Title: The experiences of people living with a vascular condition: a qualitative study

The design, development and commissioning of patient focused vascular services
NIHR Programme Grant work-stream 2b

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The experiences of people living with a vascular condition: a qualitative study

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## Abbreviations

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<th>Abbreviation</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>QoL</td>
<td>Quality of Life</td>
</tr>
<tr>
<td>PROMs</td>
<td>Patient Reported Outcome Measures</td>
</tr>
<tr>
<td>PAD</td>
<td>Peripheral Arterial Disease</td>
</tr>
<tr>
<td>AAA</td>
<td>Abdominal Aortic Aneurysm</td>
</tr>
<tr>
<td>CAD</td>
<td>Carotid Artery Disease</td>
</tr>
<tr>
<td>VV</td>
<td>Varicose Veins</td>
</tr>
<tr>
<td>VLU</td>
<td>Venous Leg Ulcers</td>
</tr>
<tr>
<td>NIHR</td>
<td>National Institute of Health Research</td>
</tr>
<tr>
<td>REC</td>
<td>Research Ethics Committee</td>
</tr>
<tr>
<td>PIS</td>
<td>Participant Information Sheet</td>
</tr>
</tbody>
</table>
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Figure two: Flow diagram showing interview recruitment numbers for each vascular condition.
Introduction

This study forms part of a larger NIHR Research Programme funded project to evaluate vascular services and make recommendations regarding patient focused care. This is a qualitative exploration of the signs, symptoms and impact of vascular conditions on aspects of quality of life (QoL) focusing on five vascular disease areas; peripheral arterial disease (PAD), abdominal aortic aneurysm (AAA), carotid arterial disease (CAD), varicose veins (VV) and venous leg ulcers (VLU).

Aims and objectives

Aim

The overall aim was to explore patient’s experiences of living with a vascular condition.

Objectives

- To identify the signs, symptoms and impact of each condition on quality of life
- To summarise the signs, symptoms and impact of QoL across the conditions

Methods

Semi-structured interviews were conducted with five patient groups PAD, AAA, CAD, VLU and VV. Patients attending a specialist vascular clinic were recruited through Sheffield Teaching Hospitals using purposive sampling techniques to ensure a range of participants at different stages of treatment, ages and genders. A consultant vascular surgeon or specialist nurse approached each patient either in clinic or over the telephone to explain briefly about the project and asked if they would be interested in participating in the research study. If the initial approach was by the clinician in clinic the researcher would then speak to the patient and give further
information about the project including a participant information sheet (PIS) before taking contact details. For those patients that were first contacted over the phone the clinician would then gain verbal consent to pass on their contact details to a researcher. Copies of the PIS were sent out through the mail to those who had not been initially approached in clinic. The researcher gave at least 24 hours for the patient to read through the PIS and consider the information before contacting each person by telephone to ask if they would be interested in participating in an interview. If they were interested in taking part a date and time was agreed for a researcher to visit the participant at home to carry out an interview. Qualitative interviews were conducted by three interviewers RD, JH and EL. A protocol was written including an interview schedule (see appendices). Questions were asked about the signs, symptoms, and impact of the condition on function and lifestyle. On the day of the interview the researcher checked the participant understood the PIS and took informed consent. Field notes were taken to aid interpretation of the interview data. Each interview was recorded and transcribed verbatim. Personal details were removed from the transcript to enhance participant anonymity. The interview transcripts were entered into NVIVO 10 (QSR International, Warrington, UK) for management and analysis.

Ethics

Ethics approval was sought and approved by NRES committee Yorkshire & Humber – Bradford Leeds REC Number: 14/YH/1117 on 25.09.2014. An amendment to the interview schedule was submitted and approved 18.06.2015.
Figure one: Flow diagram demonstrating the recruitment process.

Data Analysis

Framework analysis techniques were used to analyse the interviews (Ritchie & Spencer 1994). This included five linked distinct stages. 1) Familiarisation; this involved the researcher getting a “feel” for the data in terms of the range and diversity through reading of the transcripts and listening to the interviews. 2) Identifying a thematic framework; this involved creating a coding scheme for key themes within the interviews. This is then developed into an index that lists all the categories to be used in the analysis. 3) Indexing was the process of applying the thematic framework to the whole data set. 4) The creation of a framework matrix involved arranging the data according to the thematic references to compare the themes across cases. 5) Mapping and interpretation; the charts and notes are used to examine patterns within the data and associations with it.
Quality Checking

10-20% of the interviews were double coded by a second researcher in NVIVO 10. Interrater comparisons calculated using Cohens Kappa were carried out. Regular meetings were set up with an experienced qualitative researcher (AT) to review the frameworks and guide the analysis.

Results

As shown below in figure two, a total of 25 participants with PAD were approached, 18 participants with AAA, 18 participants with CAD, 32 with VV, and 18 with VLU. 14 (56%) participants with PAD, 13 (72%) participants with AAA, 9 participants (50%) with CAD, 10 (31%) participants with VV and 10 (56%) participants with VLU took part in semi-structured interviews. A further interview was conducted with a patient it was initially thought had a VLU; however this was incorrect so the interview was not included in any analysis, and participant information was not included in any further demographics.

Figure two: Flow diagram showing interview recruitment numbers for each vascular condition
Table one: Participant characteristics

<table>
<thead>
<tr>
<th></th>
<th>AAA</th>
<th>CAD</th>
<th>PAD</th>
<th>VV</th>
<th>VLU</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender n(%)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>10(77)</td>
<td>5(56)</td>
<td>11(79)</td>
<td>5(50)</td>
<td>8(80)</td>
<td>39(70)</td>
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<tr>
<td>Female</td>
<td>3</td>
<td>4</td>
<td>3</td>
<td>5</td>
<td>2</td>
<td>17</td>
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<tr>
<td><strong>Age Range (mean)</strong></td>
<td>53-87</td>
<td>52-86</td>
<td>47-82</td>
<td>35-77</td>
<td>47-84</td>
<td>35-87</td>
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<td></td>
<td></td>
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<tr>
<td>Sheffield</td>
<td>8(62)</td>
<td>8(89)</td>
<td>12(86)</td>
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<td>6(60)</td>
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</tr>
<tr>
<td>Rotherham</td>
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<td>1(11)</td>
<td>1(7)</td>
<td>1(10)</td>
<td>1(10)</td>
<td>6(11)</td>
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<tr>
<td>Barnsley</td>
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<td>3(30)</td>
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</tr>
</tbody>
</table>

Recruitment of participants for each condition continued until it was felt that thematic saturation had been achieved. The characteristics of participants are shown above in table one (page 10). The varieties of treatments received across all conditions are shown in table two. A summary of the findings and summary quotes have been reported below. The concepts of symptoms and quality of life for each condition have been mapped out as displayed in table three (page 51).
Table two: Treatment table across all conditions

