

“Standing still in the street”: Experiences, knowledge and beliefs of patients with intermittent claudication—A qualitative study

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Objectives: To explore the experiences of individuals living with intermittent claudication (IC) owing to peripheral artery disease (PAD), their knowledge about the condition, and their thoughts about being asked to walk more and an intervention to promote walking.

Methods: We conducted five focus group sessions with 24 people (71% male; mean age, 71 years) diagnosed with IC with no prior lower extremity revascularization.

Results: Two overriding themes emerged: uncertainty and lack of support/empathy. Participants expressed uncertainty about PAD and IC, how risk factors work, and whether lifestyle change, particularly walking, would help. They also expressed dissatisfaction with and lack of empathy from the medical professionals encountered, with feelings of being dismissed and left on their own. There was enthusiasm for an education program to support their self-management of the disease.

Conclusions: Addressing the knowledge gaps and uncertainty around the disease process and walking will be critical to providing impetus to behavior change. A structured education approach to address these issues seems to be desirable and acceptable to those living with PAD.

Practice implications: Those working with PAD patients should provide clear and consistent information about the disease process and specific information on walking, as well as support to enable and manage behavior change. (J Vasc Nurs 2015;33:4-9)

Lower extremity peripheral artery disease (PAD) affects 202 million people globally and >10% of the population aged >70 years, with incidence that is rising.^{1,2} Some 50%-80% of patients with PAD are symptomatic and suffer from intermittent claudication (IC), which is a cramp-like leg pain that occurs during walking and is relieved by rest.³ IC reduces functional status, impairs quality of life, and results in substantial morbidity and mortality, both directly and through its strong association with systemic atherosclerosis.³ In addition to these clinical concerns, PAD treatment also generates substantial costs for the health care system.^{4,5}

A primary therapeutic goal for patients with IC is to regain lost physical function through exercise rehabilitation.⁶ Medically supervised exercise programs have demonstrated clinical efficacy with large improvements noted for claudication onset and peak walking times.⁷⁻⁹ Supervised exercise programs have been given a Class 1 recommendation by the American College of Cardiology and the American Heart Association¹⁰ and recently the UK's National Institute for Health and Care Excellence (NICE) issued guidance on the management of PAD recommending that a supervised exercise program be offered to all patients with IC.¹¹ Unfortunately, supervised exercise programs conducted within a formal health care setting are not widely available for patients with IC in the National Health Service,¹² and where they do exist they often have poor patient uptake and very high drop-out rates ($\leq 50\%$).¹³ Furthermore, supervised exercise programs may not improve daily walking activity away from the program.¹⁴ Given the lack of availability of supervised exercise programs within a health care system, basic walking advice is more commonly provided. This approach, however, has very limited efficacy, resulting in little change in walking behavior.^{15,16} An alternative approach could be home-based exercise programs that require individuals to self-manage their exercise. Such an approach has the potential to improve walking behavior in patients with IC at a much lower cost compared with institution-based, medically supervised exercise programs. In addition, home-based programs are also likely to be more acceptable to this patient group as a whole because the requirement to travel, with its associated costs, would be removed. However, the evidence for the efficacy of such programs is weak and mixed.¹⁷ Many of the studies have suffered

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from methodological flaws, most notably nonrandomized study designs and a lack of accurate quantification of the exercise volume performed. A further limitation of many previous home exercise programs is that they have been impractical and have failed to consider adequately patient knowledge and beliefs about their condition.¹⁸

Currently, there are few data on how individuals with IC view their condition. The evidence reviewed by NICE¹¹ suggested that patients with PAD often lack understanding of the causes of PAD and often do not believe that lifestyle interventions such as increased walking will make a difference to the outcomes of their disease, meaning that there is little incentive to change behavior. Other work, not included in the NICE review, also supports this contention. For example, Galea et al¹⁹ reported that uncertainty about PAD and a lack of knowledge about the benefits of walking, particularly with respect to pain, represented a cognitive barrier to actually walking. Similarly, Barbosa et al²⁰ reported that the most common barriers to physical activity in PAD patients were related to the pain experienced when walking. However, much of this evidence comes from PAD patients who have been referred for operative intervention, and therefore may not reflect the understanding and beliefs of the majority of PAD patients being managed conservatively (eg, through lifestyle behavior interventions). NICE¹¹ recommended further research to explore more deeply patients' attitudes, beliefs, and knowledge about PAD and the types of physical activity and behavior change interventions that might result in improved outcomes for patients with IC. Such research is also recommended as a critical step within the development phase of complex interventions.²¹

