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Illness beliefs and walking behaviour after revascularisation for intermittent claudication - a qualitative study --Manuscript Draft--

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Abstract:	<p>Purpose Patients with Peripheral Artery Disease are recommended to increase physical activity to reduce cardiovascular risk. Vascular intervention (surgery or angioplasty) treats the symptom (intermittent claudication), but not the underlying cardiovascular disease. This study aims to explore the beliefs and physical activity behaviour of patients with Peripheral Artery Disease who have received vascular intervention.</p> <p>Methods Twenty participants who had received a vascular intervention for intermittent claudication between 6 months and 2 years previously participated in semi-structured interviews. The interviews explored illness and treatment beliefs and walking behaviour. Data were transcribed verbatim and analysed thematically.</p> <p>Results Participants described a high level of ongoing symptoms (particularly pain) in their legs, despite having received vascular intervention. They viewed their illness as acute and treatable, and believed pain was an indication of walking causing damage. They controlled their symptoms by avoiding walking and slowing their pace. Participants were generally unaware of the causes of the disease, and were unaware of their increased risk of future cardiovascular health problems. There was a low level of congruence between participants' beliefs about their illness and the recommendation to increase physical activity which may affect physical activity behaviour.</p> <p>Conclusions Our findings suggest that patients with Peripheral Artery Disease do not change</p>

	physical activity behaviour after diagnosis and treatment, because they hold dysfunctional and incongruous beliefs about Peripheral Artery Disease, treatment, and physical activity.
Response to Reviewers:	<p>I have made the following changes:</p> <p>1.To Title Page: a.I have added the country (Scotland) to the address of the 5th author.</p> <p>2.To Manuscript: a.I have included a description of where the study took place (two regional urban hospitals in Scotland). b.I have changed the format of the in-text references. c.I have used accepted journal abbreviations in the reference list.</p> <p>Thank you for accepting this paper for publication in the Journal of Cardiopulmonary Rehabilitation and Prevention.</p> <p>Yours sincerely,</p> <p>Maggie Cunningham PhD</p>

**Illness beliefs and walking behavior after revascularisation
for intermittent claudication – a qualitative study**

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STRUCTURED ABSTRACT

PURPOSE: Patients with peripheral artery disease (PAD) are recommended to increase physical activity to reduce cardiovascular risk. Vascular intervention (surgery or angioplasty) treats the symptom (intermittent claudication), but not the underlying cardiovascular disease. This study aims to explore the beliefs and physical activity behavior of patients with PAD who have received vascular intervention.

METHODS: Twenty participants who had received a vascular intervention for intermittent claudication between 6 months and 2 years previously participated in semi-structured interviews. The interviews explored illness and treatment beliefs and walking behavior. Data were transcribed verbatim and analysed thematically.

RESULTS: Participants described a high level of ongoing symptoms (particularly pain) in their legs, despite having received vascular intervention. They viewed their illness as acute and treatable, and believed pain was an indication of walking causing damage. They controlled their symptoms by avoiding walking and slowing their pace. Participants were generally unaware of the causes of the disease, and were unaware of their increased risk of future cardiovascular health problems. There was a low level of congruence between participants' beliefs about their illness and the recommendation to increase physical activity which may affect physical activity behavior.

CONCLUSIONS: Our findings suggest that patients with peripheral artery disease do not change physical activity behaviour after diagnosis and treatment, because they hold dysfunctional and incongruous beliefs about PAD, treatment, and physical activity.

CONDENSED ABSTRACT

Interviews were conducted with 20 patients who had previously received vascular intervention for peripheral artery disease. Thematic analysis revealed patients do not change physical activity behavior after diagnosis and treatment because they hold dysfunctional and incongruous beliefs about peripheral artery disease, treatment, and physical activity.

Intermittent Claudication Beliefs

Intermittent claudication (IC) is a common symptom of peripheral artery disease (PAD), characterized by cramping leg pain when walking, which relieves upon rest. PAD is a prevalent chronic condition which affects ~10% of adults over 50 years, and ~19% of adults over 70 years.¹ PAD is usually caused by atherosclerosis, and indicates systemic atherosclerosis. International guidelines for the treatment of PAD recommend risk factor management through patient behavior change, in particular smoking cessation, weight loss, and increased physical activity.² However, rates of angioplasty to treat the symptoms of claudication have dramatically increased in recent years.³

Typically, success of vascular intervention for IC is measured by walking capability in treadmill tests or with self-report quality of life questionnaires. These measures do not give an understanding of patient actual day-to-day physical activity behavior after revascularization; however, there is evidence that people with PAD walk significantly less than other older adults.^{4,5} Current treatment, including vascular intervention, supervised exercise programs, and ‘go home and walk’ advice, do not change physical activity behavior of PAD patients.⁶⁻¹⁰ As PAD typically involves multiple sites throughout the arteries, patient behavior change is important alongside vascular intervention to improve health and reduce the risk of cardiovascular comorbidity and mortality. Physically inactive patients with IC have twice the mortality risk of moderately physically active (1 to 3 hours per week moderate physical activity) patients over 5 years, suggesting that even low levels of physical activity would be beneficial for patients with IC.¹¹ The Common-Sense Model of self-regulation of health and illness (CSM) is a popular concept which has been used to understand modifiable determinants of behavior in a number of chronic diseases.^{12,13}

The CSM proposes that when faced with disease symptoms, patient behavior is influenced by their beliefs about the illness and their beliefs about treatment. The CSM proposes that these beliefs determine the cognitive and behavioral actions which the

individual will take to cope with the illness and improve health. The objective of this study was to explore the beliefs and physical activity behavior of patients with peripheral artery disease who have received vascular intervention.