<table>
<thead>
<tr>
<th>Treatment</th>
<th>PAD</th>
<th>CAD</th>
<th>AAA</th>
<th>VV</th>
<th>VLU</th>
<th>Total</th>
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<tr>
<td>Awaiting Treatment</td>
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<td>0</td>
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<td>7</td>
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<td>14</td>
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<td>Investigations/Scans</td>
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<td>0</td>
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<td>0</td>
<td>0</td>
<td>1</td>
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<tr>
<td>Managed/Monitored</td>
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<td>0</td>
<td>5</td>
<td>0</td>
<td>0</td>
<td>5</td>
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<tr>
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<td>0</td>
<td>0</td>
<td>0</td>
<td>2</td>
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<table>
<thead>
<tr>
<th>Amputation</th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
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</thead>
<tbody>
<tr>
<td>Toes</td>
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<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>3</td>
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<tr>
<td>Below Knee</td>
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<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Above Knee</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
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<th></th>
<th></th>
<th></th>
<th></th>
<th>3 total</th>
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<tbody>
<tr>
<td>Bypass</td>
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<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Triple</td>
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<td>0</td>
<td>2</td>
<td>0</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Quadruple</td>
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<td>0</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Carotid Endarterectomy</td>
<td>0</td>
<td>3</td>
<td>3</td>
<td>0</td>
<td>0</td>
<td>6</td>
</tr>
<tr>
<td>Compression</td>
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<td>0</td>
<td>0</td>
<td>5</td>
<td>4</td>
<td>9</td>
</tr>
<tr>
<td>Dressings</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>Endovenous Lasering</td>
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<td>0</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>EVAR- Endovascular Repair Surgery</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Medication</td>
<td>0</td>
<td>3</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>Revascularisation</td>
<td>5</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>5</td>
</tr>
<tr>
<td>Sclerotherapy</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Surgical Ligation/Stripping</td>
<td>0</td>
<td>0</td>
<td>3</td>
<td>1</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Venous Stent Bypass</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>

Some participants underwent more than one procedure during their treatment pathway.

**Quality Assessment**

Seven qualitative meetings were held with those conducting the qualitative analysis (AT, RD & EL); these meetings helped guide the qualitative analysis. Two researchers (RD & EL) double coded at least 10% of the interviews per condition group, demonstrating good consensus between coders.
PAD

Fourteen participants with PAD were interviewed. The mean age of participants was 69 years and ranged from 47 to 82 years of age; 79% of the sample was male. Seven participants had received revascularisation treatment; three participants were being managed through follow-up; one participant was having exploratory tests; two patients had toes amputated and one participant had received a mid-calf amputation.

A table of the coding framework used for PAD is reported in the appendices. Under the theme of signs and symptoms six domains were recorded; Pain, mobility, sleep, non-healing wounds, comorbidities and symptom progression. Under impact of PAD on QoL domains were divided under the themes of impact on physical functioning, impact on social functioning, psychological impact, financial impact and impact on lifestyle. The impact on physical functioning included the domains of personal care, hobbies, daily activities, adaptation to PAD and employment.

PAD Signs and Symptoms

Pain

Twelve of the fourteen participants interviewed reported feeling pain as a result of their condition. Only one participant reported feeling numbness but no pain. They had a co-morbidity of diabetes and the lack of sensation may have been due to peripheral neuropathy. The other participant not reporting pain had a proxy respondent who spoke for the respondent for the majority of the interview.
The sensation of the pain was described as an ache, pins and needles or cramp. “It’s all the down the back of your calf you know it’s like cramp but you can’t.” PAD03

The severity of pain was pronounced as excruciating, constant. It was so bad at times that one participant reported having to stop activities and shout with pain. “It was bringing tears to my eyes so I came back it was about a fortnight, three weeks ago, I can’t cope.” PAD20

The pain was identified as being located in the foot, calf and all the way down the leg. One participant also described having pain in their arms. “I had pains down my leg. I also had pains in my arm.” PAD21

Many of the participants reported that they felt pain on walking and that this was only relieved by rest. “I really got so that I couldn’t cope with it. I mean I was walking 10 yards and I have got to stop because it was hurting so.” PAD18

Participants also explained that the pain started whenever they walked uphill “It is much more difficult walking up hill the pain comes much sooner walking uphill.” PAD04

A minority of participants reported feeling pain even when they were at rest. “If I come out of there into here and put my legs up like this for a few minutes it goes…..” PAD09
**Mobility**

Eleven of the fourteen participants interviewed mentioned that their condition restricted their mobility; this was due to the pain experienced when walking. The pain affected the distance they could walk “phew well I can’t walk more than 150yards without having to have a rest”. PAD15

Some participants talked about having to walk more slowly, this often meant that they were left behind if walking with other people. “Sort of awful because on a Saturday I go to Hillsborough with my sister and my sister-in-law and we are shopping and my sister carries my bags mostly and I am walking and I am behind them. I am miles behind them. Now my sister-in-law I go with is in her 70’s and she is miles in front.” PAD18

**Sleep**

The majority of participants reported that PAD did not affect their sleep. Some participants cited that they were poor sleepers for other reasons. Two further participants described that the pain and discomfort of the condition did affect their sleep. “The pain level yes, I am on, I take a couple of co-codomol.” PAD13

**Non-healing wounds**

Two participants reported having wounds that that would not heal proceeding or following amputation. “They had to heal it from the bottom gradually coming up and now it is only ½cm deep.” PAD07
Co-morbidities

For six participants PAD was one of a number of chronic health problems as and they also had other co-morbidities. Four participants reported having diabetes, one participant another circulation problem and another had a spinal injury. The restrictions and impact of their PAD had a cumulative effect on their other conditions. “The thing that is disheartening is because I can’t walk I don’t get any exercise which is important anyway when I am diabetic so I need exercise to burn the sugar off.” PAD17

Symptom progression

Participants reported symptoms getting worse over time to the point where they felt intervention was necessary. This meant that, by the time they needed active treatment, PAD had a severe impact on quality of life. “So then three years ago I said no, life was ok I was walking, didn’t bother me that much and over the three year it has got worse and worse.” PAD02

Impact of PAD on Physical Function

Personal care

Two participants reported that their ability to carry out personal care was restricted by impaired physical functioning due to PAD. “I can’t do nowt. I can’t do owt. I use that to get to the toilet.” PAD11
**Hobbies**

Participants had difficulty in engaging with leisure activities because of their PAD. Seven participants said that their ability to participate in their hobbies had become restricted. This was linked to emotions as some participants reported feeling very down as a result of not being able to do the activities that they enjoy. “….at first I thought is it or am I just getting old? I am aching. Because we are very keen walkers, very keen walkers, I can’t walk anymore.”

PAD21

**Daily activities**

Twelve of the participants reported that jobs around the house were made more challenging by having PAD. Participants described difficulties shopping, cutting the grass, walking the dogs, taking grandchildren to the playground, changing bedding and pegging washing out. “I can’t get to the bank… I can’t get round the shops.”

