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TITLE PAGE

Title: What help do men in Abdominal Aortic Aneurysm surveillance want to manage anxiety? A qualitative interview study

Running short title: Interventions to manage abdominal aortic aneurysm-related anxiety

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1 **What this paper adds**

2 Existing evidence has focused on whether men in AAA surveillance experience psychosocial
3 consequences of screening such as AAA-related anxiety. This study explores men's views of what
4 interventions might help them to manage AAA-related anxiety. Having interviewed men who
5 reported AAA-related anxiety in a survey, we found that many did not consider themselves to be
6 anxious but did have numerous uncertainties about AAA. Their preferences for intervention included
7 personalised information about how to prevent AAA growth and rupture, and health professional
8 contact as well as written information. Addressing this need may help maximise benefits of AAA
9 screening.

10

Abstract

Objective: To explore the views of men in surveillance for abdominal aortic aneurysms (AAA) about how to help them manage AAA-related anxiety.

Design: A qualitative interview study

Methods: Interviews with 22 men in the NHS AAA surveillance programme in England with self-reported AAA-related anxiety, and two family members.

Results: Some men in the interviews described ongoing AAA-related anxiety, but most reported stoicism, accepting that they had AAA and finding surveillance reassuring. Some men described themselves as ‘thinking about’ the AAA rather than being worried or anxious. They described diagnosis as a time of significant anxiety, and ongoing uncertainty about multiple aspects of having AAA. They wanted information about these areas of uncertainty, particularly seeking personalised information about what they should do or not do to prevent rupture. They wanted information provided by a health professional as well as written information, so it could be tailored to their situation. One area of uncertainty was future treatment, and men welcomed the opportunity to interact with those who had experienced AAA repair. Their preferences for intervention were information-based rather than talking-therapy-based.

Conclusion: Men in AAA surveillance expressed the need for more information to address their uncertainties rather than therapeutic anxiety management options such as cognitive behavioural therapy.

Key words: Abdominal Aortic Aneurysm, Anxiety, Mass Screening, Disease Surveillance, Qualitative Research

Background

There is concern that screening programmes may cause psychological harm and detrimentally affect health-related quality of life when aiming to improve health-related quality of life. In some countries, people are screened for Abdominal Aortic Aneurysms (AAA) and enter surveillance where they are monitored prior to referral for treatment. Sweden and the United Kingdom have national screening programmes for men with AAA.

The evidence about whether AAA screening causes psychological harm is mixed. A recent systematic review, which included studies using generic quality of life measures, concluded that current evidence did not support a negative impact on quality of life¹. Yet qualitative research identified that men suffer anxiety even though they are pleased to be in surveillance.² The partners of those screened have also expressed concerns about the threat of AAA rupture.³ Recent quantitative studies of psychological harm, using AAA-specific measures of quality of life, identified that a minority of those in surveillance suffer significant amounts of AAA-related anxiety in Sweden,⁴ the Netherlands,⁵ and England.⁶ Men with larger AAA were more likely to report being anxious most or all of the time.⁶

Researchers suggest there is a need for improved patient information aimed at managing anxiety, and access to care providers, for people with screening-detected AAA.^{1,4,6} In England, a survey of staff providing AAA screening found they were supportive of interventions to address men's anxiety and suggested that support groups and improved provision of information might help.⁷ Surveys can measure the proportion and type of men who are anxious.⁶ Qualitative research can explore men's views of issues important to them. It is important to understand what interventions - if any - men want. We undertook a qualitative interview study to explore the views of men in AAA surveillance.

Methods

Setting

England in the United Kingdom has a screening programme where men are screened aged 65, entering surveillance if found to have AAA. Screening and surveillance is delivered by 38 regional screening providers. In 2023/24 there were approximately 15,300 men in surveillance in England.⁸

Design

We undertook a qualitative interview study with men in AAA surveillance, and their family members, as part of a wider study exploring the psychosocial consequences of AAA screening (www.sheffield.ac.uk/scharr/research/centres/hcru/pcaaas).⁹

Sampling

We sampled men in AAA surveillance who had completed a survey of the psychological consequences of AAA in our wider study⁶ and who had agreed to participate in further parts of our study. We invited men who reported some level of AAA-related anxiety on the e-PAQ-AAA quality of life measure.¹⁰ We selected men for maximum diversity in terms of age, levels of social deprivation, ethnicity, and different sizes and growth rates of AAA. After men had participated in an interview, we asked for permission to contact a family member.