METHODS

Semi-structured interviews were conducted with participants in their own homes. Interview transcripts were analysed using Thematic Analysis.¹⁴ Participants were recruited from vascular outpatient clinics in 2 regional urban hospitals in Scotland. The local NHS Research Ethics Committee approved this study.

Participants and Procedure

Consecutive patients attending vascular outpatient clinics following angioplasty or bypass surgery were invited to participate in the study. Inclusion criteria included an original diagnosis of IC, and revascularization surgery or angioplasty between 6 months and 2 years previous to recruitment. This time scale was a pragmatic choice to reduce the risk that participants were still experiencing the short-term effects of surgery (6 months), and so that participants were captured before discharge from followup (2 years). Potential participants were excluded from the study if they were unable to speak English, had a psychiatric illness or were known to be taking part in other studies. Sample size was determined by minimum sample size (10 participants) and stopping criteria (no new information identified from preceding 3 interviews).¹⁵ The final sample had 20 participants.

Informed consent was taken prior to the interview commencing. Interviews were conducted by a researcher trained in qualitative methods and interviewing techniques. Interviews were taped and transcribed verbatim and their accuracy checked against the original tapes. The interviews followed an interview schedule guided by the study aims to

1 explore participant physical activity behavior and beliefs about their illness, with questions
2 based on the CSM. This model proposes that people form lay illness beliefs which contain
3 information about the identity of the illness, the temporal features of the illness, the imagined
4 and real consequences of the illness, the causes of the illness, and beliefs about whether the
5 illness can be cured or controlled.¹² The interview included the open questions: Can you tell
6 me all about what has happened with your legs? What are your current symptoms? What do
7 you believe caused the peripheral artery disease (problems in your legs)? What do you think
8 will happen to your health in the future? How can you control your peripheral artery disease?
9 How have you changed your health behaviors since the operation? How active are you on a
10 typical day? Can you describe what kind of walking you usually do? What are the advantages
11 or disadvantages of doing more physical activity? Participants were also asked to describe
12 what they believed happened inside their leg to cause the walking pain. Probing questions
13 were posed as necessary during the interview in response to issues raised by participants.
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34 Analysis

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36 The interview transcripts were analysed using thematic analysis,¹⁴ which is a common form
37 of qualitative analysis. Our analysis was concerned with the experiences, meaning, and
38 reality of participants. We took a theoretical approach to thematic analysis, coding the
39 interview transcripts in relation to the specific aims of the study, ie, focusing on the beliefs
40 and physical activity behavior of participants.
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Two researchers, a psychologist and exercise physiologist, conducted independent
initial analysis of the transcripts - familiarization with the data, initial code generation, and
searching for initial themes. The researchers read and re-read the transcripts fully in order to
form a sense of the whole interview (familiarization). The transcripts were then searched
systematically for statements related to the study aims (beliefs and physical activity behavior

of participants). Coding was performed manually by marking relevant statements with a highlighter and assigning a brief descriptive label for each statement in the transcript margins (initial code). All data sets were coded, and then statements were collated together under each code in a separate notebook. Initial codes were then sorted into subcategories by grouping statements with similar meaning, and these were reviewed between the researchers. The researchers discussed initial coding decisions and subcategory groupings in detail, with the goal of reaching consensus. There was a high level of agreement between the researchers of subcategories identified in the analysis. The researchers then worked together to discuss, agree and refine the final themes, by grouping and integrating inter-related subcategories. The researchers then re-read the interviews and considered whether the individual final themes accurately reflected the meaning in the interviews. Each theme represented a pattern of meaning identified in the set of interviews which related to the aims of the study. The analysis was therefore deductive in that it focused on the specific aims of the study. A vascular surgeon independently reviewed the transcripts, checking his agreement with the coding of the themes.

RESULTS

Of the 25 patients invited to participate, 3 declined to take part in the study and 2 participants failed to attend interviews, therefore 20 interviews were conducted. Participant characteristics are shown in Table 1.

Five themes were identified in the analysis, which help to explain the physical activity behavior and illness and physical activity beliefs of patients with IC after they have received vascular intervention. These themes are described in the following section.

Walking Avoidance

While most participants were aware that they should be trying to walk, no participants had a clear understanding of how much walking they should be doing, the recommended intensity of walking, or critically, the mechanism by which walking would improve their health. Despite having received vascular intervention, the majority of participants felt they couldn't exercise because of the pain they experienced when walking, loss of confidence in their walking abilities, the feeling that their legs had lost power, and because they tired very quickly when they tried to walk. As a result of claudication pain, most participants had given up trying to exercise.

Male, 73 *Again it just comes down to the walking, so you can't exercise as much. I mean even going round the shopping centre, you cannae, I mean you've just got to stop and rest.*

Critically, participants did not view walking as a potential treatment for their IC. Participants avoided walking into the claudication pain, worrying that the pain was an indication of damage to the leg. While avoidance is a natural reaction to pain, claudication pain does not cause damage – this highlights the incongruity between participant perception of pain, and the reality of the disease.