PAD03

**Adaptation to PAD**

Some participants had adapted the way they did things because of having PAD, for example driving rather than walking long distances or taking more time over activities. Whilst this meant they could keep some physical and social activities going, the level at which they were able to participate had lessened. “Don’t get me wrong I can manage, as long as I take my time.”

PAD23
Impact of PAD on Social Functioning

**Social support**

The findings above indicate that reduced physical functioning did have an impact on social engagement. Ability to continue with and enjoy leisure activities was lessened.

In addition people were increasingly reliant on the support of others. The majority of participants talked of having someone there who would take them to hospital or take them shopping. “No I can go out like because I have got a friend of mine, a lady friend of mine who lives up there she takes me in the car for shopping, she drives me to shops.” PAD23

A couple of participants mentioned the loss of a partner; this had a significant combined impact on their psychological health. One participant felt that this affected their ability to get out and about and want to do activities. For some their partners or family members were having problems with their own health, and this was reported to have an increased psychological impact of their own condition. “Err, we used to dance. We don’t dance so much anymore because that, and also my wife has had a heart attack and you know she gets a little bit breathless so it’s cut that out a bit.” PAD02
Impact of PAD on Psychological Functioning

Health expectations
For some older participants their age meant they had lower expectations regarding physical activities. These expectations lessened the psychological impact of PAD and its physical restrictions. Five participants reported that due to age they did not expect to be able to do the activities they used to be able to do when they were younger. “…at 81 you would, we would expect these sorts of things but we don’t do the long distance walking we used to do.”

PAD04

Illness beliefs
Illness beliefs are how people think about the symptoms or illness being experienced. Some participants discussed their beliefs about what had might have caused their illness, their beliefs about the consequences of the illness, and beliefs about treatment. This was associated how people felt about the condition and their thoughts on treatment. “I have said ‘I will chop this leg off myself if they don’t do something’ and I really many, many a times think I am sure I would be better with an artificial leg but then again my sister-in-law who is nurse said ‘You know you can still feel your leg and your foot *participants name*’. She said ‘I look after patients that have had amputations and they go I can feel pain in my foot’. So I would rather have my leg and feel pain than not have my leg and feel pain.”

PAD18
**Emotions**

Five of the participants talked directly about how having PAD got them down. This direct link was often made to their loss of ability to do the activities they enjoyed or not being able to get on with household chores. “Yeah, yeah it makes you feel miserable doesn’t it? You know if someone’s in front and you can’t catch up.” PAD02

One participant talked about feeling frustrated when activities took more time. “Well I don’t know, because I have got the experience of one I know what it is and it frustrates me more than anything else. Like cutting the grass that used to take me an hour up and down, up and down.” PAD17

Only two participants thought that PAD had no effect on their mood. “No I’ve always been jovial. My father told me if you’ve got owt to say, say it.” PAD03

**Impact of PAD on Lifestyle**

Some participants reported that they had been advised to cut down on smoking, walk through the pain or change their diet. Some made lifestyle changes and others did not. “Well I tried to walk but I am not walking to make it hurt me. It is absolutely silly that.” PAD20
Implications of PAD for Work

PAD was reported to have an impact on ability to work. Whilst many of the participants had already retired, for some this had been influenced by their PAD. One participant reported having to leave work due to PAD and a second had found that it affected their ability to do some aspects of their job.

“At work, I work at *supermarket*, can’t work a shop floor job putting things on shelves. Can’t work on check out because I can’t scan but luckily my job is kiosk and I do stand in kiosk I do a nine hour shift and it never worries me”.

PAD21

Financial Impact of PAD

The financial impact of PAD was not explored in great detail in any of the interviews aside from cost of travel and the financial impact of lost or reduced employment. One participant talked of the loss of expensive fish due to his time in hospital. “There was something round about £8,000 or £9,000 worth of coi carp.” PAD07
AAA

Twelve participants with AAA were included in the analysis. The audio file for one interview was missing so could not be included. 75% of participants were male. Ages ranged from 50 to 86 years old, date of birth was missing for one participant and was unable to be retrieved. Seven participants were being managed for their AAA; three participants had endovascular repair; one participant had undergone open surgery and one was awaiting surgery.

A table of the coding framework for AAA is available to view in the appendix. The domains were divided into 6 overarching themes; signs and symptoms, impact on physical functioning, social impact, psychological impact, financial impact and lifestyle.

AAA Signs and Symptoms

No physical symptoms

Although some participants did report physical symptoms related to having an AAA, six participants reported having no physical symptoms. “No symptoms for anything.” AAA14

This meant that the news of having an aneurysm came unexpectedly; this was linked to concern over bodily symptoms detailed further under the theme of uncertainty further in this section.
**Size of the aneurysm**

Five of the participants reported the size of their AAA. One did not know the size and said they had not been given this information. The size of the aneurysm was linked to illness beliefs and feelings of anxiety detailed later under the psychological impact theme. “It was unexpected so he said ‘It’s only 2.5 which is nothing to worry about’ and he gave me a print out of everything to do with how they can burst.” AAA09

Participants who had been monitored for some time reported the changes in size of the aneurysm. This was linked to perceived risk of AAA rupture. “They just kept monitoring it, it was only small. It was ok for about a couple of months, it stopped at 1 not much but then gradually as time went on it gradually started getting bigger and I think it came to 5.4 and they said we need to say what is going to happen so they take me in for more tests and all.” AAA16

**Pain**

Participants discussed experiencing pain in their ankles, legs, stomach, back and chest. One participant talked about having pain come all the way up to their stomach. “Yes, I mean I had slight cramps before where you have had to get out of bed and you think oh no, and then the following night I got it up to my knees but then it came right up to my stomach.” AAA07
Some spoke of having an aching, tightening or pulsating sensations in their legs. Two participants described having had chest pain and thinking they were having a heart attack. “It all started with me having chest pain.” AAA13

**Mobility**

Five participants referred to reduced mobility due to the pain in their legs. This meant having to stop at short distances. “Yes and I had to keep stopping I was only going stupid distances really.” AAA07

One participant described the pain as being greater going uphill.

**Co-morbidities**

Eight participants discussed experiencing a range of co-morbidities. These included COPD, lung problems, damaged spine, hip problems, and arthritis. “I don’t smoke, I don’t drink. I can’t exercise much because I have got a damaged spine.” AAA15

**Impact of AAA on Physical Functioning**

The majority of participants did not feel the aneurysm had affected their physical functioning. However some noted changes to their daily activities, for example a reduced ability to lift heavy objects or drive.

**Daily activities**

None of the participants identified any impact on their ability to undertake daily activities such as doing the shopping, cleaning or walking the dog.
**Exercise**

One participant had been advised to stop doing press-ups as part of their exercise routine.

