The Patient Path to a diagnosis of Atrial Fibrillation: a qualitative study in primary care

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Method Article

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Abstract

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Background

Atrial Fibrillation (AF) is a common heart rhythm disorder. AF leads to a five-fold increase in the risk of stroke and double the risk of death. These risks can be reduced by anticoagulation therapy. However, AF can be difficult to detect because it is often intermittent and not always symptomatic, and where symptoms are present, they can be non-specific. Currently at least one-third of people with AF remain undiagnosed; this equates to an estimated 500,000 people in the UK.

Aim

The study aims to explore the patient path to a diagnosis of AF and develop recommendations to improve the detection of AF.

Methods

This is a qualitative study set in GP practices in the West Midlands. Approximately 30 semi-structured interviews will be conducted with patients with AF, within 6 months of diagnosis, to explore their journey to diagnosis. Up to 20 interviews will be conducted with GPs and practice nurses to explore their experiences of the presentations of AF.

A workshop will be held with relevant stakeholders, including patients, to interpret the data and identify key messages to improve recognition of AF. These will be used to develop educational resources for healthcare professionals and the public.

Evaluation

The interviews will be analysed using framework analysis. Andersen's model of Total Patient Delay will be applied to understand the trajectory to a diagnosis of AF.

Conclusions

Recommendations to improve the detection of AF will be made, drawing on the identified patient pathways.

Introduction

Background
Atrial Fibrillation (AF) is the most common clinically significant arrhythmia in the adult population worldwide. AF affects 1-2% of the global population, and people aged 40 and above have a 25% lifetime risk of developing AF[1]. Prevalence of AF increases steeply with age; in the UK prevalence increases from 7.2% in those aged 65 and over to 10.3% in those aged 75 and over[2].

AF leads to a fivefold increase in risk of stroke and double the risk of death compared with patients without AF[3]. AF-related strokes constitute about 20% of strokes, with 12,500 strokes per years in England directly attributable to AF[4]. Strokes suffered by people with AF are typically more severe, frequently more fatal, and more likely to lead to long term disability, and increased healthcare costs[5]. Anticoagulation therapy has been shown to dramatically reduce the risk of AF-related stroke and death, with a 68% relative risk reduction for stroke and 25% reduction in the relative mortality[6].

AF is largely undiagnosed; over 1.5 million people are currently diagnosed with AF in the UK[7], and at least one-third of all AF patients remain undiagnosed[8]. In up to 50% of AF-related strokes, stroke is the first manifestation of AF[9].

The irregularity of heart rhythm can be detected by palpation of the pulse. The current NICE guidelines recommend a manual pulse palpation to assess the presence of an irregular pulse if AF is suspected, listing patients presenting with breathlessness, palpitations, syncope or dizziness, chest discomfort and stroke or TIA[10]. The guidelines further recommend an ECG to make a diagnosis of AF if an regular pulse is detected in people with suspected AF with or without symptoms, with additional ambulatory ECG to detect AF in people with suspected paroxysmal AF[10]. Nevertheless, detection and diagnosis of AF can be challenging in practice because AF is frequently intermittent and an irregular pulse or irregular rhythm on ECG may not be present at the time of testing, and there is no clear indication for a suspicion of paroxysmal AF.