Male, 68 *I'm scared of walking in case I damage my legs.*

Participants generally had a limited understanding of the reason why they experienced leg pain when walking. Although some participants understood that they had a narrowing in their circulatory system, they did not understand how this caused pain when walking.

Female, 72 *It's a vein. I've got a lot of wee veins. I've been led to believe the vein's narrowed. I don't know how it's causing the pain.*

Other participants had no understanding of what happened within their leg to cause leg pain.

Female, 66 *The pain starts in the foot and works its way up my legs and into my hips and then my back. I've no idea why.*

Female, 70 *Maybe like an oil change in a car, the older you get it's maybe needing renewed ken, like your blood supply, ken? I don't know. I don't know.*

When asked about the advantages of doing more physical activity, participants responded in terms of tasks or activities they would like to be able to do, rather than with disease-specific benefits. No participants mentioned the potential for symptom reduction, or development of a collateral blood supply as an advantage of increased physical activity.

Male, 73 *Well, I'd like to be able to go to the fishing, things like that. I cannae dae that now. I used tae dae a lot of walking. The legs wouldnae be up to it, nae, nuh, nuh.*

Participants adapted to having limited mobility by changing the way they spent their leisure time, giving up hobbies which involved physical activity and instead finding hobbies where they didn't need to walk. By reducing their physical activity levels, and slowing their pace, participants avoided experiencing pain.

Male, 81 *I don't really go out. I stay in and watch the telly.*

Male, 77 *I never got another dog, because I wasnae fit to take him walks, wi' my legs. I never got another dog. That's the first time I've been without a dog all my life....*

Treatable Condition

Participants viewed their illness as acute and treatable, rather than a chronic condition which required self-management. Patients focused solely on the symptom (IC) rather than the disease (PAD). Despite having received vascular intervention all participants reported having current symptoms including claudication pain, swelling, tightness, throbbing, numbness, cramps at night, problems bending the knee and nerve damage, although symptoms varied greatly in severity. While some of these symptoms are attributable to PAD, others occur as a

result of surgery, and this indicates the participants may have had unrealistic expectations about vascular intervention, and lack of knowledge about the consequences of surgery.

Several participants spoke about the lack of information they were given about their postoperative health, especially their lack of knowledge about what to do about nerve damage and swelling after surgery. Participants generally viewed the pain as something which they hoped could be treated by further surgical intervention or which would disappear magically with time – critically, they did not feel there was anything they could do to improve their symptoms or disease.

Male, 58 *I wanted the operation thinking obviously this was going to cure it.*

Female, 70 *So I'm hoping and praying that (the surgeon) will be able to cure me.*

Female, 72 *I'll just take it a day at a time, and see what happens. So I feel, well, if it happens it happens, what can I do, eh? But eh, I just hope it doesn't get any worse. Hopefully it'll go away.*

Participants viewed surgeons as the gatekeepers over treatment and control of claudication symptoms. Participants originally received a diagnosis of PAD from vascular surgeons, and this appears to have triggered their acute belief system that surgical intervention was the standard treatment and cure for their symptoms.

Causal Beliefs

Participants cited a wide variety of factors which they felt had caused their PAD. The main cause mentioned by participants was smoking, 14 of the 17 (82%) participants who were either current or past smokers, mentioned smoking as a possible cause of their disease.

However, several participants mentioned that they were reporting this as a cause because their doctor had told them that smoking was a cause, but indicated that they did not necessarily believe this:

Female, 65 *It's cos of this (waves cigarette). Well, that's what they said anyway.*

Female, 72 *Well, they say the smoking. I mean, I don't know.*

Only 1 participant had quit smoking as a result of being diagnosed with PAD. Participants had no clear conceptual framework which explained how, eg, smoking could cause calf pain. This was especially the case when there was a time lag between ceasing the causal behavior and onset of claudication symptoms.

Female, 66 *I've given up (smoking) for 5 year. So, it's not the smoking any more (causing the PAD).*

Several participants said that they had no idea what had caused their disease. Of this group, some were or had been smokers, and some had diabetes – they had risk factors for the disease but were not aware of this:

Female, 70 *I've no idea, that's what I'm saying I just wondered if the metformin for the diabetes had anything to do with it? I don't know... I don't know. As I say, I thought maybe the medication had something to do with it.*

Several participants felt that some form of physical activity had caused their claudication symptoms. Lack of physical activity is a risk factor for developing IC, however, it is logical that patients with poor understanding of the circulation system may develop the belief that physical activity is the cause of their muscle pain.

Male, 70 *Right, I had 2 dogs, 3 actually, and I used to take them a walk every day and every night, I always walked them. So I don't know whether that could have been it, maybe going out in the damp weather, I used to go out in all weather, you know? And I don't know whether that caused it, you know?*

Later in the interview, this participant went on to describe how he had given up his dog because he did not feel able to take it for walks due to the leg pain. The participant model of his illness was logical and coherent (to him) and clearly led to his choice of behavior-nonadherence to walking advice, ie, walking had caused his illness, therefore it would be illogical to walk now.