**Lifting heavy objects**

Two participants avoided lifting heavy objects. This did not appear to be due to pain, discomfort or physical restriction, but mainly because of the fear that this might rupture the aneurysm. “I daren’t even lift outh now you know… our baby I can’t lift her up now. I am watching myself all the time now.” AAA08

**Driving**

Two participants spoke of the difficulty of not being able to drive for the recommended six weeks post-surgery until they had got the all clear from the surgeon. “No not really because I was doing everything. The only thing that after I had had the operation what put me off a bit was that I was advised not to drive for about six weeks.” AAA13

**The Social Impact of AAA**

The participants did not report much impact on social activities related to their AAA. Some participants spoke of how their family had provided support in getting to hospital clinics and taking them to the supermarket.
Travel

Four participants related that the AAA diagnosis had impacted on their ability to travel long distances or abroad. Insurance prices to travel abroad had increased and some did not want to travel long distances from their family, or a hospital in case the AAA should rupture. “It is, that is the only way it affects me and so we have been taking holidays here. I said I would rather go into a hospital here if anything happens.” AAA09

The Psychological Impact of AAA

Worry and anxiety

Being diagnosed with an AAA did have an impact on people psychologically. Seven of the participants interviewed reported worry and anxiety due to the aneurysm being on their mind, either occasionally or constantly.

“No but no matter how brave you are it never leaves your mind and as soon as you have had it you never think about it again I know that. I shan’t think about it again once I have had it but before you have had it, it is up there all the time it never leaves you.” AAA03

For some this anxiety was severe. One participant reported being upset and tearful as a result of worry.

Health expectations

A number of participants expressed that they were not worried about having an AAA due to age expectations. For some older participants they believed that they were older and so expected their health not to be as good. “No I told
them I said I might as well get it done I say because it takes me ages because I am getting on now. I said I could walk down the street and it could burst. I said I would rather get it done”. AAA16

Younger participants expressed that they expected to be in good health and the aneurysm lead to distress. “I am only 63, I just kept bursting into tears on holiday.” AAA07

**Illness beliefs**

Illness beliefs are the thoughts that people have around an illness, for instance about whether they can control their symptoms, what they think caused their illness and what the consequences of their illness are for their QoL. Some participants with an AAA expressed that they felt very uncertain about what was going to happen to them and that they had very little control over the outcome. This was a source of anxiety and worry for some.

**Impact of AAA on Lifestyle**

Participants described advice they had been given by health professionals about stopping smoking, changing their diet and exercising more. The extent to which the diagnosis of AAA and the potential impact on lifestyle varied, as did any advice offered. Some participants described cutting down on smoking and trying to exercise more.

“Even during the surgery and hospital I didn’t smoke and since I have been back I have sort of dwindled away but I am still on it slightly.” AAA14
“On a diet and that. They were good but it wasn’t that *doctor’s name* it was another one, another one was there instead.” AAA08

Financial impact of AAA

Financial impact was limited, but a number of participants reported that their travel insurance had increased in price since being diagnosed with an AAA.

“I: Has it affected your insurance then? R: Oh yes it’s through the roof.”

AAA09
CAD

Nine participants with CAD were interviewed. Age related data was irretrievable for two participants however the remaining age range was 52-86. Five male and four female participants were interviewed. Following their diagnosis two participants did not need treatment, three were on medication, one had undergone two amputations on the same leg and three had a carotid endarterectomy. A table of the CAD thematic framework is reported in the appendices. The main themes were signs and symptoms, impact of CAD on physical capabilities, social activities and psychological function, and lifestyle effects.

Signs and Symptoms

There was a wide range of signs and symptoms reported by CAD participants. This most commonly included, but was not restricted to, the following:

Headaches

Three participants talked of headaches they had experience before receiving their diagnosis. Two participants had sought medical opinion as they had thought the headaches had been unusual, however the other one only connected the headaches to CAD after being questioned by a medical practitioner.

“I had a headache…. I haven’t been on sick for anything for about 7 years. I have had no tablets no nothing and I just started getting headaches here, but a right funny headache do you know I thought they were migraines and I was
asking people what’s migraines like you know and they said if you lay down in a dark room it will go and it did. It used to ease it a bit.” CAD01

**Problems with eyes**

Three participants discussed having experienced issues with their eyes related to CAD. Participants descriptions of this varied as it could be losing eyesight for a few seconds, a shadow appearing in the corner of their eyes or a line appearing briefly across their field of vision.

“On a couple of occasions my right eye lost sight for about 30 seconds, it would like shut down and come back and it did that two or three times and so I went and had it checked.” CAD01

**Stroke, mini stroke, transient ischemic attack (TIA)**

One participant reported having a stroke and five described having a mini-stroke or TIA. For those that had a TIA there was related anxiety about having a more serious stroke in the future. There was a varied response inpatient understanding of what had happened to them.

“I think what might have happened I don’t know. When I did that, it might have triggered, I don’t know what they call it a slight stroke.” CAD04

“But apparently they said it was the blood clot dispersing that caused the stroke. Well TIA”. CAD17
Losing balance

One participant recounted having lost their balance frequently since they had experienced a mini stroke. “Yes I was fitting a carpet down the stairs which I have not even finished it all yet and basically I lost my balance like and I started to lose my balance recently since then like falling down like you know bit unsteady on my legs and that like.” CAD09

Swelling/Stiffness of the neck

Two participants described their neck feeling swollen or stiff. One of them was post-operative and still had effects a number of months after their operation. “Yes. Some days it feels swollen and even now the ear is quite numb”. CAD10

Pain and sleep

Only one participant reported pain. “It is like as though if feels like as though you have been punched in the neck.” CAD09. The same participant was the only one to suggest that CAD effected their sleep “Sometimes I have to sleep on my back because if I sleep on my side that’s when it gets worse.” CAD09

Cognitive effects

Two participants reported symptoms of confusion. “It does yeah because it feels like dementia doesn’t it, something to do with that”. CAD09

One lady was not aware herself at the time that she had sounded confused. “My eldest daughter….she said ‘mum you were talking so stupid’ but I didn’t know….” CAD17
**Co-morbidities**

Five participants reported having multiple other co-morbidities that also impacted on their quality of life. Across the participants this included liver damage, schizophrenia, cataract operation, fractures, COPD, diabetes, leg ulcers and heart conditions. “Well I had two drainages on my liver at one bit and blood transfusions and it really scared me like about drinking and like liver damage, sclerosis of the liver and everything so they said I had only got two years to live but I have scraped that two years.” CAD09

**Impact on Physical Function**

CAD did not generally appear to have had any major impact on physical function for the majority of participants.