The aim of the current research was to inform the development of a pragmatic self-management intervention for promoting walking in patients with IC in the United Kingdom. The approach proposed for the intervention was structured education, modelled on the self-management programs used in diabetes care.^{22,23} This approach encourages patients to participate in an interactive way in their learning about their medical condition and associated risk behaviors, usually through nondidactic educational workshops that include group discussions, experiential learning and practice, self-monitoring, and goal setting to promote self-efficacy and self-managed behavior change.²² The current study sought to ascertain individuals' experience of living with PAD, their knowledge about the condition, and their thoughts about physical activity and intervention programs, particularly structured education.

METHODS

Design

This study adopted a qualitative approach, and utilized a focus group methodology to explore patients' perceptions.

Sample

Twenty-four patients with IC owing to PAD were recruited via screening vascular clinic letters at a hospital in the midlands in the United Kingdom. Participants took part in one of five focus groups. The groups were 71% male and 100% White British, with a mean age of 71 years (SD = 8) and a median duration of claudication symptoms of 17.5 months (range, 3-180 months).

TABLE 1

TOPIC GUIDE FOR FOCUS GROUPS

Outline topic areas

Experiences of living with PAD/IC
 Attitudes and beliefs about PAD/IC
 Educational needs of people with PAD/IC
 Attitudes and beliefs about physical activity/exercise
 Levers and barriers for exercise behavior change
 Opinions of behavior change interventions, particularly structured education

IC = intermittent claudication; PAD = peripheral artery disease.

Inclusion criteria were age ≥ 18 years, an ability to understand and speak English to a sufficient standard to allow participation in a focus group session, and stable IC for ≥ 3 months accompanied by an ankle-to-brachial systolic blood pressure ratio of ≤ 0.90 in their most symptomatic leg at rest. Exclusion criteria were an absence of PAD, asymptomatic PAD, critical limb ischemia, previous lower limb revascularization, and the presence of contraindications to exercise or comorbidities that limited walking to a greater extent than the IC (eg, severe arthritis). Written, informed consent was obtained before patients entered the study.

All focus group sessions were undertaken and audio recorded by two researchers. The topic guide is presented in Table 1. Participants were asked to complete a brief questionnaire before the focus group discussion on physical activity, which assessed their level of interest, readiness, and confidence in making a change to their walking behavior (0%–100%), the importance they place on making a change (0%–100%), the main barriers they have to being physically active, and any potential solutions to these barriers. This questionnaire was used to prompt participants' thoughts about their own physical activity behavior. Sessions lasted between 60 and 75 minutes and were conducted over a 3-month period between May and August 2013. The audio recordings were transcribed verbatim by an independent source and checked for accuracy by one researcher. After five focus groups, there was consensus agreement between the interviewers that no new information was emerging; therefore, further groups were not required.

Data analysis

A thematic analysis was employed to analyze the focus group data. This involved reading and rereading the transcripts to become familiar with their content, the identification of themes within the data, using the themes to code the interviews, identification and development of higher order themes and linkages, and interpretation of findings. All interviews were coded using the NVivo qualitative data indexing package (NVIVO 10) with two of the research team identifying the initial thematic structure. Themes were indexed and charted with accompanying quotes. A third researcher then independently read the transcripts and reviewed the identified thematic framework. Consensus and agreement was reached on key subthemes.

RESULTS

The data presented herein illustrate the main themes arising from the analysis with overriding themes of uncertainty and

lack of support/empathy pervading all of these. There was uncertainty about PAD and IC, uncertainty about how risk factors work, and uncertainty about whether lifestyle change, particularly physical activity, would help. There was a strong sense of dissatisfaction with and lack of empathy from the medical professionals encountered with a feeling of being dismissed, being left on their own, and a lack of awareness of them as a person.