Perceived Consequences

Participants were not concerned about the implications of PAD and atherosclerosis to their general health. No participants mentioned any concern or awareness about their risk of stroke or heart trouble. Concerns for future health were instead around whether or not participants would be offered or would require further vascular intervention for their legs. Participants saw symptoms and disease as being one and the same thing, they believed they had a disease in the legs and they had no concept of the broader cardiovascular risks from generalized atherosclerosis. For those who had not been offered further vascular intervention, there was concern about what would happen to their mobility in the future.

Female, 66 *Well, I'm actually thinking I might end up in a wheelchair, you know?
And I would hate for that to happen.*

Participants feared that a consequence of claudication would be increasing dependence on family for help with transport, shopping and housework, due to reduced mobility.

Male, 63 *Well, I'm not getting any younger, I'm 63 year old. I hate to think my
legs would ever get that bad, and my son, would have to look after me,
I don't want that, you know what I mean? Sometimes I think my whole
life's went, I cannae walk, I just sit in the house.*

Surgeon Patient Communication

A number of participants commented that they did not understand the complicated, technical language used in surgical consultations; that consultations were rushed; and that they were unable to question surgical staff. These factors contributed to making several participants feel that they were not clear why decisions had been made.

Male, 65 *And when I was in the last time he (surgeon) was talking to a lady doctor and he said I was needing more but he started talking funny words that I didnae understand.*

This was especially the case for participants who were suffering claudication pain, but had had no further procedures offered - they did not understand why.

Female, 78 *At that point he said he didn't think there was really too much they could do, where it was or something. He showed me all the x-rays, I tried to look intelligent (laughs). I said "oh well, you know, fair enough.*

Surgical consultations were the main source of support and information for participants about PAD. There did not appear to be any congruence between participant understanding of PAD and the circulation system, and that of the surgeons. This could mean that although surgeons give patients information about PAD and treatment options (including physical activity), the patient cannot process the information in a way which is meaningful to them, reducing the likelihood that the patient will change their behavior.

Female, 72 *he seemed to know that this pain going up here is to do with the blood. But I didnae feel he explained it very well to me on Monday. He seemed to know exactly what I was saying, but there's nothing they can do. He said "There's nothing I can actually do, because it's it's up there", he sort of pointed up at my stomach. I felt he didnae really explain it clearly.*

DISCUSSION

From this qualitative interview study we found that patients with PAD continue to experience significant symptoms, including claudication pain, after receiving vascular intervention for IC. Patients with PAD have dysfunctional beliefs about their illness and about walking. In particular, patients with PAD viewed their illness as an acute, curable condition, which was the responsibility of health professionals; they did not appreciate the long-term health implications of PAD. Although many participants were aware they should be exercising, they had negative outcome expectations of walking, believing that walking was too painful, may damage their legs, and they lacked confidence in their ability to walk, therefore they tended to slow down and avoid exercise.

The Common-Sense Model of self-regulation of health and illness (CSM) suggests that whether or not people change health behaviour when faced with illness is influenced by their beliefs about the illness and their beliefs about treatment.¹² Coherence between an individual's illness beliefs and their beliefs about possible treatment is thought to be a key issue in self-regulation.¹² Weinman et al found that when patients did not have congruence between their illness and treatment representations, they did not undertake that treatment.¹³ We identified a number of areas of incongruence between patient beliefs about their illness, and beliefs about treatment, including communication from surgeons, and recommendations to increase physical activity. Our study suggests that the dysfunctional beliefs of patients after revascularisation leads to suboptimal coping actions which directly contravene evidence-based treatment guidelines, including avoiding exercise, reducing walking and slowing pace.

Participant causal beliefs were often incongruent, with some participants seeming to underestimate the role of smoking in the development of PAD. Yong et al found older smokers tend to underestimate the harm of smoking, believe smoking had not damaged their

health and believe medical evidence against smoking is exaggerated compared to younger smokers.¹⁶ Only 1 participant in this study had quit smoking as a result of diagnosis with PAD. Smoking cessation interventions for patients with PAD should target these incongruent beliefs about smoking. Validity and reliability was increased by following strategies outlined to increase the rigor of qualitative healthcare research,^{17,18} including having a clearly described process of analysis; peer debriefing through the presentation of methods and findings to relevant health professionals; and having more than one researcher involved in analysis. The sample represented patients who had all been treated for claudication with either angioplasty or surgery. Previous qualitative research into the experience of coping with PAD has not been theory based and has included patients with different levels of severity of PAD, and at different stages of treatment.¹⁹⁻²³

This study does however have some limitations. Participants were recruited from outpatient clinics, therefore there was a risk that we might miss the chance to recruit patients who had no ongoing leg problems or who had very poor health if they had failed to attend the clinic. However, scrutiny of the 'did not attend' list against the inclusion criteria by the vascular assessment nurse at each relevant clinic determined that all patients who met the inclusion criteria attended clinics on the days when recruitment for the study was taking place. All patients are followed up at clinics for at least 2 years after revascularization. The interview questions specifically explored the physical activity behavior and beliefs of participants. There may be other factors which influence the health behaviour of patients which were not covered by the interview.

