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## **Multifaceted needs of individuals living with peripheral arterial disease: a qualitative study**

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Running Head: Living with peripheral arterial disease

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## **Abstract**

### **Objectives**

To ascertain a comprehensive perspective of the impact of peripheral arterial disease (PAD) on people including needs for access to disease specific information, education, services, and support.

### **Methods**

Participants were recruited from outpatient clinics at a tertiary hospital in metropolitan Australia. Telephone and face-to-face semi-structured interviews were conducted with nine individuals living with PAD and analysed using qualitative content thematic analysis.

## **Results**

The nine participants were on average 74.2 (SD 10.9) years and predominantly women (67%). Lack of understanding of PAD and inconsistent information resulted in confusion regarding self-management strategies. Effects of pain and mobility problems were amplified for participants who lived alone and did not have an informal carer.

## **Discussion**

Poor quality of life in PAD reflects pain, social isolation and fear of falls. Multidisciplinary teams with case managers should consider older people's living situations and needs for additional support services and education to facilitate integrated care.

## **Multifaceted needs of individuals living with peripheral arterial disease: a qualitative study**

### **Introduction**

Advanced age brings increased prevalence of peripheral arterial disease (PAD) which is a common and debilitating chronic cardiovascular disease <sup>1-3</sup>. Lower limb pain or discomfort (known as intermittent claudication (IC)) is the main symptom that is stereotypically brought on by walking and relieved by rest <sup>4</sup>. As PAD progresses, IC may increase in severity and critical limb ischaemia may occur. This may result in constant lower limb rest pain, leg ulceration, sepsis, and possibly gangrene and amputation <sup>4</sup>.

PAD leads to decreased functional status <sup>5</sup>, reduction in quality of life <sup>6</sup>, increased healthcare utilisation and dependence on government support and services, if available and accessible. In the ageing population of Australia, these outcomes are especially salient for individuals who live alone and have less support <sup>7</sup>. Loss of independence and social roles compounded by adjusting to living with and managing one or more chronic conditions, can also impact on psychological wellbeing and potentially manifest in depression and anxiety <sup>8</sup>.

Occurring mainly among older adults, PAD is likely to increase as the population ages <sup>9</sup>. It is a major health problem with an estimated 20% of people over the age of 65 years having symptomatic or asymptomatic PAD <sup>10</sup>. While surgical and pharmacological interventions can provide short-term symptom relief, long-term benefits to quality of life and outcomes can only be achieved through behaviour change <sup>11</sup>. Self-management strategies can induce behaviour change through increasing self- efficacy and knowledge about PAD, its treatment and outcomes to better inform and upskill patients in activities that promote their own health, manage their symptoms, and adhere to any prescribed therapies.

Unfortunately, for many people with PAD, there are limited opportunities available that offer specialised and tailored self-management programs to support behaviour change and management of the physical and psychological burdens of this debilitating chronic cardiovascular disease. Although such programs are used in the USA <sup>12,13</sup>, UK <sup>14</sup>, and Germany <sup>15</sup> such programs do not exist in Australia. Thus, unlike patients with other chronic forms of cardiovascular disease, such as heart failure, people with PAD often have to do manage their own health without dedicated multidisciplinary teams to support them.

Literature has emphasised the impact of IC on the lives of individuals, including pain-induced physical and social limitations <sup>16, 17</sup>. This study sought a more complete perspective of the impact of PAD on people's quality of life and perceived needs for better access to disease-specific information, education, services, and support. By gaining this knowledge, appropriate and effective self-management interventions can be designed and trialed to address the needs of individuals with PAD.

## **Methods**

This qualitative descriptive study was guided by a realist approach using semi-structured interviews and qualitative content analysis <sup>18</sup>. Participants were eligible to participate if they had a confirmed diagnosis of symptomatic PAD and were able to communicate in English. They were ineligible if they were suffering from other serious illness, such as multi-organ failure and non-cardiovascular-related leg amputation or a terminal illness such as cancer, moderate, severe or very severe chronic obstructive pulmonary disease, or New York Heart Association (NYHA) Functional Class II-IV heart failure that might overshadow the experience of PAD. Individuals who were unable to speak and understand English or who had cognitive impairment were also excluded from participating in this study.

Participants were recruited from an outpatient wounds clinic and a podiatry clinic at a tertiary hospital in a metropolitan area of Australia between March 2016 and October 2017. Servicing an inner-city catchment encompassing a range of socio-economic demographics, these clinics were targeted for recruitment because they provide care to patients who require assistance with wound management related to peripheral arterial and venous disease. Clinicians, including podiatrists, nurse specialists and consultant physicians, identified patients who met the study criteria and a coordinator external to the research team approached patients to elicit written informed consent. This study received ethics approval from St Vincent's Hospital Sydney (LNR/15/SVH/341) Human Research Ethics Committee. Written informed consent was obtained from all participants.

