the text speaks about) (Dreyer & Pedersen 2009). An example on how the main theme "Visiting the clinic – an overwhelming experience" emerged is illustrated in table 2.

The transcribed fieldnotes and interviews were read and reread, and parts of the text were enhanced when there was a reference to how the consultations progressed, how interactions with health care professionals proceeded and were experienced, and how thoughts of illness were expressed. In this analysis step, main themes and subthemes related to the purpose of the study were generated. Results of the structured analysis were subsequently critically interpreted and discussed by the authors. The intention of critical interpretation and discussion was to move from an understanding of participants' experiences to a possible understanding of what their experiences refers to in the consultation processes in the AF-clinic and in the patients thoughts of living with AF. The critical interpretation and discussion appears in the discussion section of this article where the naive reading, the findings from fieldworks and interviews, and results from the literature review form a comprehensive understanding of the generated data.

Ethical considerations

The study was reported to the Danish Data Protection Agency (no. 2008-58-0035) and conducted according to the principles outlined in the Helsinki Declaration (Association 2013). All participants gave written informed consent. We applied for Ethical approval but formal approval from the local ethical committee was not required according to legislation in Denmark.

RESULTS

Participants

As illustrated in Table 1, fourteen patients (7 males and 7 females), aged between 40 years and 82 years (mean: 68.2, $\pm$ 10.2) were consecutively included from February 2013 to September 2014. Symptoms of AF were asymptomatic (3) or reported mild or severe palpitation and dyspnoea. Types of AF: Paroxysmal (5), persistent (1), permanent (8); the total number of consultations with the HRS t and the nurse ranged from 2 to 5, with an average of 3.

Naive reading

The overall impression of the naive reading was that although patients were very satisfied with the consultation in the AF clinic, it did not lead to a clear understanding of AF and why they received the suggested treatment. The patients described uncertainty what causes the AF symptoms and why they were treated with oral anticoagulation medicine. They adhered to the prescribed treatment, but did not understand the effects of the medications. Furthermore, it was difficult for them to explain AF in their own words. The most important value of the consultations was that patients were told that they would not die from AF in itself.

The results from the structured analysis of the transcribed fieldnotes and interviews indicate similarities in the results. These results could be associated with certain themes and subthemes (table 2) and sequenced according to the patient journey in the AF-clinic. The themes are: "Uncertainty about the atrial fibrillation before first consultation"; "Focus on the medical aspects of atrial fibrillation"; "Atrial fibrillation is no fatal disease"; "Professionalism and

competence in the care of atrial fibrillation”, and “Visiting the clinic – an overwhelming experience”.

Uncertainty about the atrial fibrillation before first consultation

In some patients, AF was detected by coincidence, when consulting a GP for a regular control of their diabetes or hypertension. Patients were surprised that they had a heart disease and describe the AF diagnosis as shocking. For other patients, mild or more severe symptoms had been interpreted driven by age, poor lifestyle or lack of fitness:

FJ: “I was just sitting quietly not doing anything and then something suddenly happened. At the first time I thought it was caused by smoking a pipe, because that could raise the pulse. I refrained from smoking for a week or so to see if it stopped but nevertheless it came back. This was dammed surprisingly – without any form of physical activity... And then I consulted my GP”.

Almost none were told anything about AF by their GP. They were referred to the outpatient clinic because of “something with my heart rhythm” and only one patient had searched for information before the first consultation in the AF-clinic. Furthermore, patients were not informed about procedure in the AF-clinic beforehand. Therefore patients often did not discuss with their relatives how to prepare for the first visit to the AF-Clinic (e.g. important questions) and also they did not know what to expect.

A patient and her husband said:

HN: “We [patient and her husband] did not know, what was going to happen during the first consultation. We expected an examination, but we did not know how.”

Another patient expressed:

JT: "It was difficult to prepare not knowing what was going to happen during consultation and when consultation in the AF clinic ended"

Focus on the medical aspects of atrial fibrillation

The medical examination at the first visit by HRS lasted on average 35 minutes.

Finally patients were given information about the AF and about decision making of medical treatment for the last 10 to 15 minutes.