Although AF is thought to be largely asymptomatic[11], it is known that patients who undergo cardioversion do feel better[12], suggesting that it is more symptomatic than is realised. Recent research found 90% of male patients and 95% female patients experienced symptoms, including classic symptoms such as dyspnoea, fatigue, palpitations, as well as atypical symptoms such as dizziness, anxiety and chest pain[13]. The most common symptom is thought to be palpitations or a feeling of the heart racing, however it is now known that patients with AF experience a broad spectrum of symptoms with a moderate proportion experiencing only atypical symptoms such as light-headedness and decreased exercise tolerance[14]. Detection of symptomatic AF is therefore complex and patients who experience and report symptoms are not diagnosed immediately. One survey reported that on average patients experience a delay of 2.6 years between onset of symptoms and diagnosis of AF[15]. These delays are due to both patient and clinician factors and largely attributed to the unspecific nature of symptoms experienced[15], and the initial diagnosis depends on associating symptoms with AF rather than existing co-morbid conditions. Another survey found patients delayed treatment seeking due to lack of severity of symptoms[16].
Undiagnosed AF is a major health problem as it leaves patients at risk of serious preventable sequelae, especially ischaemic stroke and death[17, 18]. There is a strong case for early detection of AF after onset - the rate of adverse events is higher early after AF onset or diagnosis, particularly during the first 4 months; the rates of all-cause mortality and stroke in patients newly diagnosed with AF in the global GARFIELD-AF registry were significantly higher during the first 4 months of follow-up (mortality +29%; stroke +35%) compared with 2 year event rates of 3.83 (3.62; 4.05), 1.25 (1.13; 1.38) per 100 person-years, respectively[19]. Further data indicates that the rates of death and AF-related stroke were significantly higher during the first month than in subsequent periods of follow-up at 2 to 4, 5 to 8, and 9 to 12 months[20].

It is estimated that 12,500 strokes per year in England are directly attributable to AF. Each stroke costs the NHS between £13,452 in the first year after the event and £17,963 after five years[21]. Improving the pathway to diagnosis of AF will allow timely intervention to improve mortality and reduce the risk of stroke.

There are two broad ways that AF may be detected: patient based and health facility based. The patient based methods are:

(i) Patients may present to a healthcare professional following experience of symptoms and recognising that the symptoms require medical attention.

(ii) Patients may detect their AF through technology. This includes the use of a home blood pressure monitor that picks up arrhythmias such as the WatchBP Home-S blood pressure monitor, or modern wearable technologies such as Apple Watch or the ALiveCor Karia ECG monitor which offers a smartphone-based ECG recording for the detection of AF.

(iii) Patients may detect their AF through checking their pulse. ‘Know your pulse’ is a public education campaign promoted by the AF Association which educates the public how to do a 30 second pulse check to detect an irregular pulse.

The health facility methods include:

(i) Detected in the healthcare setting through opportunistic screening via pulse palpation.

(ii) Incidental detection during ECG for other purposes

(iii) Post-op during routine monitoring

In order to improve the detection of AF we need to understand the pathways to diagnosis.
This proposed research seeks to address the patient identification gap in AF through generation of knowledge to improve awareness of the presentations of AF in the public and among health professionals, and to make recommendations to improve the detection of AF.

Theoretical framework

The theoretical framework guiding the process of enquiry is the concept of illness behaviour. Mechanic defined patient illness behaviour as ‘the way in which given symptoms may be differently perceived, evaluated and acted upon- or not acted upon- by different kinds of people’[22]. This includes earlier experiences of illness and differential interpretation of symptoms[22]. The impact of learned behaviour in dealing with symptoms, in terms of what symptoms an individual recognises as important and what they neglect or tend to neglect, largely conditions when and for what reasons they might present for medical diagnosis. This has been demonstrated in cancer studies, and improved public awareness of particular cancers is associated with significant increases in detection and subsequently resulting in timely medical intervention, improved prognosis and survival[23, 24]

Andersen’s model of Total Patient Delay[25] will be applied as a guide to understand the trajectory to a diagnosis of AF. Andersen’s model of Total Patient Delay provides detailed stages of a patient’s pre-diagnostic pathway from awareness of a symptom to diagnosis and treatment and can be applied to a variety of disorders. It comprises of ‘appraisal delay’, which is the delay between detecting a symptom and inferring illness, this includes misattributing symptoms to pre-existing conditions, illness delay, the time between a person recognizes that they require medical care, and behavioural delay, the time between a person deciding an illness requires medical care and deciding to act on this decision. We will assess the stage between first representation to a healthcare professional and diagnosis of AF.

We have drawn on these concepts in developing the topic guides to explore and unpack the patient factors relating to detection of AF and identify any clinician and systemic barriers to detection of AF. These concepts will also be used as a framework for data analysis and interpretation.