CONCLUSIONS

The management of PAD should aim to reduce cardiovascular risk factors in order to achieve secondary prevention of both leg and other serious cardiovascular complications, in particular

1 myocardial infarction and stroke, and promote durable outcomes of endovascular/surgical
2 interventions. Our findings suggest that patients with PAD do not change physical activity
3 behaviour after diagnosis and treatment for IC, because they have dysfunctional and
4 incongruent beliefs about PAD, treatment, and health behaviors.
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9 Patients currently receive encouragement to change health risk behaviours in
10 consultations with health professionals, however, the information is not integrated into the
11 individual's framework of how they view their illness or their understanding of the
12 circulation system. This may be due, at least in part, to rushed consultations and the technical
13 language used. Further research is warranted to study how health professionals currently
14 approach health risk behavior change in patients with PAD, and the barriers and facilitators to
15 changing health risk behavior in this patient group.
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arterial disease. *J Nurs Scholarship.* 2002;34:55-60.

Table 1 Demographic characteristics of the participants (n=20)

DEMOGRAPHICS	Participants
Age, mean (SD)	70.9 (6.6)
Male, n (%)	11 (55)
Retired, n (%)	19 (95)
Education – highest level attended, n (%)	
Secondary schooling	19 (95)
Tertiary education	1 (5)
Living Arrangements, n (%)	
Living alone	12 (60)
Risk factors, n (%)	
Diabetes	5 (25)
Smoker	
Yes	5 (25)
Never	3 (15)
Quit	12 (60)
Comorbidities, n (%)	
Heart Disease	9 (45)
Stroke	3 (15)
Vascular Interventions, n (%)	
Bypass graft	12 (60)
Angioplasty	8 (40)

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**Illness beliefs and walking behavior after revascularisation
for intermittent claudication – a qualitative study**

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Intermittent Claudication Beliefs

Intermittent claudication (IC) is a common symptom of peripheral artery disease (PAD), characterized by cramping leg pain when walking, which relieves upon rest. PAD is a prevalent chronic condition which affects ~10% of adults over 50 years, and ~19% of adults over 70 years.¹ PAD is usually caused by atherosclerosis, and indicates systemic atherosclerosis. International guidelines for the treatment of PAD recommend risk factor management through patient behavior change, in particular smoking cessation, weight loss, and increased physical activity.² However, rates of angioplasty to treat the symptoms of claudication have dramatically increased in recent years.³

Comment [maw1]: Please use JCRP citation format. This paragraph has been corrected to example for the remainder of the paper

Typically, success of vascular intervention for IC is measured by walking capability in treadmill tests or with self-report quality of life questionnaires. These measures do not give an understanding of patient actual day-to-day physical activity behavior after revascularization; however, there is evidence that people with PAD walk significantly less than other older adults^{[4,5], 4,5}. Current treatment, including vascular intervention, supervised exercise programs, and ‘go home and walk’ advice, do not change physical activity behavior of PAD patients^{[6-10], 6-10}. As PAD typically involves multiple sites throughout the arteries, patient behavior change is important alongside vascular intervention to improve health and reduce the risk of cardiovascular comorbidity and mortality. Physically inactive patients with IC have twice the mortality risk of moderately physically active (1 to 3 hours per week moderate physical activity) patients over 5 years, suggesting that even low levels of physical activity would be beneficial for patients with IC^{[11], 11}. The Common-Sense Model of self-regulation of health and illness (CSM) is a popular concept which has been used to understand modifiable determinants of behavior in a number of chronic diseases^{[12,13], 12,13}.

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The CSM proposes that when faced with disease symptoms, patient behavior is influenced by their beliefs about the illness and their beliefs about treatment. The CSM proposes that these beliefs determine the cognitive and behavioral actions which the

individual will take to cope with the illness and improve health. The objective of this study was to explore the beliefs and physical activity behavior of patients with peripheral artery disease who have received vascular intervention.

METHODS

Semi-structured interviews were conducted with participants in their own homes. Interview transcripts were analysed using Thematic Analysis ^{[12], 14} Participants were recruited from vascular outpatient clinics in 2-two regional urban hospitals in Scotland. The local NHS Research Ethics Committee approved this study.

Comment [maw2]: Were there any basic differences in the 2 hospital, eg, urban vs, rural; inner-city vs suburban, etc?

Participants and Procedure

Consecutive patients attending vascular outpatient clinics following angioplasty or bypass surgery were invited to participate in the study. Inclusion criteria included an original diagnosis of IC, and revascularization surgery or angioplasty between 6 months and 2 years previous to recruitment. This time scale was a pragmatic choice to reduce the risk that participants were still experiencing the short-term effects of surgery (6 months), and so that participants were captured before discharge from followup (2 years). Potential participants were excluded from the study if they were unable to speak English, had a psychiatric illness or were known to be taking part in other studies. Sample size was determined by minimum sample size (10 participants) and stopping criteria (no new information identified from preceding 3 interviews) ^{[13], 15} The final sample had 20 participants.

Informed consent was taken prior to the interview commencing. Interviews were conducted by a researcher trained in qualitative methods and interviewing techniques. Interviews were taped and transcribed verbatim and their accuracy checked against the original tapes. The interviews followed an interview schedule guided by the study aims to

explore participant physical activity behavior and beliefs about their illness, with questions based on the CSM. This model proposes that people form lay illness beliefs which contain information about the identity of the illness, the temporal features of the illness, the imagined and real consequences of the illness, the causes of the illness, and beliefs about whether the illness can be cured or controlled^[12].¹² The interview included the open questions: Can you tell me all about what has happened with your legs? What are your current symptoms? What do you believe caused the peripheral artery disease (problems in your legs)? What do you think will happen to your health in the future? How can you control your peripheral artery disease? How have you changed your health behaviors since the operation? How active are you on a typical day? Can you describe what kind of walking you usually do? What are the advantages or disadvantages of doing more physical activity? Participants were also asked to describe what they believed happened inside their leg to cause the walking pain. Probing questions were posed as necessary during the interview in response to issues raised by participants.