**Mobility**

One participant reported that their mobility had been affected due to their legs not seeming to work. “It just, my legs, I don’t know whether it was that what affected my legs but I couldn’t walk.” CAD5

**Daily activities**

Few participants reported any effects on their day to day functioning. “Just get on with it. Independent. I still put my own pictures up and stuff with one leg, why not.” CAD14
Driving

One participant reported that their main restriction is that they couldn’t currently drive following their CAD diagnosis. “But I am restricted with driving. I can’t drive.” CAD02

Impact on Social Function

The majority of the participants did not discuss any major effects on their ability to get out and socialise; however two participants reported that loss of confidence and anxiety about having a stroke prevented them from going out alone. A few mentioned that they felt supported by their partners.

Psychological Impact

Anxiety and worry

The most significant psychological impact was anxiety and worry, particularly about worsening symptoms or further problems. Five of the participants voiced such feelings with a wide ranging extent of emotions.

“….I sat there and immediately typed in mini stroke so I started reading up about it and finding a bit more out about it and yeh I suppose I was a bit concerned.” CAD06

“That’s right yes. I am worried about it, I still am worried about it.” CAD02

“….I mean that week I was in hospital I was terrified, literally terrified because you don’t know what is going to happen do you….” CAD17.
**Age related health perceptions**

Four of the nine participants voiced an expectation of some changes to their health due to their increasing age. “I don’t mean the fact that I lost my speech for a few minutes but obviously I was shocked and worried. I know I am 85 but still you don’t want to be popping off yet do you.” CAD02

“I do not know. I don’t know. I think sometimes when you get as old as I am you start to accept life as it is. I am sure you do. You know when you are younger, when you are middle aged and that you think I don’t want to die yet you know, I don’t want to die but I think as you get older your mind changes and you are accepting things as it comes your way sort of thing” CAD10

Although there was in general an acceptance and a sense of inevitability about this for some there was still a resolve that their condition was not going to define their lives and they would try and carry on as normal. “Well I think my determination helped a lot.” CAD05

“….I have always been like that because to be quite honest my children were amazed at me because it really didn’t bother me…….It’s never got me down, I have never had to see the psychologist or these sort of people I don’t need them, you know if it happens you get on with it.” CAD14
Impact of CAD on Lifestyle

Following their diagnosis most participants were now aware of a link between CAD and lifestyle habits such as smoking, poor diet and lack of exercise. Six of the nine participants were past or current smokers. It varied amongst the CAD group as to whether or not they had been advised about the risks of smoking, or given exercise or dietary advice by the clinical team. It also differed as to whether or not participants had given up smoking.

“Well I have been told that because I smoked most of my life, I don’t smoke so much now, but I used to be a heavy smoker and they say that is what has caused me to have bad circulation, arteries blocked and that sort of thing so I have taken their word for it.…” CAD14

“And just using the electronic occasionally just when the moment comes when I think oo I used to have a cigarette at that point and then I take my mind off and forget about it. So that seems to be working but the, but I think it has kicked in that I have got to stop smoking so the will power factor has kicked in.” CAD06
VV

Ten patients with VV were interviewed. One of the interviews was conducted over the phone and the recording quality was poor and therefore could not be transcribed verbatim; however extensive field notes had been taken during the interview and were used to help with the analysis.

Participant’s ages ranged from 35 to 77; a 50:50 ratio of male and female. Five participants were waiting for surgery to strip the vein; one participant was waiting for funding for surgery; three participants had already had treatment consisting of sclerotherapy, lasering or surgical stripping, one of whom was waiting for further treatment; one participant solely had compression.

A table of the VV thematic coding framework is reported in the appendices. The theme of symptoms encompasses sub-categories of pain, mobility, progression, appearance, swelling and sleep. The impact of VV on QoL was divided into sub-themes of physical function, social interaction, psychological effects, work and lifestyle.

Signs and Symptoms of VV

Pain

Eight of the ten participants reported pain related to their VV; however pain severity differed within the group. Where pain was less severe it was described as uncomfortable, stinging or more of an ache. “My legs were aching. I got achey legs” VV18.

“It doesn’t hurt so much it just feels uncomfortable after a while” VV01.
“It stings, it started, it was starting to sting in three locations” VV30.

For those with moderate pain it did not prevent them from undertaking activities or jobs. “I was doing what I was doing, it was becoming uncomfortable and at times painful but I was carrying on” VV30.

“At work it doesn’t stop me doing anything but it’s painful” VV32.

For others with more extreme pain it was described as overwhelming like a severe cramp. “When you started it used to go like cramp….oh agony….it is just like cramp, really bad cramp you know in your calf.” VV05.

**Movement and Rest**

There was a differentiation amongst participants in the relationship between pain or discomfort and movement or rest. Walking exacerbated pain for some “It got to the point when I was walking even after a few minutes aches and pains and really funny sensation.” VV17

“I did a lot of walking and was noticing that the ankle was becoming more painful, so not just swollen but becoming painful” VV30.

However another participant found walking relieved her symptoms “I am better when I am walking about, when I sit down oooooh.” VV03

Standing was painful for some “I had a lot of cluster veins in my foot, very painful because I work in a shop now and I am standing a lot and I was sort of conscious that my foot was getting swollen and sore” VV14.

“It started going red, very painful and swelled up this was after I had done a mornings work” VV17.
Two participants said pain was not an issue for them.

**Mobility**

VV did not appear to have an impact on mobility for the majority (7/10) of participants. Two patients reported a minor impact on their walking ability

“Yes it did because I used to go with my husband walking the dog like.” VV17

However, one patient (VV30) reported a major effect on mobility, particularly in terms of the distance he was able to walk; he also found it difficult to stand sometimes. This had a great impact on his usual activities and his quality of life. “What I don’t think is acceptable in this day and age is having to put up with not being able to walk properly……I can walk but I am 60 not 93 ……too far seems to be about four miles now which is not very far at all. I then have to seek assistance to get home and then for the next three or four days I am hobbling around.” VV30

**Sleep**

Five participants did mention difficulties with sleep, although one was unsure if her disturbed sleep was due to the VV.

For one participant it was a particular problem sleeping because of discomfort and itching due to the VV. The lack of sleep had an impact on his life as he had to get up for work at 3.30am. “It is more like at night time I must wake up four or five times you know. Sometimes when I wake up and I have made a right mess of it, cut it and you know scratched there.” VV32

Another participant managed the problem with discomfort and lack of sleep by adopting a certain position in bed to alleviate their symptoms “It’s not as bad,
it’s not too bad if you just get, if I lay back I am not so bad, if I lay with that leg on it.” VV03

Progression

Nine of the participants talked about having their symptoms for long periods of time. The shortest period was two years, and the longest twenty years. There was an underlying stoicism indicated. A worsening of symptoms appeared to trigger a need to seek help. “So for the last four years I have not done anything I have just put up with it.” VV14

“The symptoms were, well I had symptoms for ten years or so.” VV01

Appearance

Seven participants mentioned being upset by the appearance of their VV.

“Yes it was like, it was that and also the clots in the veins you just like, it is a bit unpleasant.” VV01

The appearance of VV is addressed in more detail under psychological effects of further in the paper.