Data collection

We aimed to interview 20-24 men and 12-20 family members. This sample size offered the opportunity to increase sample diversity, although evidence suggests data saturation was likely, in this relatively homogenous population, with a smaller sample of 9-17 interviews.¹¹ Aiming for larger samples offered the opportunity to increase diversity within the sample. We offered the option of virtual, telephone or in-person interviews. The interviewer (EL) was an experienced qualitative researcher with a nursing qualification who had previously undertaken research about AAA. We undertook 24 interviews between February and July 2024. Most interviews took place by telephone

(n=21), one was online, and two were in-person. Interviews with family members were conducted separately from the man. Interviews lasted between 20 and 50 minutes, 35 minutes on average. We asked men about their experiences of being diagnosed with AAA, what - if anything - caused them worry or anxiety, if there was a trajectory of worry over time, what they thought about options to help with any worry such as counselling, support groups, extra information (see supplementary file 1 for the topic guide). We took informed consent. All interviews were audio-recorded and transcribed verbatim.

Patient and public involvement

Five men who had experienced AAA screening reviewed all documents used to invite men, offered advice about recruitment, and gave feedback about the findings.

Ethics

We obtained ethics approval from the WalesRec6 Ethics Committee IRAS project ID 321528.

Analysis

We used the framework approach for analysis given there were specific questions to explore (see earlier for the range of questions asked)¹². BF read each transcript for familiarisation, and co-developed a coding framework with EL. BF coded the data in NVivo, identifying themes and connections between them. The team discussed themes. Quotes from participants are used to illustrate findings, labelled P1 to P22 for men and F1 and F2 for family members.

Results

The participants

We interviewed 24 people: 22 men in surveillance and two family members (both wives). To recruit these people, we invited 128 men for interview. We started by selecting men with the highest scores on the anxiety scale on e-PAQ-AAA in the survey we had undertaken in our wider study.⁶ We then

1 approached men with lower scores because many men with higher scores did not respond to our
2 invitation. Four family members replied saying that the man had died or was too ill to participate. For
3 family member interviews, men often did not want to put forward anyone for interview. Those that
4 did, offered their partner. Partners did not always want to be interviewed because they felt that they
5 knew little about the man's experience of AAA surveillance. We contacted six family member
6 spouses but only two responded.

7 We included men of different ages, social deprivation levels, AAA size and AAA growth rate (Table 1).
8 We failed to recruit men from ethnic minority groups because they made up only 2% of the survey
9 responders.⁶ Men could score between 0 and 16 on the e-PAQ-AAA anxiety scale. Five men in the
10 sample had a high score (9-15), four had a medium score (6-8), and 13 had a low score (3-5).

11 **[Table 1, placed after references, as per author guidance]**

12

13 Overview of themes

14 We identified four themes. Men described a sense of stoicism - in terms of accepting their AAA
15 diagnosis – rather than describing anxiety or worry about AAA. They identified multiple areas of
16 uncertainty related to AAA. They expressed a need for trustworthy personalised information to
17 address their uncertainties. They preferred information-based interventions to therapeutic
18 interventions like cognitive behavioural therapy.

19

20 A sense of stoicism, acceptance and 'thinking about it'

21 Most men interviewed did not describe themselves as anxious or worried. Some described how
22 having an AAA limited specific physical activities such as carrying heavy shopping bags. Men and
23 family members identified three time points that raised anxiety levels. First, some men described
24 feeling worried when initially diagnosed with AAA; 17 men talked about the shock, worry and concern
25 they had felt at this time. However, they felt that these feelings reduced over time as they gained

1 reassurance about the AAA growth from surveillance. Second, when preparing to attend a scan; 13
2 men and a family member described how they worried if the AAA had grown, but that this worry
3 dissipated once the results were known. Third, the move from annual to three monthly surveillance,
4 when their AAA reached a specific size, although again men described how this worry tended to
5 dissipate over time.