Analysis

The interview transcripts were analysed using thematic analysis^[12],¹⁴ which is a common form of qualitative analysis. Our analysis was concerned with the experiences, meaning, and reality of participants. We took a theoretical approach to thematic analysis, coding the interview transcripts in relation to the specific aims of the study, ie, focusing on the beliefs and physical activity behavior of participants.

Two researchers, a psychologist and exercise physiologist, conducted independent initial analysis of the transcripts - familiarization with the data, initial code generation, and searching for initial themes. The researchers read and re-read the transcripts fully in order to form a sense of the whole interview (familiarization). The transcripts were then searched

systematically for statements related to the study aims (beliefs and physical activity behavior of participants). Coding was performed manually by marking relevant statements with a highlighter and assigning a brief descriptive label for each statement in the transcript margins (initial code). All data sets were coded, and then statements were collated together under each code in a separate notebook. Initial codes were then sorted into subcategories by grouping statements with similar meaning, and these were reviewed between the researchers. The researchers discussed initial coding decisions and subcategory groupings in detail, with the goal of reaching consensus. There was a high level of agreement between the researchers of subcategories identified in the analysis. The researchers then worked together to discuss, agree and refine the final themes, by grouping and integrating inter-related subcategories. The researchers then re-read the interviews and considered whether the individual final themes accurately reflected the meaning in the interviews. Each theme represented a pattern of meaning identified in the set of interviews which related to the aims of the study. The analysis was therefore deductive in that it focused on the specific aims of the study. A vascular surgeon independently reviewed the transcripts, checking his agreement with the coding of the themes.

RESULTS

Of the 25 patients invited to participate, 3 declined to take part in the study and 2 participants failed to attend interviews, therefore 20 interviews were conducted. Participant characteristics are shown in Table 1.

Five themes were identified in the analysis, which help to explain the physical activity behavior and illness and physical activity beliefs of patients with IC after they have received vascular intervention. These themes are described in the following section.

Walking Avoidance

While most participants were aware that they should be trying to walk, no participants had a clear understanding of how much walking they should be doing, the recommended intensity of walking, or critically, the mechanism by which walking would improve their health. Despite having received vascular intervention, the majority of participants felt they couldn't exercise because of the pain they experienced when walking, loss of confidence in their walking abilities, the feeling that their legs had lost power, and because they tired very quickly when they tried to walk. As a result of claudication pain, most participants had given up trying to exercise.

Male, 73 *Again it just comes down to the walking, so you can't exercise as much. I mean even going round the shopping centre, you cannae, I mean you've just got to stop and rest.*

Critically, participants did not view walking as a potential treatment for their IC. Participants avoided walking into the claudication pain, worrying that the pain was an indication of damage to the leg. While avoidance is a natural reaction to pain, claudication pain does not cause damage – this highlights the incongruity between participant perception of pain, and the reality of the disease.

Male, 68 *I'm scared of walking in case I damage my legs.*

Participants generally had a limited understanding of the reason why they experienced leg pain when walking. Although some participants understood that they had a narrowing in their circulatory system, they did not understand how this caused pain when walking.

Female, 72 *It's a vein. I've got a lot of wee veins. I've been led to believe the vein's narrowed. I don't know how it's causing the pain.*

Other participants had no understanding of what happened within their leg to cause leg pain.

Intermittent Claudication Beliefs

Female, 66 *The pain starts in the foot and works its way up my legs and into my hips and then my back. I've no idea why.*

Female, 70 *Maybe like an oil change in a car, the older you get it's maybe needing renewed ken, like your blood supply, ken? I don't know. I don't know.*

When asked about the advantages of doing more physical activity, participants responded in terms of tasks or activities they would like to be able to do, rather than with disease-specific benefits. No participants mentioned the potential for symptom reduction, or development of a collateral blood supply as an advantage of increased physical activity.

Male, 73 *Well, I'd like to be able to go to the fishing, things like that. I cannae dae that now. I used tae dae a lot of walking. The legs wouldnae be up to it, nae, nuh, nuh.*

Participants adapted to having limited mobility by changing the way they spent their leisure time, giving up hobbies which involved physical activity and instead finding hobbies where they didn't need to walk. By reducing their physical activity levels, and slowing their pace, participants avoided experiencing pain.

Male, 81 *I don't really go out. I stay in and watch the telly.*

Male, 77 *I never got another dog, because I wasnae fit to take him walks, wi' my legs. I never got another dog. That's the first time I've been without a dog all my life....*

Treatable Condition

Participants viewed their illness as acute and treatable, rather than a chronic condition which required self-management. Patients focused solely on the symptom (IC) rather than the disease (PAD). Despite having received vascular intervention all participants reported having current symptoms including claudication pain, swelling, tightness, throbbing, numbness,

cramps at night, problems bending the knee and nerve damage, although symptoms varied greatly in severity. While some of these symptoms are attributable to PAD, others occur as a result of surgery, and this indicates the participants may have had unrealistic expectations about vascular intervention, and lack of knowledge about the consequences of surgery.