Swelling

Half the participants reported swelling of their legs and/or feet as a problem.

“They were getting bigger and bigger….well it was just bulging out all over.” VV18.

Although the effects did not appear too troublesome it was considered unsightly and impacted on what participants could wear.
“Yes it is always swollen…it is just ridiculous, so it has an effect on what shoes I can wear.” VV30

“I can’t get my jeans on anymore, I know I am carrying fluid.” VV14

**Itching**

Three participants found that the VV itching was a problem for them. One participant particularly had trouble with this. “….that is what really bothered me it is just non-stop. Scratching and itching.” VV32

**Impact of VV on Physical Function**

**Activities of daily living**

None of the participants reported that their VV had any particular impact on their ability to physically take care of themselves or upon activities of daily living such as shopping, cooking, cleaning etc.

**Hobbies and Exercise**

Half of the participants, both male and female, described how they were physically unable to undertake their usual exercise routines or take part in their hobbies due to their VV. This had a knock on effect socially, in addition to missing the activity and its health benefits.

“The only thing it stopped me doing for a while was playing football….because I just didn’t want to get hit on it.” VV01
“I used to play football Saturday, Sunday at a decent standard….I’d have like four week off and then play again and then it would go again.” VV03

“Yes it did because I used to go with my husband walking the dog like.” VV14

“I don’t play football as much now because obviously when it gets like, you know if you do running or anything it flares up. I haven’t played football for a while because of it.” VV32.

One participant had made adaptations to his workshop to enable himself to carry on with his hobbies “I have got myself a seat now because standing there for more than 20minutes, half an hour becomes painful.” VV30

Impact of VV on Social Interaction

VV do not appear to have had much impact on social interactions, aside from not being able to participate in hobbies and exercise with a social element. Only two of the ten participants discussed not taking part in social activities because of embarrassment.

“Going swimming or to aqua fit or something like that I, it was hard and then I didn’t go for it, I wouldn’t go.” VV18

For one woman this resulted in missing out on doing things with her family.

“I kept thinking I want to go swimming and I’m not because I am embarrassed so things with the children I wouldn’t do.” VV14
Psychological Effects of VV

**Self-conscious**

The appearance of the VV appears to have been the most prominent psychological effect with seven of the participants remarking on this or describing feeling self-conscious.

“Well it is not only sort of physically it is psychologically as well because it affects what you wear, I always wear trousers or really thick tights and long skirts.” VV18

This was true of both men and women. Men were more likely to say it looked unsightly rather than it altering their behaviour or dress. However, they did still claim the veins had an impact on clothing choice.

“No it’s not nice but obviously I don’t wear a skirt or anything so it not really, not bothered me that much….if I had been a lady obviously it would have been really bad but…….when I go out I can cover it up.” VV32

“It doesn’t look very nice. You think twice about wearing a pair of shorts as you would do previously but that is it.” VV01

However, for women it had a more profound impact. “It was everything I chose was length dependant, how will that look with my veins, how will everything look.” VV14

“I am always in leggings or jeans. I am paranoid about people seeing my legs. I have done for a few years now and it’s worse you know now so.” VV17
Negative reactions of others or comments on how unsightly the VV were also had an effect on self-esteem.

“I will never forget once somebody said we were talking and she said “patients name* you are lovely and brown what’s that on your leg’. You know what I mean….Yes I am conscious of it.” VV03

Another participant who was a professional singer had also heard members of the audience commenting upon her VV and consequently started to change what she wore on stage.

*Health expectations*

Two participants described how the VV made them feel older than their years. This was partly because they were not as active as they expected to be at their age, or they were unable to dress how they wished. There was a feeling of loss of their youth and they described feeling old compared to their peers.

“I was thinking I am not 60 and at the time I was sort of early 40’s and thought my friends are still going out and on holiday….but on holiday you want to wear shorts and I wouldn’t you know.” VV14

“At 60 there is no reason why with a decent ankle I couldn’t walk you know 20 mile. I used to regularly….so yes I would like to be able to do the simple things that I have been doing all my life.” VV30

*Health fears*

The VV also triggered health fears in three participants, sometimes based in the health experiences of family members. One (VV15) spoke of the worry
that the VV would lead to a thrombosis when she was pregnant as her mother had suffered one after childbirth.

Another worried about the VV leading to VLU. “I remember my mother she had ulcers on her legs they were terrible and I thought I don’t want to get into that state.” VV18

The prospect of treatment caused anxiety for another participant. “I was a bit apprehensive coming home and my husband was saying ‘why what’s the matter?’. ‘Oh I’m scared I’m scared’.” VV17

**Impact of VV on Lifestyle**

Four of the participants mentioned being advised to make lifestyle changes including being more active, stopping smoking and losing weight; three of them had successfully made these alterations. Treatment was initially denied to two participants due to having a BMI over 35. The participants suggested that this was a big incentive for them to lose weight. None of the four participants were given any advice on how to make lifestyle changes, they were simply told to go away and do it.

“Yes and then I went to that first appointment that was ok and they said at that appointment that I was 18 stone 13 so I was too fat so I had to…..I had to lose some weight basically which I did.” VV32

Of the two participants told to lose weight to qualify for treatment only one successfully managed to do this. VV32 reduced his weight by nearly three stone and was awarded funding for treatment.
Implications of VV for Work

Not all participants were working as some had retired. For four of those that were working their VV had an impact on their work. For example being in pain at work or having to have time off due to VV symptoms or treatment.

“I have gone in pain before but I had to go, it’s a family business so I have got to go do you know what I mean.” VV32

“The other thing is two weeks off work so I was a bit like that would not go down well.” VV01

“Doctor wouldn’t let me go back to work; she said it is not wise for you going back after surgery.” VV17

VLU

Ten patients with VLU were interviewed. One of the recordings was irretrievable however field notes were used as data for the analysis. Ages ranged from 47 to 84; with 8 men and 2 women. Five patients had compression bandages in place and dressings that were done by the district nurse between visits to the nurse specialists in the out-patient clinic. Of those without compression bandages, one participant used cream daily on his legs to prevent reoccurrence; one participant had undergone vein removal; two had balloon angioplasty (one of whom also had a venous stent bypass and amputation of toes); one participant had below knee amputation.

A table of the VLU thematic coding framework is reported in the appendices. The theme of symptoms encompasses sub-categories of pain, mobility, sleep, non-healing wounds, comorbidities and progression. The impact of VLU on QoL concepts was divided into sub-themes of physical function, social interaction, psychological effects, work and lifestyle.

Signs and Symptoms

**Pain**

Six of the participants discussed the pain of the VLU. The sensation differed within the group with some describing a consistent but dull ache whilst for another it was more severe and a burning sensation. “*It is a peculiar sensation. I have severe burning…..it feels as though my legs are under a radiator. They really burn like mad.*” VLU12

Although the sensation differed participants reported suffering from quite high levels of pain. “*I have been near on incapacitated at times.*” VLU10
Two participants described needing pain relief to help. “I was terrible. I was in agony. I have been on morphine since Christmas.” VLU07

Two participants reported no problems with pain whilst another reported pain due to a different condition.