6 Descriptions of stoicism and acceptance were much more common than descriptions of anxiety in
7 this sample. Men described how they felt there was little to be done about their situation, how it
8 was important to accept it and get on with life. Some also described comorbidities as a more
9 immediate concern, compared to their AAA, because this impacted on daily life more e.g. heart
10 disease. This acceptance appeared partly enabled by the reassurance men obtained from being in
11 AAA surveillance.

12 *“The thing is [...] I’m not one of these people who worry about it [...] Whatever happens,*
13 *happens now, so it doesn’t bother me.” (P5, medium AAA)*

14 Half of the men interviewed had reported low levels of anxiety on the survey but the other half had
15 reported medium or high levels of anxiety. Two of the five men who had reported high levels of
16 anxiety on the survey also reported high levels of anxiety in their interviews. They had unusual
17 circumstances, around being given discrepant measurements outside the screening programme, and
18 having a significant family history of death from AAA. Surprisingly, three of the five men who scored
19 highly on the survey for anxiety described themselves as not anxious about AAA within the
20 interview. One of these men described how he ‘thought about’ the AAA but that he did not consider
21 himself anxious:

22 *“I hesitated quite a bit when I used the word anxious before because it’s, I don’t get anxious.*
23 *[...] To me it’s just thinking about it. [...] I certainly don’t get into a state where I need*
24 *anything, counselling or that sort.” (P7, medium AAA)*

1 The words 'anxiety' and 'worry' did not appear to offer an accurate description of interviewees'
2 feelings. Instead, men and family members described feeling an increased sense of their own
3 mortality, having a heightened perception of risk when they considered or carried out physical
4 activities, or used terms such as 'crossed my mind' 'back of my mind' and 'think about it'. One man
5 perceived that his wife felt this as much, or if not more, than him.

6 Multiple areas of uncertainty

7 While men mostly described not being anxious, they did raise four areas of uncertainty around AAA.
8 First, they wanted to know more about things they should and should not do to prevent rupture.
9 Interviewees (nine men, one family member) said they would like to know more about what they
10 could or could not do in daily life. Men who discussed this were unsure about the types of exercise
11 or physical exertion they should avoid e.g. how much weight to lift in a gym without risking a
12 rupture. They wanted more personalised advice about these activities, based on the size of their
13 AAA and their health.

14 *"...I felt that some of [of the nurse's] answers to our questions were very generic. Like, don't*
15 *lift heavy weights. Well, what, what is a heavy weight? [...] You're left going: well, how much,*
16 *how much is safe for him to actually start lifting? (F1)*

17 Second, six men were unclear about how AAA was measured. They had been given different
18 measurements when having ultrasound scans within their AAA surveillance compared to
19 measurements when having other types of scans (CTs, MRIs) for other health conditions. This raised
20 uncertainty about the accurate size and growth rate of the AAA, and potential need for future
21 surgery. Third, some interviewees (five men, one family member) expressed uncertainties about
22 how decisions about surgery were made and different surgical options, for example advantages and
23 disadvantages of different treatment options and the role comorbidities played in decision-making
24 about surgery. Fourth, three men voiced concern about the hereditary nature of AAA, and the

1 potential for their family to have the condition. They did not know when their relatives could be
2 screened or how to facilitate this.

3 *"My mother died of one [...] I mean I know for women it's pretty rare. My main concern is my*
4 *grown-up daughter, and I've got a granddaughter."* (P19, medium AAA)

5 Sources of trustworthy personalised information needed

6 Even though most men interviewed did not describe themselves as being anxious, during interviews,
7 it was clear that they wanted more information to address their uncertainties.