Several participants spoke about the lack of information they were given about their postoperative health, especially their lack of knowledge about what to do about nerve damage and swelling after surgery. Participants generally viewed the pain as something which they hoped could be treated by further surgical intervention or which would disappear magically with time – critically, they did not feel there was anything they could do to improve their symptoms or disease.

Male, 58 *I wanted the operation thinking obviously this was going to cure it.*

Female, 70 *So I'm hoping and praying that (the surgeon) will be able to cure me.*

Female, 72 *I'll just take it a day at a time, and see what happens. So I feel, well, if it happens it happens, what can I do, eh? But eh, I just hope it doesn't get any worse. Hopefully it'll go away.*

Participants viewed surgeons as the gatekeepers over treatment and control of claudication symptoms. Participants originally received a diagnosis of PAD from vascular surgeons, and this appears to have triggered their acute belief system that surgical intervention was the standard treatment and cure for their symptoms.

Causal Beliefs

Participants cited a wide variety of factors which they felt had caused their PAD. The main cause mentioned by participants was smoking, 14 of the 17 (82%) participants who were either current or past smokers, mentioned smoking as a possible cause of their disease.

However, several participants mentioned that they were reporting this as a cause because

their doctor had told them that smoking was a cause, but indicated that they did not necessarily believe this:

Female, 65 *It's cos of this (waves cigarette). Well, that's what they said anyway.*

Female, 72 *Well, they say the smoking. I mean, I don't know.*

Only 1 participant had quit smoking as a result of being diagnosed with PAD. Participants had no clear conceptual framework which explained how, eg, smoking could cause calf pain. This was especially the case when there was a time lag between ceasing the causal behavior and onset of claudication symptoms.

Female, 66 *I've given up (smoking) for 5 year. So, it's not the smoking any more (causing the PAD).*

Several participants said that they had no idea what had caused their disease. Of this group, some were or had been smokers, and some had diabetes – they had risk factors for the disease but were not aware of this:

Female, 70 *I've no idea, that's what I'm saying I just wondered if the metformin for the diabetes had anything to do with it? I don't know... I don't know. As I say, I thought maybe the medication had something to do with it.*

Several participants felt that some form of physical activity had caused their claudication symptoms. Lack of physical activity is a risk factor for developing IC, however, it is logical that patients with poor understanding of the circulation system may develop the belief that physical activity is the cause of their muscle pain.

Male, 70 *Right, I had 2 dogs, 3 actually, and I used to take them a walk every day and every night, I always walked them. So I don't know whether that could have been it, maybe going out in the damp weather, I used to*

go out in all weather, you know? And I don't know whether that caused it, you know?

Later in the interview, this participant went on to describe how he had given up his dog because he did not feel able to take it for walks due to the leg pain. The participant model of his illness was logical and coherent (to him) and clearly led to his choice of behavior—nonadherence to walking advice, ie, walking had caused his illness, therefore it would be illogical to walk now.

Perceived Consequences

Participants were not concerned about the implications of PAD and atherosclerosis to their general health. No participants mentioned any concern or awareness about their risk of stroke or heart trouble. Concerns for future health were instead around whether or not participants would be offered or would require further vascular intervention for their legs. Participants saw symptoms and disease as being one and the same thing, they believed they had a disease in the legs and they had no concept of the broader cardiovascular risks from generalized atherosclerosis. For those who had not been offered further vascular intervention, there was concern about what would happen to their mobility in the future.

Female, 66 *Well, I'm actually thinking I might end up in a wheelchair, you know? And I would hate for that to happen.*

Participants feared that a consequence of claudication would be increasing dependence on family for help with transport, shopping and housework, due to reduced mobility.

Male, 63 *Well, I'm not getting any younger, I'm 63 year old. I hate to think my legs would ever get that bad, and my son, would have to look after me, I don't want that, you know what I mean? Sometimes I think my whole life's went, I cannae walk, I just sit in the house.*

Surgeon Patient Communication

A number of participants commented that they did not understand the complicated, technical language used in surgical consultations; that consultations were rushed; and that they were unable to question surgical staff. These factors contributed to making several participants feel that they were not clear why decisions had been made.

Male, 65 *And when I was in the last time he (surgeon) was talking to a lady doctor and he said I was needing more but he started talking funny words that I didnae understand.*

This was especially the case for participants who were suffering claudication pain, but had had no further procedures offered - they did not understand why.

Female, 78 *At that point he said he didn't think there was really too much they could do, where it was or something. He showed me all the x-rays, I tried to look intelligent (laughs). I said "oh well, you know, fair enough.*

Surgical consultations were the main source of support and information for participants about PAD. There did not appear to be any congruence between participant understanding of PAD and the circulation system, and that of the surgeons. This could mean that although surgeons give patients information about PAD and treatment options (including physical activity), the patient cannot process the information in a way which is meaningful to them, reducing the likelihood that the patient will change their behavior.

Female, 72 *he seemed to know that this pain going up here is to do with the blood. But I didnae feel he explained it very well to me on Monday. He seemed to know exactly what I was saying, but there's nothing they can do. He said "There's nothing I can actually do, because it's it's up there", he*

sort of pointed up at my stomach. I felt he didn't really explain it clearly.