**Mobility**

Five participants reported that their VLU had had an affected their mobility, with one saying the reduced mobility was the factor that had the most impact on his life. The effect appears to be both on walking and standing. “I just can’t walk.” VLU01

“I found trouble not being able to walk so far.” VLU10

“Because I can’t stand very long and then I can’t do things what I wanted.” VLU05

Two participants said there had been no effect on their mobility; whilst a further two had mobility problems due to other conditions.

**Sleep**

Six participants found that their sleeping was affected by their VLU. The severity of the impact ranged. “I haven’t slept. I just started sleeping now.” VLU07

“Er it’s not too bad once I get settled down it is not so bad.” VLU10

With some trying different methods of combatting it.
“It does affect my sleep because if I sit up in bed put my foot up on the pillow I am far better. I do that for about quarter of an hour then I try again you know” VLU01.

The three other participants did not comment on the impact of their VLU on their ability to sleep.

**Co-morbidities**

Seven participants had comorbidities, four of whom had diabetes. One of the diabetic participants knew that their VLU may be linked to their diabetes.

“I said with me being diabetic I thought I better come and check, have it checked out and he (GP) had a look at it and he said ‘you know it is an ulcer.’” VLU01

**Progression**

All of the participants had had their VLU for relatively long periods of time; the shortest being six months and the longest six years. The difficulty in progressing a VLU to healed was highlighted by participants

**Non-healing wounds**

Only one participant had experienced a VLU that had healed and not reoccurred. One participant had an open VLU that had healed after six years but did go on to have a further reoccurrence. Another participant described how their VLU had almost healed. “It got going lovely didn’t it, it was just new skin and it started swelling going. Well then it broke out again as though you split your skin open so I had to fetch all nurses back in you see.” VLU05
Some felt they had some success by reducing the size or number of VLU. “I had seven but I am down to two. Because they were all round my ankle but they have healed but these two are being bloody stubborn.” VLU09

Between the participants many different treatment had been tried. “Manuka honey, different iodine and all things like that. Nothing is lifting it off.” VLU01

One participant had a particularly long process of non-healing toes wounds, gangrene, abscesses and infections that eventually lead to amputation.

**Impact of VLU on Physical Function**

**Activities of daily living**

None of the participants reported that their VLU had any particular bearing on their ability to physically take care of themselves; however at one point a participant had not been able to shower properly for months due to the dressing he was having on his legs. Three participants described an impact upon activities of daily living such as shopping, cooking, cleaning etc. “Yes it has been a lot of things. Changing my bedding and all that, I can’t do that now. You know.” VLU05

“Have you ever been in an *supermarket* store? I can’t walk round without a supported trolley.” VLU09

**Hobbies and exercise**

Two participants were unable to exercise or undertake their usual hobbies due to their VLU. “I noticed it more when I was dancing I would get through
one and then I would just have to go and sit down and it was just too much for me.” VLU10

“I can’t walk the dog which is the biggest problem. She must think I have thrown the lead away, dog.” VLU09

Impact of VLU on Social Interaction

Four participants were no longer able to participate in their usual social activities to the same extent due to their VLU. “It is the pain I have when I am sat in the club….I think no I would sooner stop here than go.” VLU01

“Unless we have got to go, we don’t go out….I mean I used to enjoy going to pub like or a club, especially on a Sunday afternoon. I haven’t been to pub now for two year and I used to go a lot four or five times a year.” VLU09

One participant found socialising could be difficult as he felt self-conscious that his wounds smelt if they hadn’t been dressed for a day or two.

“Well it does. When you go to a restaurant and sit at a table there are other people sat around you and things like that. Yes, yes definitely but you just got to hope they don’t point the finger at you sort of thing.” VLU12
Psychological Effects of VLU

**Mood/Emotions**

The greatest psychological impact of VLU seemed to be on people’s mood and emotions. Six of the participants discussed this. For some described feeling ‘fed up’ or ‘mardy’. Others described great levels of distress and anxiety. “I’ve never known anything get me down like this.” VLU01

“I have been very tearful. I cry at anything at the moment.” VLU10

“R: I got to the stage I was so low I was crying. I was sitting crying that was when I came out wasn’t it, when I came out. W: He just said ‘I wish I was dead’.” VLU07

Two participants also spoke of feeling bereaved due to the loss of being able to do the things they used to do such as being active, sports or walking.

“I come out of that bedroom and I am walking round and I think I can’t put up with this no more. I cannot put up with this anymore you know what I mean? I am used to being active, I mean I am 81 but I am still very active.” VLU01

“Just a lovely walk on cliff tops would do me.” VLU09
Impact of VLU on Lifestyle

One participant believed that his past lifestyle was responsible for his current health problems.

“It is my lifestyle that has knackered me up….I am a smoker yeah I have had a go to stop but failed miserably. I am going to have to go and see somebody I think.” VLU10

Three other participants had been told to lose weight to help their conditions. One participant said they had been advised to lose weight but did not specify by whom or if they had done so. Another participant had seen a dietician although it is not clear if they had been referred by the vascular service; they had lost over two stone. A further participant had successfully managed to lose nearly a stone without any help or advice.

Implications of VLU for Work

Not all participants were still working; however for those that were four had experienced VLU impacting on their work in some way. One was still able to work but had to take care to protect the VLU with compression stockings and dressings. One had tried to carry on working despite being in pain, although he reported having to take significant amounts of time off work the previous year due to VLU. He was eventually forced to take time off again.

“So they finished me saying they had a duty of care….so I am not allowed to work and I threw on sick.” VLU09
Another had to return to work due to the financial impact. “I have been back at work for the last three months because I just couldn’t afford to be off.” VLU10

The participant who described the greatest impact of his VLU on work was self-employed. He had lost work contracts as a result of his VLU because of time off work. This led to him having to sell the family home and move into rented accommodation. The financial difficulties further impacted on his children as he was now unable to pay for his children’s university fees.
Summary of concepts across the five vascular conditions

Table three (page 53) provides a summary of the symptoms and the impact of each of the five vascular conditions on QoL.

Many of the participants with AAA reported no major physical symptoms; whereas for those with CAD there was a wide range of different symptoms. The impact of the condition on physical functioning was associated with the psychological impact of the conditions as people experienced anxiety and distress over the potential of symptoms getting worse. For those with an aneurysm they were worried about rupture and death and those with CAD were fearful of having a stroke.