8 *"...perhaps a more detailed conversation at the initial thing might have allayed any fears so*
9 *that they give more time rather than it being...yes, we've identified this, it's this size, it's*
10 *that... because at that initial stage...when it's dropped on you like that you don't really have*
11 *a chance to take that into account and work out questions."* (P12, large AAA)

12 There was a desire for more personalised information, tailored to a man's AAA size, growth rate and
13 state of health. When men reported where they obtained information, some described using
14 trustworthy websites (e.g. the NHS website). However, some described how other sources of online
15 information did not always allay anxiety, and indeed could provoke anxiety, so several men
16 suggested it was important to signpost men and their families to trustworthy information sources.
17 They described the need for written information but also a desire to obtain information from a
18 health professional who could tailor information to their context.

19 *"The sort of questions that I ask are related to what I can do or I'm going to be able to do*
20 *between being referred and the operation taking place...think I did read somewhere that*
21 *when it got to 6 you should stop driving...so that sort of information is useful...I'm the only*
22 *driver in our house, that would have quite an impact..."* (P4, medium AAA)

1 Information-based, rather than therapeutic-based, interventions

2 The idea of group education or information days was welcomed by some men (n=3), although
3 convenience of location and current co-morbidities would influence their attendance. One man
4 valued a group intervention he had attended that focused on exercise and offered opportunities to
5 speak with other men and health professionals from the surveillance service. Three other men
6 highlighted that peer support groups could potentially be helpful if they could meet those who had
7 experienced AAA repair to address information needs about future treatment.

8 *“...To go along and meet other people that have got the same thing? I wouldn’t mind doing*
9 *that. I don’t think I’d need counselling at all, at least I hope I don’t. It’s always nice to meet*
10 *people with the same thing” (P16, small AAA)*

11 As can be seen from the quote above, interviewees did not report a personal preference for
12 therapeutic anxiety management interventions such as cognitive behavioural therapy. Some
13 interviewees acknowledged that other people might find such approaches helpful. Instead, four men
14 raised how they would prefer the opportunity for some kind of contact or follow-up after a
15 surveillance appointment, for example a telephone call with the screening service between annual
16 surveillance appointments, especially when newly diagnosed or early in the surveillance process.
17 This was because they had found it difficult to process information they had been given at
18 surveillance appointments, especially if the diagnosis was a shock.

19 *“...something afterwards to say what was found because most of the time you leave the*
20 *surgery you’ve forgotten half of what’s been said. My wife worries about things as well so*
21 *you know, just a phone call every now and again would be good” (P16, small AAA)*

Discussion

Summary of findings

A minority of men in the sample expressed ongoing AAA-related anxiety despite indicating they were experiencing some anxiety in a previous survey.⁶ Instead, they reported stoicism, accepting that they had AAA and finding surveillance reassuring. The modern definition of stoicism is silence, non-admission and endurance of a problem without complaint.¹³ Researchers suggest it may be helpful to question why individuals take this stance.¹³ In our study some men described ‘thinking about the AAA’ rather than being worried or anxious, and they described ongoing uncertainty about multiple aspects of having AAA. They wanted information about these areas of uncertainty, particularly seeking personalised information about what they should do or not do to prevent rupture. They wanted information provided by a health professional as well as written information. Their expressed preferences for intervention were information-based. Their desire to discuss uncertainties with health professionals did not appear to be about wanting counselling, and indeed therapeutic talking-based interventions were seen as suitable for other men, not themselves.

Context of other research

Most of our interviewees did not think they were anxious about their AAA. This differs from other studies reporting that some people in AAA surveillance are anxious.⁴⁻⁶ This may be because men reporting high levels of anxiety in our previous survey tended not to respond to our request for an interview, or that men with lower levels of anxiety do not label their feelings using the term ‘anxiety’– or both . Many of our findings align with published research. A recent survey from The Netherlands showed that men and women were anxious if they had a family history of AAA.⁵ Other researchers have shown that people with low educational levels have poor knowledge about AAA, which they suggest leads to anxiety.¹⁴ International studies have promoted the need for men with AAA to have more personalised information, and more contact with healthcare professionals providing surveillance.^{1,4} A study that recruited more family members than our study recommended

that partners of men with AAA needed advice and information.³ Staff providing screening in the national programme in England also reported the need for men to have more information.⁷