One patient expressed his thoughts after the first consultation like this:

NH: "It was very difficult to understand and remember what was told and what was decided during the consultation. I needed to visit my GP to have more information about what it all means"

The nurses carried through consultation in almost the same way as physicians by starting consultation doing an ECG and afterwards talked with the patient how he / she handled the treatment, if there were any side-effects, and how AF symptoms affected the daily life. Nurses did not asked patients about their experiences of their previous consultation and how patients react on having a disease as AF and to be treated with anticoagulation.

Before ending each consultation, patients were asked whether they have any questions. Almost none of the patients had any question and one patient mentioned afterwards that *"It was difficult to know what I should ask for"*.

Questions concerning AF and treatment appeared while patients were at home and when relatives asked what had happened.

Atrial fibrillation is no fatal disease

Prior to the first consultation, severe symptoms with episodes of rapid palpitation unleashed fear of dying and concerns on whether the heart was damaged over

time or could wear out. Metaphors such as “a machine going too fast and needing oil” or “the machinery” or “tick-tick nearly stops” were used. Their situation was compared to friends and relatives who have a heart disease without knowing what kind of disease it is. A patient expressed it like this:

AH: “I had been told horrible stories and was really afraid that my heart would be damaged because of the [AF] attacks”

Recurrences had a disabling impact on the daily life and could appear when patients were in rest while reading or watching TV. They did not know how to react. The patient cited below had several episodes for a longer period without consulting a GP:

KL: “It [the attack] continued during the whole night, and I did not dare to fall asleep.”

Some had an episode during exercise:

FJ: “I was playing badminton, and I made – yes I don’t think that Peter Gade could have made it better - a dream stroke and we won the game. And at the same time, I had an attack and thought: damned – now it is your turn [to die]”

HRS as well as nurses reassured the patients that they would not die from AF in itself and information on risk factors was focusing about bleeding risk and how to handle this. The knowledge that their arrhythmia was not fatal was crucial and important in coping to their situation. A patient expressed it like this concerning information on not going to die because of AF:

JT: “Knowing that I was not going to die because of AF was the most important information from the consultation. To be referred to the AF clinic was the best that could happen for me”

Professionalism and competence in the care of atrial fibrillation

The medical examination (ECG, echocardiography and medical history) by the HRS lasted on average 35 minutes and was described as profound. The HRS was seen as very competent and meticulous as well as the nurses in the follow-up consultations. HRS and nurses handled the consultation in a confidence-building way for most of the patients, taking their situation seriously and took sufficient time for the consultations. A patient expressed it like this:

EH: "When I left the first consultation, I had a feeling that he knew a lot about this disease. But he also listened to what it did to me. And it made a big difference. You left with a feeling of how my situation was maintained or noted or however – that's me"

And another patient says:

JH: "It was very confident to be examined by a person who was competent and did it in a meticulous way".

The patients were being seen by the HRS as well as the nurses who took the time to listen to the patients and there was no rush during consultations. Afterwards, AF recurrences with palpitations and other AF-symptoms seem to result in less concern compared to pre-consultation.

Visiting the clinic – an overwhelming experience

The medical examinations and the extensive information on AF in a complex situation during were difficult for patients to follow and to understand. At the same time, most patients were elderly and some were using a hearing aid and the physician was talking fast and for the most of the time.

After the first consultation, some patients were confused regarding AF as a condition, the AF diagnose, and the prescribed therapy.

FJ: “When I came home, my wife asked: Why do you get this medicine and why do you get this other medicine? I really can’t explain – it has something to do with my heart. [pause] My wife sees things as bigger problems whereas I [pause] well.... I do have a more relax way of handling the situation... Looking back, I would have preferred, that my wife had participated during the first consultation”

Before the second consultation asymptomatic patients expressed that they hoped AF was cured by treatment with anticoagulation and that they could stop taking these medications, given that they were in sinus rhythm again. Symptomatic patients hoped that the examination (e.g. ECG recording) would show a reduction of AF due to the treatment, even in the case when they were only treated with anticoagulation, and that they could reduce or terminate the medical treatment. Most patients did not understand the association between AF, anticoagulation and stroke and how AF was a lifelong disease. Some of them did not take the medicine as prescribed for various reasons, e.g. having discomfort linked to medicine altogether, forgetting to take the medicine several times and not redeeming the prescription.

Some patients received a brochure about treatment at the end of the first consultation – others did not. They did not read the brochures afterwards, and there was no follow up on the contents in the brochures by the nurses. During the final interview, almost none could describe in own words, what AF is and why medical treatment was prescribed as it was. They just took the medicine without knowing details about how it would affect their disease.