Pain was prevalent across the conditions and varied widely in sensation and severity. Pain for PAD was predominantly in the lower limbs, although there were patients who reported pain in their abdomen. Mobility problems were present in all five conditions although the extent varied widely within each sample. Comorbidities were prevalent in all conditions and many patients with PAD, AAA and VLU reported symptoms of other vascular conditions. Participants with VV were overall younger and reported the lowest impact on quality of life. There appeared to be a belief across the conditions that ill health was to be expected with increasing age. In addition there was an underlying stoicism where people accepted their conditions and ‘just got on with it’.

Participants mentioned the impact of their condition on lifestyle as well as advice they had been given by either clinical practitioners or relatives. The majority of participants discussed smoking, cutting down or giving up but some did report changes to weight, diet and exercise.
**Table three:** Map of symptoms and quality of life concepts reported across the five vascular conditions

<table>
<thead>
<tr>
<th>Symptoms</th>
<th>PAD</th>
<th>AAA</th>
<th>CAD</th>
<th>VV</th>
<th>VLU</th>
</tr>
</thead>
<tbody>
<tr>
<td>No symptoms</td>
<td></td>
<td>x</td>
<td>x</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pain</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Neck pain</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Leg pain</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Abdominal pain</td>
<td>x</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Arm pain</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cramp/aching</td>
<td>x</td>
<td>x</td>
<td></td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>Burning sensation</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>Pain severity</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Pain on walking</td>
<td>x</td>
<td></td>
<td>x</td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>Pain at rest</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>Pain when standing</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>Mobility</td>
<td>x</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Distance</td>
<td>x</td>
<td></td>
<td>x</td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>Speed</td>
<td></td>
<td>x</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stairs/ slopes</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>Non-healing wounds</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Co-morbidities</td>
<td>x</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Progression of symptoms</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>Sleep</td>
<td>x</td>
<td>x</td>
<td></td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>Swelling</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>Loss of balance</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>Confusion</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>x</td>
</tr>
</tbody>
</table>

**Impact on physical functioning**

| Hobbies                               |     |     |     |     |     |
| Exercise                              | x   |     |     |    | x   |
| Daily activities                      |     |     |     |    | x   |

**Social impact**

| Travel                                | x   |     |     |    | x   |
| Social activities                     | x   |     |     |    | x   |
| Social support                        |     | x   |     |    | x   |

**Psychological impact**

| Anxiety                               | x   | x   |     |    | x   |
| Depression                            | x   |     |     |    | x   |
| Feelings of loss                      |     | x   |     |    | x   |
| Health expectations                   | x   | x   |     |    | x   |
| Unsightly appearance                  |     |     |     |    | x   |
| Feeling self-conscious                |     | x   |     |    | x   |
Fear of worsening symptoms | x | x | x | x | x | x
Fear of rupture death | x |
Fear of amputation | x | x |
Fear of stroke | x |

**Financial impact**

| Income | x | x | x | x |
| Time off work | x | x |

**Lifestyle**

| Smoking | x | x | x | x | x |
| Exercise | x | x | x | x |
| Diet | x | x | x | x |
| Weight | x | x |

**Discussion**

The aim of this study was to explore people’s symptoms and experiences of one of five vascular conditions; PAD, AAA, CAD, VLU and VV. The specific objectives were to compile the signs, symptoms and impact on quality of life of the five vascular conditions and to map these identified domains across the conditions.

**Key Findings**

Pain and mobility were the most commonly reported domains by participants with PAD. The extent to which they impacted on QoL was associated with the severity, age expectations and social support. Fear of the symptoms worsening and amputation was evident.

The majority of participants with an AAA reported having no physical symptoms, a small number of participants reported abdominal pain and pain in their legs. Uncertainty, anxiety and fear of rupture and death appeared to impact most greatly on people’s QoL.
This was similar for patients with CAD who again reported few impactive symptoms, the majority having what they described as a “mini-stroke”. However participants with CAD appear to have the widest range of signs and symptoms, with nine different ones reported. This condition seemed to have had the least impact on physical and social function, although psychologically it created a sense of worry and anxiety for some participants. The main reported outcome was fear of having a major stroke.

VV do not appear to have had a major impact on overall QoL for the majority of the participants. Pain was the most common issue, affecting eight of the ten individuals. Mobility was not unduly affected in general, although for one individual the reduction in his mobility had significantly diminished his QoL. The perceived unpleasant appearance of the VV seemed to have the greatest psychological impact, and was described in detail by several of the group. Many of the participants had had their VV for very long periods of time, often just “putting up with it” for numerous years before seeking help.

The impact of VLU on QoL differed within the group. For some there were no major issues and having a VLU was accepted as part of their current life, with the hope that it would heal eventually. For others there was a far more significant effect. Pain was reported by six of the group; it was quite severe for some participants leading to a significantly reduced QoL. Pain also had a bearing on people’s mobility and their ability, or desire, to go out and socialise. Sleep was also often disturbed due to pain. The progression of VLU had resulted in participants suffering for long periods of time. In addition the non-healing or reoccurring nature of the condition had a
significant impact for many. VLU appeared to have a significant psychological impact causing a high degree of distress for some.

There were many overlapping domains between the conditions. Pain was experienced in varying degrees within and across the conditions. A good proportion of the participants interviewed had more than one vascular condition that contributed to some of the overlap in reported symptoms. For instance a number of participants with AAA reported symptoms of claudication. Comorbidities were common in all of the conditions but particularly for patients with PAD or VLU who described the cumulative impact the other conditions had on their QoL and functioning. Overall those with VV were the youngest and reported the least impact on QoL. Age expectations were evident in all groups, some of the older participants reported that they expected ill health due to their age, whereas younger people often reported being much more distressed by the condition.

**Strengths and Limitations**

This study provides an overview of the important symptoms and quality of life domains of participants with five different vascular conditions. A multi-disciplinary team of methodological experts, clinicians and researchers carried out the study meeting regularly to guide recruitment and the analysis of the data. Efforts were taken to include a sample that included a range of ages, and reflected the range of severity experienced in each of the conditions that present to vascular services.

Whilst this report provides an overview of the signs, symptoms and experiences of participants living with the condition, the sample sizes are small, and further work
needs to be done to clarify the identified domains important for each condition. It is anticipated that the information from the interviews will be triangulated with data from a qualitative review of patient experiences, a Delphi study and a qualitative review of existing PROMs.

Recruitment to the study was conducted only at one site through secondary vascular care at the Northern General Hospital in Sheffield. It would be preferable to explore if there are any differences in patients’ experiences that access different services at different sites. The conversion rates of participants who were approached that took part in an interview were lowest for the VV population in the study. One of the reasons for this appeared to be that this population were younger (mean age 50) and therefore had less time to complete an interview. This could have meant a skew in the sample characteristics for this group.

**Summary**

This study provides a summary of the outcomes identified by people with PAD, AAA, CAD, VV and VLU. There was notable overlap in the reported symptoms and impact of across the conditions. This study provides valuable information about the impact vascular conditions may have on QoL and to inform the selection of outcomes for use in vascular services.