The need for information to address uncertainty has been found in other surveillance programmes. 'Lack of certainty' is a key theme in the lived experiences of men in active surveillance for prostate cancer.¹⁵ A scoping review of interventions to address psychosocial burden in prostate cancer surveillance identified three types: information and education, social support, and lifestyle.¹⁶

Limitations

Although all the men we interviewed reported some AAA-related anxiety on a survey,⁶ most of the men scoring high anxiety levels on the survey who we approached did not respond to our request for interview. The men scoring high levels of anxiety who did not respond to our request for an interview may differ from those who did. For example, they might be more reticent to discuss their anxiety. We managed to interview some men with high levels of anxiety on the survey. They sometimes said they were not anxious, suggesting that the words 'anxiety' and 'worry' do not capture their feelings about living with AAA. It is possible that these men felt more able to disclose anxiety within the private space of a self-completion questionnaire than within a one-to-one interview.¹⁷ It is also possible that intolerance of uncertainty expressed by men in our study is an indicator of anxiety because it is associated with anxiety and other mental health conditions.¹⁸

Reflecting on our study design, future studies should consider the possibility that interviews may feel too intrusive for some men, and offer men the option of completing a 'qualitative survey' rather an interview.¹⁹ It is also possible that the telephone interviews we used yielded different information from face-to-face interviews, although studies comparing the two modes conclude they yield similar findings.^{20, 21}

We did not succeed in interviewing men from ethnic minorities communities in England so findings may not be transferable to them. In our study, part of the survey invitation was in four different languages but did not yield responses from people who preferred a language other than English.⁶ Future research could involve community workers to identify men from ethnic minority groups.²² Undertaking this research in other countries may also identify cultural differences in men's preferences and needs. Also, we did not succeed in recruiting the numbers of family members intended. This limits the transferability of the findings from family members, although the views of the two we interviewed aligned with a published study of family members.³

Implications

Men wanted written information and discussions with health professionals to address key uncertainties tailored to their individual situation. AAA surveillance services could develop information that addresses men's uncertainties, and ways of increasing contact between men and healthcare professionals within the context of limited resources. In our wider study we are working with men and family members to develop written information to address their uncertainties. The ESVS 2024 guidelines Section 11 document the latest guidelines in a format suitable for patients.²³ This can be used as the basis for any information leaflet or booklet developed to address patient uncertainty. When evaluating interventions to manage anxiety it would be important to measure AAA-related anxiety before and after the intervention using a postal or online survey rather than an interviewer administered survey. Consideration could be given to increased contact with vascular nurse specialists within the AAA screening programme. Our study may have implications for other conditions where active surveillance is used, and interventions are being sought to help anxiety management.²⁴

Conclusions

Men in AAA surveillance expressed the need for more written information and discussion with health professionals to address their uncertainties about AAA.

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1 **Table 1 Characteristics of men interviewed (n=22)⁺**

Characteristic	Categories	No. of participants
Age group	65-70	4
	71-74	7
	75-80	8
	81-84	2
Size of AAA	Small (3.0-4.4 cm)	11
	Medium (4.5-5.4 cm)	9
	Large (5.5+ cm)	1
	Not applicable (AAA repaired)	1
Surveillance frequency	Annual	12
	3 months	9
	Not applicable (AAA repaired)	1
Time in surveillance programme	Less than one year	2
	1-2 years	2
	3-4 years	5
	5-9 years	11
	10 years+	2
Self-reported growth rate	Not changing	5
	Growing slowly	14
	Growing quickly	1
	Not applicable (AAA repaired)	1
Social deprivation measured by Index of Multiple Deprivation (IMD) quintile	IMD 1=most deprived	1
	IMD 2	3
	IMD 3	8
	IMD 4	2
	IMD 5=least deprived/most affluent	8

2 ⁺ some characteristics missing for one man

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