DISCUSSION

AF is a complex condition and its association with underlying cardiovascular comorbidities and risk factors makes the treatment a very complex process. One can imagine that it is difficult for patient to understand this process and to understand the association between AF, medical treatment and risk factors. In this study we examined the effect of a specialized outpatient AF-clinic on a large university hospital in Denmark by following a group of patients during the consultations. Our study showed that providing extensive information on AF in a complex situation made it difficult for patients to understand AF and why treatment (especially anticoagulation) was prescribed. Furthermore, our study shows how an AF clinic provides structured care in a professional and confidence-inspiring way. Communication between health care professionals and patients was dominated by medical aspects with patients having a more passive role. The most valued information for the patients was to hear, that their AF was not a fatal condition intrinsically. Nevertheless, mortality does not only relate to AF but also to underlying (cardiovascular) co-morbidities and risk factors (Kirchhof *et al.* 2016), and these issues were not discussed with the patients.

The AF service as described in this paper can be interpreted as an integrated approach to care, which facilitates guideline-adherent management for AF patients provided within a multidisciplinary team approach, with the main goal to improve outcomes. This is in line with recommendations from the recently published ESC guidelines on the management of AF stating that structured organisation of care and follow-up should be considered in all patients with AF, to improve guideline adherence but also to keep patients out of hospital and reduce mortality. Guidelines advocate for a patient-centred approach where patients

should be placed in a central role in the decision making, in order to individualize the care to patient needs and preferences and also improve adherence to long-term treatment. Before patients can take these important roles, tailored patient education is of utmost importance and recommended in all phases of AF management (Kirchhof *et al.* 2016). However in this study it was demonstrated that this was not completely the case. When patient's understanding of their condition is lacking, it is difficult for patients to understand symptoms and participate in their own care process is, as demonstrated in this study.

Furthermore, our research showed how visiting the AF-clinic was overwhelming with complicated information in a short time. Overwhelming information may increase the risk of not understanding the effect of medical treatment and reduced patient involvement in decision making about choice of anticoagulation treatment. A consequence may be that patients do not take anticoagulation as described, with potential ischaemic stroke (Berian & Livingston 2015) or brain haemorrhage (Deitelzweig *et al.* 2013, Vestergaard *et al.* 2016) as a fatal complication.

According to a report from the World Health Organisation in 2003, non-adherence is caused by e.g. social economic conditions or influenced by several factors in health care system or in patient related factors. The consequences of poor adherence are poor health outcome and increased health costs (Sabaté 2003).

During the interviews, the patients in our study expressed their concerns about taking medication altogether. A review from 2005 concludes that non-adherence is not due to failure of patients, doctors, or system but a general reluctance of patients taking medicine (Pound *et al.* 2005).

The recent ESC guidelines on the management of AF recommend patient involvement in decision making about medical treatment since it has a positive effect on adherence (Kirchhof *et al.* 2016). It is crucial that patient involvement requires patient education as well as attention to interpersonal aspects in the consultation situation (White *et al.* 2013). Active patient involvement relates to how patients are able to prepare before decision-making, how they receive information during consultation which can improve patients' understanding of their own situation and how they are able to follow up consultations with health care professionals (Siouta *et al.* 2015). In our study, patients were not so much involved in their care. Active involvement requires health care professionals that invite patients for active participation. Most patients in our study did not ask for further information at the end of consultations, even though they were invited and even though they did not understand the link between AF, stroke, and anticoagulation. They took the medicine as prescribed and did not want to be involved in decision-making about treatment. As shown by Borg Xuereb *et al.* (Borg Xuereb *et al.* 2012), some patients want to be an active part of treatment decision-making, while others are satisfied to leave it to the expertise of the health care professionals. Health care professionals as well as patients need to become more comfortable and confident with decision-making, including medical evidence (objective) as well as life context for patients (social and subjective world) to ensure the best treatment decisions (Kirchhof *et al.* 2016, Martin *et al.* 2005). A Swedish study shows that patients need a sense of trust in the care they received as well as feeling secure by patient-centred communication in terms of a patient involving approach during consultations (Siouta *et al.* 2015). Patient-