DISCUSSION

From this qualitative interview study we found that patients with PAD continue to experience significant symptoms, including claudication pain, after receiving vascular intervention for IC. Patients with PAD have dysfunctional beliefs about their illness and about walking. In particular, patients with PAD viewed their illness as an acute, curable condition, which was the responsibility of health professionals; they did not appreciate the long-term health implications of PAD. Although many participants were aware they should be exercising, they had negative outcome expectations of walking, believing that walking was too painful, may damage their legs, and they lacked confidence in their ability to walk, therefore they tended to slow down and avoid exercise.

The Common-Sense Model of self-regulation of health and illness (CSM) suggests that whether or not people change health behaviour when faced with illness is influenced by their beliefs about the illness and their beliefs about treatment^{[15].¹²} Coherence between an individual's illness beliefs and their beliefs about possible treatment is thought to be a key issue in self-regulation^{[15].¹²} Weinman et al⁴⁶ found that when patients did not have congruence between their illness and treatment representations, they did not undertake that treatment.¹³ We identified a number of areas of incongruence between patient beliefs about their illness, and beliefs about treatment, including communication from surgeons, and recommendations to increase physical activity. Our study suggests that the dysfunctional beliefs of patients after revascularisation leads to suboptimal coping actions which directly contravene evidence-based treatment guidelines, including avoiding exercise, reducing walking and slowing pace.

Participant causal beliefs were often incongruent, with some participants seeming to underestimate the role of smoking in the development of PAD. Yong et al¹⁷ found older smokers tend to underestimate the harm of smoking, believe smoking had not damaged their health and believe medical evidence against smoking is exaggerated compared to younger smokers.¹⁶ Only 1 participant in this study had quit smoking as a result of diagnosis with PAD. Smoking cessation interventions for patients with PAD should target these incongruent beliefs about smoking. Validity and reliability was increased by following strategies outlined to increase the rigor of qualitative healthcare research,^{18,19,17,18} including having a clearly described process of analysis; peer debriefing through the presentation of methods and findings to relevant health professionals; and having more than one researcher involved in analysis. The sample represented patients who had all been treated for claudication with either angioplasty or surgery. Previous qualitative research into the experience of coping with PAD has not been theory based and has included patients with different levels of severity of PAD, and at different stages of treatment^{[20-24].¹⁹⁻²³}

This study does however have some limitations. Participants were recruited from outpatient clinics, therefore there was a risk that we might miss the chance to recruit patients who had no ongoing leg problems or who had very poor health if they had failed to attend the clinic. However, scrutiny of the 'did not attend' list against the inclusion criteria by the vascular assessment nurse at each relevant clinic determined that all patients who met the inclusion criteria attended clinics on the days when recruitment for the study was taking place. All patients are followed up at clinics for at least 2 years after revascularization. The interview questions specifically explored the physical activity behavior and beliefs of participants. There may be other factors which influence the health behaviour of patients which were not covered by the interview.

CONCLUSIONS

The management of PAD should aim to reduce cardiovascular risk factors in order to achieve secondary prevention of both leg and other serious cardiovascular complications, in particular myocardial infarction and stroke, and promote durable outcomes of endovascular/surgical interventions. Our findings suggest that patients with PAD do not change physical activity behaviour after diagnosis and treatment for IC, because they have dysfunctional and incongruent beliefs about PAD, treatment, and health behaviors.

Patients currently receive encouragement to change health risk behaviours in consultations with health professionals, however, the information is not integrated into the individual's framework of how they view their illness or their understanding of the circulation system. This may be due, at least in part, to rushed consultations and the technical language used. Further research is warranted to study how health professionals currently approach health risk behavior change in patients with PAD, and the barriers and facilitators to changing health risk behavior in this patient group.

ACKNOWLEDGEMENTS

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Comment [maw3]: Please use accepted journal abbreviations for all citations

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Table 1 Demographic characteristics of the participants (n=20)

DEMOGRAPHICS	Participants
Age, mean (SD)	70.9 (6.6)
Male, n (%)	11 (55)
Retired, n (%)	19 (95)
Education – highest level attended, n (%)	
Secondary schooling	19 (95)
Tertiary education	1 (5)
Living Arrangements, n (%)	
Living alone	12 (60)
Risk factors, n (%)	
Diabetes	5 (25)
Smoker	
Yes	5 (25)
Never	3 (15)
Quit	12 (60)
Comorbidities, n (%)	
Heart Disease	9 (45)
Stroke	3 (15)
Vascular Interventions, n (%)	
Bypass graft	12 (60)
Angioplasty	8 (40)



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29th October 2013

To Dr Mark A. Williams,

RE: JCRP-D-13-00074R1, entitled "Illness beliefs and walking behaviour after revascularisation for intermittent claudication - a qualitative study"

Please find attached the amended manuscript for the above study. I have made the following changes:

1. To Title Page:
 - a. I have added the country (Scotland) to the address of the 5th author.
2. To Manuscript:
 - a. I have included a description of where the study took place (two regional urban hospitals in Scotland).
 - b. I have changed the format of the in-text references.
 - c. I have used accepted journal abbreviations in the reference list.

Thank you for accepting this paper for publication in the Journal of Cardiopulmonary Rehabilitation and Prevention.

Yours sincerely,

Maggie Cunningham PhD