Knowledge and experience of living with PAD

The participants all experienced leg pain on walking that was worse or came on more quickly when trying to walk faster or on slopes. Some participants also described experiencing cold or numb feet. The pain was described as being “just like somebody gripping the calf muscle really tightly”, “crippling”, “stops me in my tracks”, and having a “wearing effect”.

What is PAD?

It was evident that the participants for the most part had a general idea of what PAD was: “a blockage with either plaque or fat”, and “hardening of the arteries, where the blood just doesn’t flow properly”. A few participants were uncertain and professed not to know, saying “I don’t understand anything about it”. Many were unsure what IC was and this was not a term many used. All groups recognized that PAD was permanent, although one group discussed that it was something to manage and that symptoms might improve: “I think it’s something you’ve got and there’s not an awful lot that can be done about it, help yourself to walk as much as you can, and watch your diet basically, watch your cholesterol level”.

Causes

There was widespread awareness that smoking was a risk factor for PAD, with all groups raising this. Other risk factors (eg, family history, age, overweight) were identified across the groups, but only one group identified lack of physical activity as a risk factor. There was uncertainty about the nature of risk factors, with some participants seeming to struggle with the idea of risk, perhaps seeing a risk factor as all or nothing or confounding risk and outcomes: “If it’s age then why does it affect some and not others?”; “Is it always caused by smoking then, because I know my father, he had from him being about 60, he had leg problems same as what I got, and he’d never smoked in his life”; “But I mean my husbands as thin as a rake and he’s got high cholesterol”.

Impact/consequences

PAD was seen to have had a negative impact on the lives of the participants. It created embarrassment when they had to stop walking to let the pain subside and had resulted in a contraction of activities. For example, one participant commented that, “You feel such an idiot standing in the street, you know, standing still in street while your legs recover, you sort of try and look as though you’re waiting for somebody or something”. Participants also noted how it had reduced their ability to be spontaneous and they had to plan any walking activity to avoid hills and allow greater time. As examples, one participant noted, “But the problem that I find, and I think the gentlemen will find same, is that

you really have to plan how you’re going to get from A to B. Like I was going to football the other day and I hadn’t been for ages, and I thought how much walking have I got to do. So you really have to plan if you want to be comfy how far you can walk yourself, and plan where you’re going so it’s not too uncomfy for you”. Another said, “I think that’s one of the biggest problems that we face isn’t it, having to plan it instead of just being spontaneous like we used to be”. There was evidence of an impact on self-identity and pride: “He [doctor] said have you got a stick, I said, I’ve got a walking stick but I don’t like using it because old ladies stand up on the bus and let me have a seat. You know what I mean? I just don’t like using it”. Others described it as life changing and decreasing enjoyment.

Experience of diagnosis and care

Many had delayed seeking medical attention because they either ignored the symptoms, were too busy, or thought it was just a cramp. There was a strong perception that they did not get as much attention or treatment as other conditions with little planned follow-up: “When I actually got diagnosed, I was there 10 minutes, then it was this, this, this and that, right you’re discharged, that’s it, go”. There was a perceived lack of empathy or awareness of them as a person, with a sense of being left alone with little specific information or advice: “I mean everything I’ve got I want to know about, and you don’t get to know, simple as that, you ask and you don’t get a full explanation”. Often, they had received mixed advice, which created confusion. Few recalled being given any written material to take away and all groups mentioned that they would have liked consistent, clear, and specific information, and a much greater sense of support from medical professionals.

What can you do to manage your PAD?

There was awareness of surgical treatment options, but most had been told these carried a lot of risk and were not appropriate for them, or had chosen not to take the risk: “Well he told me a bypass and there was a good chance of losing my leg, so I said well I won’t go down that route”.

Most participants were aware that there were things that they could do themselves to help to manage their condition, but these were general suggestions with little specificity. For example, participants made general comments about stopping smoking, losing weight, watching their diet, and doing some exercise. However, they seemed uncertain as to exactly what they should do and whether these would necessarily have any effect. For example, one participant who had recently quit smoking suggested that if it was not going to be of benefit she would start smoking again: “Is it going to help having stopped smoking or not, because if not I’ll start again”. One group suggested that they should only look to change one thing at a time. One participant said there was nothing they could do and another said they had no control over the condition.