centred care empowers patients and respect patient values, preferences and needs (Kirchhof *et al.* 2016). In some way, this is opposite the tendency over the last decades with more task-oriented consultations, where patients talk less, while health care professionals provide medical information (Butalid *et al.* 2014). The same tendency was present in our study. Consultations were handled in a professional way by the HRS and the nurses following a medical and disease approach in the communication between them and the patients. Patients were more or less silent and did not talk about their thoughts of AF and their fear of dying before the first consultation. A Dutch study shows, how nurses performed outpatient consultation based on a conventional medical model of medical history taking. The authors conclude that it is not beneficial for self-management support, when little attention is paid on patients' perspective on their illness (Ter Maten-Speksnijder *et al.* 2016). According to Kleinman *et al.* (Kleinman *et al.* 2006), there is an important distinction between disease and illness. Disease focuses on malfunction biological processes in patients whereas illness focuses on personal reaction to the disease. There needs to be more attention on the patient's perspective of his or her situation as an illness, using questions such as: "What do you think sickness does to you?" or "What do you think caused your problem?" In that way, clinicians show concerns about, how patients react to sickness and how it affects patients daily life (Kleinman *et al.* 2006).

Furthermore, of the organisational level integrated care with a patient-centred view (Kodner & Spreeuwenberg 2002) and an interdisciplinary approach (Körner 2010) supports nurses and HRS working closely together and form an AF treatment team. Consequently, patients are educated and involved in their care

process and form an active partner in shared decision- making on treatment, care and lifestyle aspects of AF (Hendriks & Strömberg 2015).

In our study, patients with asymptomatic AF detected by a coincidence by their GP were very surprised at having AF. Asymptomatic patients seemed to have difficulties accepting AF as a chronic disease and hoped treatment would cure AF. The GP is important in detecting AF, and the ECS guidelines (Kirchhof *et al.* 2016) demonstrate the importance of screening in older populations using either pulse palpation or short-term ECG to detect undiagnosed or silent AF (Kirchhof *et al.* 2016). Patient education is recommended in all phases of AF management to support patients' perception of AF and to improve management (Kirchhof *et al.* 2016). As a consequence, patients should be informed about AF and how medical examination takes place at the AF outpatient clinic before the first consultation, as well as tailored follow-up education during AF management should be initiated. Patients with mild AF-symptoms pre-consultation, tried to explain their symptoms as a consequence of age or physical deconditioning. Thereby, they did not consult their GP or considered that they had a heart disease. Previous research indicates that symptoms can be misinterpreted by patients, and by healthcare providers who dismissed symptoms as insignificant and thereby delayed diagnose and medical treatment. Instead, patients make self-care strategies such as rest, or avoiding particular activities to manage symptoms (January *et al.* 2014).

Patients with severe symptoms were afraid of dying during attacks and described the importance of being told by health care professionals that they were not going to die from AF. They explained that later recurrences of AF-symptoms resulted in less concern. As reported by McCabe *et al.* it is important for patients to find

meaning of symptoms which are close associated to diagnosis verification and initiate AF-treatment, and by that give relief to those who had been seeking an explanation for symptoms and validation that they were not “crazy” (McCabe *et al.* 2011) or as stated in our study ‘not going to die’.

Study limitations and strengths

First, this is a single centre study, and the number of health professionals involved was small. It would be of value to investigate several outpatient clinics for patients with AF that follow such structured approach and involve a larger group of consulting health professionals.

Second, fieldwork with the presence of a researcher during consultations may in some way have influenced the behaviour of health care professionals as well as patients, and consequently may have affected how patients experienced the consultations. At the same time, the researchers’ presence yielded valuable incremental information and insights over only interviewing patients. Furthermore, being present as researcher during consultations qualified the interviews, since the researcher could refer to the actual situations from the consultations and ask patients to reflect on them.

Finally, only a small number of patients were involved in the study and a larger group of informants could probably have stronger supported transferability to other settings. However the strength of this study was that all patients were referred from a GP to the outpatient clinic with newly diagnosed AF, but without a final AF-diagnosis made by the GP before first AF-clinic consultation.

CONCLUSION

This study indicates how patients were uncertain on AF before as well as after consultation even though consultations were performed in a professional and confidential way. The communication was concentrated on the medical aspects of atrial fibrillation and visiting the clinic was an overwhelming experience. Patients had difficulty understanding why they were treated with anticoagulation, and that it was a lifelong treatment.