Aims and objectives

The aim of the study is to explore the patient path to a diagnosis of AF and develop recommendations to improve the detection of AF

Objectives

1. To explore the experiences and perceptions of patients of the trajectory to a diagnosis of AF
2. To explore the knowledge and experiences of primary care health professionals on detection of AF
3. To hold a workshop with stakeholders to identify key messages to improve awareness and recognition of AF from study findings

4. To develop, in collaboration with PPI educational resources aimed at the public and health professionals from findings

Reagents

Equipment

Procedure

1. Interviews with patients

Semi structured interviews will be carried out with patients recently diagnosed with AF, using the narrative method of inquiry to explore the journey to diagnosis from symptoms first manifesting to receiving a diagnosis of AF. We will limit the time from diagnosis to 6 months or less to improve recall. We will include patients aged above 50 years as prevalence below 50 is very low and it is often atypical [25]. The patient journey is a description of how patients experience AF from the first awareness of symptoms through to diagnosis

The interviews with patients (n=30) will explore their perceptions of any pre-diagnostic symptoms they experienced, and their evaluation of and response to these [22] and any events leading up to AF diagnosis. A topic guide developed by the research team with input from PPI contributors will be used to guide the interviews. Participants will initially be asked an open-ended question to retell their experience and sequence of events as it happened. After the narration comes to a natural end, there will be a questioning phase where the researcher will attempt to fill any gaps in the story.

Interviews will be conducted either face-to-face or virtually by zoom or Microsoft Teams. Face-to-face option, interviews will be conducted in the patients home, or at the GP practice if they prefer. All participants will provide informed consent before interview and interviews will be audio recorded with permission of the patient. The study researcher will take notes for patients who do not wish for their interview to be audio recorded. Patients will receive a £30 voucher in thanks for their participation.

Inclusion criteria

· Men and women aged 50 years and above

· With a diagnosis of AF within the last 6 months

· Ability to understand the information provided in the participant information sheet and consent form
Ability to provide informed consent

Exclusion criteria

- Patients that the GP determines are not suitable to be approached to participate e.g. patients receiving end of life care
- People aged below 50 years
- People who lack capacity to consent

Recruitment process

A diverse sample of up to 20 GP practices in the West Midlands will be recruited to include different practice types according to list size (small <6000 to large >12000), deprivation index, rural/urban location and practice type (group practice etc.). Research nurses from the West Midlands Clinical Research Network will undertake a search of the electronic records of participating GP practices to identify patients meeting the inclusion criteria. A GP at the participating sites will then screen the list to ensure patients are eligible and suitable to be approached. The Practices will send eligible patients an invitation to participate in the study, including a participant information sheet detailing the purpose of the research and what participation would entail, together with a response slip indicating willingness to participate to be returned to the research team in a pre-paid envelope. The participant information sheet will include contact telephone number of a member of the research team for potential participants get in touch if they have any questions. The research team will then contact the patients who have returned the response slip and arrange a mutually convenient time for interview.

2. Interviews with primary healthcare professionals

General practice is well placed to detect AF as it is the first point of contact with healthcare services, with individuals presenting with a range of unspecific symptoms. It is also the main setting where AF is detected and currently 60% of AF is diagnosed in primary care, diagnosis in other care settings is often incidental.

Interviews will be conducted with GPs and practice nurses to explore knowledge and experiences of AF presentations and their views on the complexities of detecting AF in primary care. A semi-structured interview topic guide will be developed within the context of the literature, preliminary findings from the patient interviews, and discussion within the study team with PPI input. The principle of data saturation will be adhered to, however we anticipate up to 20 interviews with healthcare professionals. Interviews
with healthcare professionals will be conducted remotely by University of Birmingham Zoom or Microsoft Teams platform.