Most sources of information about their condition and what they could do were from outside medical contact. For example, they sought information from books, family, the Internet, and word of mouth. One participant said they did not want to know more: “I don’t [look for further information], I’d sooner not know ... it’d scare the living daylights out of you”.

Physical activity as a treatment

When asked specifically about physical activity, the participants recognized many forms of physical activity (eg, walking, things you do at home, swimming, gardening, stretching, cycling), but there was an element of uncertainty as to what counts and whether it works: "I don't know [if walking helps], that's what we need to know". In addition, there was a suggestion of conflict as walking causes pain, yet they were being asked to walk to reduce the pain: "[E]xercises causes pain which you're trying to get rid of". Participants also expressed fear that physical activity might make things worse: "I think that's one of the fears is that you're going to do damage by doing a lot of walking". There was also concern about whether they could do enough physical activity to make a difference: "I'm on the fence with this, because I'm not quite sure whether it will or not because I don't know how much you can push yourself to do what is necessary to improve it. You can only do so much can't you before you have to stop, and I think maybe you'd need to go that extra bit to show improvement, which I don't know whether we could do that. Will walking improve the condition?" There was a general impression that the participants lacked information on what exercise works and how to handle the pain: For example, should they stop or try to walk through the pain?

Benefits of physical activity

Many general benefits of physical activity were identified including "helping heart", "feeling fitter", "weight management", "feeling better mentally", and "not stiffening up". Some benefits specific to PAD were mentioned, such as being able to walk farther without pain and recovering quicker from pain. One individual mentioned the potential for collateralization: "I'm hoping that I will develop peripheral circulation. It means that another blood vessel grows around the blockage, and I understand that it's not impossible even at my age". One group also mentioned being "able to do what normal people do". Despite recognizing many potential benefits of physical activity, the majority of participants either said they were not doing enough or were unsure whether they were.

Barriers to physical activity

Not surprisingly, pain was seen as the biggest barrier: "It's just the pain, you can't get that far, so I said half the time what's the point? That's the reason I won't go out". Other barriers included a lack of motivation for exercise in general ("I don't think there's any kind of inspiring exercise, and that's what I seek"), lack of time, age ("why bother at my age?"), weather/season ("I don't do as much walking in winter. Because with being on slopes they never grit [spreading of salt to prevent formation of ice] the pavements you see"), a fear of damage ("I think that's one of the fears is that you're going to do damage by doing a lot of walking"), and a lack of confidence to be either able to do enough to get benefit, or that the walking is having any benefit ("and even though like you stop and you carry on, the pain's there so you don't know whether, actually whether the walking is doing [anything] because the pain still comes back").

Motivation

The participants saw significant motivation challenges to walking more. The participants indicated that the key to taking up and maintaining walking was a need to believe that it would make a difference and then to see some changes: "[J]ust a hint that it would make it better and I would make more of an effort" and "if you can see a result at the end of it they'll put more effort into it". There was acknowledgement from some that improvement may be slow and it may take a long time before distances improve. For example, one of the participants who walked regularly said: "I found that the thing to do was to stop, let your pain go away and then start again. And if I did that incrementally, slowly it built up, the amount of distance I could walk built up and built up and built up ... and it's slow, there's no doubt about it, you don't get 100 yards in a month, you get 100 yards improvement in probably 6 months. But it does happen".

Also, a lack of understanding about the pain or lack of clear advice about walking had led some people to stop: "I mean when I first got the pain I was understanding that the more I walked the more damage I was doing, so, and then now I've found out more about walking, so we can actually go back walking again".