RELEVANCE TO CLINICAL PRACTICE

This study demonstrates some lack of patient-centred care and an absence of tailored patient AF-related education within the specialized AF-clinic. Patients were referred from the GP without preparing the patients to the AF-clinic and the professionals were not aware of these circumstances. The study highlights the actual need and importance of active patient involvement in consultations decision-making by taking into consideration patients' values and beliefs as well as knowledge about AF as a starting point.

There is a need of more knowledge of how consultations in other AF-clinic settings are performed, how consultation affects patients handling AF and how AF affects health related quality of life over time.

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Summary box

What does this paper contribute to the wider global clinical community?

- This study **included** patients newly diagnosed with atrial fibrillation referred from general practitioner to an outpatient AF-clinic. **The results significant some lack of patient-centred care and an absent of tailored patient AF-related education.**
- There is a need of more active patient involvement in shared decision making taking patient beliefs and knowledge in consideration
- In the content of changes in global health care services more information on how outpatient clinic is managed is required.

Table 1 Characteristics of the participants

Pseudo initials	Sex	Age	Consultations number, clinicians Nurses: pseudo initials	Symptoms	Numbers of consultations in all
HN	Female	66	1. HRS*	Intermittent. Only few symptoms	2
			2. Nurse C)		
EH	Male	74	1. HRS	Permanent. No symptoms	2
			2. Nurse L)		
AH	Female	71	1. HRS	Intermittent. Periodic palpitation	2
			2. Nurse C)		
FJ	Male	59	1. HRS	Persistent. Periodic palpitation, Dyspnoea	3
			2. Nurse L)		
			3. Nurse L)		
JT	Male	63	1. HRS	Permanent. Few periods with dyspnoea	3
			2. Nurse C)		
			3. Nurse L)		
AD	Female	77	1. HRS	Permanent. No symptoms	2
			2. Nurse C)		
IC	Female	67	1. HRS	Permanent. Fatigue	2
			2. Nurse C)		
NH	Male	67	1. HRS	Permanent. No symptoms	3
			2. Nurse C)		
			3. Nurse L)		
JP	Female	70	1. HRS	Permanent. dyspnoea, some Palpitation	4
			2. Nurse L)		
			3. Nurse C)		
			4. Nurse C)		
KL	Male	79	1. HRS	Permanent. Periods with palpitation	5
			2. Nurse L)		
			3. Nurse C)		
			4. Nurse L)		
			5. Nurse C)		
JH	Male	40	1. HRS,	Intermittent. Dyspnoea, palpitation	3
			2. Nurse C)		
			3. Nurse C)		
MC	Female	82	1. HRS	Permanent. dyspnoea, fatigue	5
			2. Nurse C)		
			3. Nurse C)		
			4. Nurse L)		
			5. Nurse L)		
IL	Female	70	1. HRS	Intermittent. Few periods with palpitation	3
			2. Nurse C)		
			3. Nurse L)		
JA	Male	71	1. HRS	Intermittent. Palpitation, fatigue	3
			2. Nurse C)		
			3. Nurse C)		

* HRS= Heart Rhythm Specialist

Table 2 Units of meaning, units of significance and main theme: *"Visiting the clinic – an overwhelming experience"*

Units of meaning (What the text is saying)	Units of significance (What the text speaks about)	Subthemes
HN: <i>"After the first consultation we did not know much more about the name of the game. No, I do not think so. I did a google search afterwards and know where I can find more."</i> After consultation: NH: <i>"I need to go to my general practitioner and hope, that he can explain my what kind of disease I have and what is going to happen."</i>	Difficult to understand information	- information during consultation
JA: <i>"No – I cannot tell you what atrial fibrillation is and why I am medical treated as I am. (Pause) I really do not understand what kind of disease I have. But I do take the medicine as prescribed"</i>	Difficult to describe AF and treatment	- knowledge after consultations are ended

Table 3 Results Themes and subthemes

Themes	Subthemes
Uncertainty about the atrial fibrillation before first consultation	Pre-consultation knowledge
Focus on the medical aspects of atrial fibrillation	Beginning consultation with medical examination Not knowing what to ask for
Atrial fibrillation is no fatal disease	Metaphors Fear of dying Crucial information
Professionalism and competence in the care of atrial fibrillation	Confidence inspiring way Taking time
Visiting the clinic – an overwhelming experience	Precondition before consultation Information during consultation Knowledge after consultations ended