Topics to be explored in the interviews include:

· Knowledge of how AF may present
· Experiences of detecting AF and strategies used in detecting AF
· Perceptions of patients’ awareness of AF and symptoms
· Views on any barriers and facilitators of detecting AF in primary care
· Exploring what measures could be taken to promote earlier detection of AF
· Exploring the best way of communicating findings to primary healthcare professionals

Inclusion criteria

· General practitioners
· Practice nurses
· Ability to provide informed consent

Recruitment process

Primary healthcare professionals (to include gender and years of experience, GPs and practice nurses) will be invited from the participating practices through emails from the practice managers as well as more widely from our contacts with the CCG’s primary care team through E-bulletins and newsletters. Primary care professionals who express interest will be given a participant information sheet detailing the rationale for the study and what participation would entail with a response slip with their details to be returned to the research team if they are willing to participate in an interview.

3. Stakeholder workshop

A workshop will be held with relevant stakeholders to interpret the data and identify key messages to empower the public to improve the detection of AF, as well as key messages for primary healthcare professionals. It will also unpack learnings to impact day-to-day practice in primary care to improve detection of AF, and strategies for addressing any identified barriers to detection and diagnosis of AF.
This may include barriers due to gaps in knowledge, gaps in skills, or practices or broader systemic barriers.

In particular, the objectives of the workshop will be:

• Consensus on range of symptoms and early signs experienced by patients

• Factors affecting decision-making on seeking medical help

• Mapping out patient paths to diagnosis

• Key theme for public educational campaign

• Consensus on key lessons for healthcare professionals

• Identify strategies for addressing any identified barriers to detection and diagnosis of AF

The meeting will adopt a combination of modified nominal group technique and open discussions to reach the above objectives. The nominal group technique is a structured variation of a small group discussion to reach consensus, and gathers information by asking individuals to respond to questions posed by a moderator, and then asking participants to prioritize the ideas or suggestions of all group members. The process prevents the domination of the discussion by a single person, encourages all group members to participate, and results in a set of prioritized solutions or recommendations that represent the group’s preferences.

12 - 15 stakeholders will be carefully selected to include:

• Three patients and a member of the public (aiming for some diversity in age, sex and ethnicity)

• GPs and a cardiologist with expertise in AF

• General Practice nurses

• A representative from the Coventry and Warwickshire CCG

• Representatives from relevant charities such as AF Association, the Stroke Association, British Heart Foundation, and Age UK

4. Development of resources

The learning identified in the stakeholder meeting will be used to develop educational resources for the public and for healthcare professionals. Resources for the public will include a lay summary of the study findings, a leaflet in a question and answer format aimed at helping the public understand AF, highlighting common symptoms as well as other possible symptoms and early signs, and with vignettes
of how patients came to recognise or interpret symptoms, and a one-page poster highlighting symptoms and early signs.

5. Data analysis

The qualitative data will be analysed using framework analysis[27]. All interviews will be transcribed verbatim. Two researchers will read three interviews from each category to identify emerging themes and together develop a thematic framework for coding the interviews. All interviews will then be coded according to the thematic framework, aided by Nvivo software. Interpretation will be by discussion and consensus between the study team including the PPI panel who will give additional insight.

Data analysis will be iterative, occurring as data collection progresses. Investigations will include the stages to diagnosis guided by Anderson's model, the impact of co-morbidities on interpretation of symptoms and time to presentation to health professional, as well as the pathways of asymptomatic patients. The experiences of each scenario will be fully described and barriers and facilitators to early detection identified. The pathway to diagnosis and symptoms will also be explored by gender.

The patient and healthcare professional interviews will be first be analysed separately, then triangulated to identify areas of convergence and divergence and identify areas of disconnect between patients and healthcare professionals that needs to be addressed, for example inconsistencies between lay symptom definitions and medical definitions.

Troubleshooting

Time Taken

This will be a 15 month study.

Month 1 to 3: Study set up

Month 4-12: Data collection and data analysis

Month 13-15: Dissemination

References


8. NICE *Nice Clinical Guideline 180; Atrial Fibrillation: the management of atrial fibrillation*.