Structured education

A possible intervention strategy based around a single, structured education session focused on walking promotion was described to participants and their opinion sought. An overwhelming majority of participants felt this would be a good approach and something they would be very interested in attending. Only one participant said it did not interest him because he was already walking. When asked about who should deliver an intervention, there was a clear sense that knowledge and empathy were the key factors, and the formal role of the person delivering the intervention was less important: "As long as they knew what they were talking about, as long as they knew what we were suffering". The group setting for the workshop appealed to participants because it could provide support, insight, and motivation: "I think it's better as a group because you hear other people's versions of how they're suffering with it, and how they're putting up with it and whatever they're doing about it. And you're not just thinking about your own problem, you can see various sides of it as well". The participants were personally ambivalent about inviting a significant other to accompany them, with most saying they would not want this but at the same time acknowledging that it might be important for some people and therefore should be offered.

The participants expressed a preference for some level of direct follow-up either by phone or face to face. A sense that this would aid motivation and create a perception of empathy emerged: "You think oh somebody cares about me, they're interested to know how I'm proceeding with this exercise and what have you". The participants were not clear on how often follow-up should occur, but one group mentioned it would need to be more frequent at the beginning.

DISCUSSION

This qualitative study provides insight into the experiences and knowledge of individuals with PAD and their perceptions on a proposed structured education intervention to promote

walking. Consistent with Egberg et al,²⁴ PAD had a significant impact on the lives of the participants and resulted in a curtailing of activities and a loss of enjoyment. Although the participants had some understanding about the condition, they expressed a degree of uncertainty around the specifics of the condition and about whether lifestyle change, particularly physical activity, would help. In addition, the participants reported a lack of empathy from the medical professionals encountered with a feeling of being dismissed, being left on their own, and a lack of awareness of them as a person.

Similar to Galea et al,¹⁹ the participants expressed a lack of certainty about the benefits of walking. In addition, there was uncertainty about how much walking was required. There was also uncertainty as to how walking, which causes pain, could actually lead to a reduction in symptoms. There was also a lack of clarity about whether they should stop on the onset of pain or attempt to walk through it. The inevitable onset of pain, and often severe pain, presents a substantial motivational challenge to the participants. Clearly demonstrating how much walking to do, what to do in response to pain, and how this walking would lead to changes that benefit the participant will be critical to the success of any intervention promoting walking. The participants will need to believe in the outcomes associated with walking if the pain to achieve them is to be tolerated.

These findings also highlight the importance given by participants to a sense of person-centered care with specific, consistent, and clear information provided. In common with the patients interviewed by Treat-Jacobsen et al,²⁵ participants perceived that they had received little help in achieving risk factor management, and advice was too general and often conflicting. The results also highlight the importance participants place on feeling that health professionals view them as individuals and demonstrate empathy for what the patient is experiencing.

Participants were enthusiastic about the structured education intervention that was proposed to them. By its very philosophy, such an approach would address many of the concerns raised by the participants and would provide potentially a structured and defined pathway of care and support that many sought. The opportunity for time with knowledgeable individuals, and also with others experiencing the same disease, was seen as valuable.

Although we adopted a rigorous, qualitative methodology to gain insight into the experience of living with PAD and a potential intervention strategy, this study has several limitations that should be acknowledged. First, we conducted focus groups that contained both men and women with varying degrees of disease progression and length of time living with PAD, and such an approach does not allow the association of particular experiences with specific disease characteristics or demographics. Second, our study population was drawn from one vascular care unit in one city and therefore responses may not generalize to those receiving care in other units. Finally, we excluded participants who had already undergone lower limb revascularization surgery and their experiences of living with the disease and the care received may differ from those managed more conservatively.

CONCLUSION

Participants with PAD emphasize uncertainty about the disease and the role that walking may play in its management.

They express uncertainty about how much walking, and with what level of pain, is required to achieve benefits. Addressing patient's knowledge gaps and uncertainty around the disease process and walking will be critical to providing impetus to behavior change. This study provides evidence to inform the development of an educational intervention to address these issues. Such an approach, in the form of a structured education intervention, would seem to be desirable and acceptable to those living with PAD.

PRACTICE IMPLICATIONS

From our findings, the following may be considered:

- Provide a treatment and management plan at the point of diagnosis.
- Written information about the condition to take away, in conjunction with ongoing support, is recommended.
- Provide clear and specific advice on walking and other behavior change recommendations.
- Consistent advice on managing pain when walking is recommended
- Group education was acceptable to participants and could be considered a pragmatic solution to provide support with limited resources

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