Semi-structured telephone and face-to-face interviews, as preferred by participants, each lasted for approximately one hour. The interviewer (MD) was an experienced qualitative health researcher who had a general understanding of PAD and experience in behaviour change interventions and health services research. The interview schedule was informed by a Cochrane review of disease management interventions in PAD<sup>19</sup> and key stakeholder input. The schedule was used to guide exploration of topics including participants' understanding of PAD and IC, living with the condition, management, and needs for support, services, and information. Basic demographic information was collected as well as the Charlson Comorbidity Index<sup>20</sup> to quantify participants' concurrent health conditions.

Recruitment ended upon data saturation when it became clear through interviews and confirmed via analysis that no new information was emerging from interviews. Interviews were audio-recorded and transcribed verbatim. The lead researcher listened to audio recordings of interviews while reading transcripts to correct any errors and replace participant names with pseudonyms to ensure the anonymity of study participants. Interviews were inductively analysed using qualitative content thematic analysis<sup>18</sup>. The initial stage of analysis involved

familiarisation with the data via multiple readings of transcripts. Next, the analyst open coded transcripts by adding notes and comments throughout these documents. Notes were then grouped into categories in a separate document and these categories were defined via abstraction. Excerpts from transcripts were pasted into relevant categories to reflect actual utterances of participants. Descriptive summaries were then written and refined for each major category. Two co-authors (MD & RP) reviewed categories independently and discussed analysis until consensus was reached.

## Results

Participants were nine individuals with a mean age of 74.2 years (SD 10.9) who had a confirmed diagnosis of PAD (Table 1). Six of the nine participants were women (67%), the majority were not currently employed (88%), and a third (33%) reported having been previous smokers. Participants reported a variety of co-occurring chronic conditions including diabetes, cardiovascular disease permutations, osteoarthritis, and depression, among others.

Qualitative findings are presented with respect to challenges to maintaining daily activities and patient, provider, and systems-related factors that shape self-management in PAD.

**Table 1. Participant characteristics (n = 9)**

<b>Demographic characteristics</b>	<b>Mean (SD)</b>
Age (years)	74.2 (10.9)
	<b>n (%)</b>
<b>Gender</b>	
Female	6 (67)
<b>Employment Status</b>	
Currently employed	2 (22)
<b>Marital status</b>	
Married	3 (33)
Divorced	1(11)
Widowed	2 (22)
Never married	3 (33)
<b>Smoking status</b>	
Previous smoker	3 (33)



Never smoker	6 (67)
<b>Geographic area</b>	
Metropolitan	8 (89)
Inner-regional	1 (11)
<b>Living situation</b>	
Lives alone	6 (67%)
Aged care facility	1 (11)
<b>Medical history and comorbidities</b>	
Peripheral Arterial Disease	9 (100)
Intermittent claudication	9 (100)
Amputation (leg)	2 (22)
Myocardial Infarction	1 (11)
Hypertension	6 (67)
High Cholesterol	5 (55)
Diabetes Mellitus Type 1	1 (11)
Diabetes Mellitus Type 2	4 (44)
Heart Failure	0 (0)
Stroke/Transient Ischaemic Attack	1 (11)
Depression	2 (22)
Other mental illness	2 (22)
Irregular Heart Beat/Atrial Fibrillation	4 (44)
Angina	1 (11)
Coronary Artery Disease	2 (22)
Renal	1 (11)
Asthma/Lung disease	4 (44)
Rheumatic Arthritis	1 (11)
Osteoarthritis	5 (55)
Eye Disease	2 (22)
Stomach Ulcer	2 (22)
Cancer	2 (22)

### *Challenges to maintaining usual daily activities*

As part of participants' descriptions of the daily impact of living with PAD, IC pain and mobility impairments featured prominently. All participants described pain or numbness in their legs and feet and this was depicted as 'burning' that worsened at nights, while some participants also had painful skin ulcers. Pain disrupted sleep in all participants and impeded physical and social activity in some.

*I'm taking a number of pills every day because, um – the whole leg feels like it's on fire and, ah, it's very – it's worse at night as you can imagine... Well I can't go anywhere really, um, at the moment. I mean ... my leg is all bandaged up and I'm wearing one of my husbands' slippers on the affected foot because I can't get into a shoe. So, you know, we haven't really got any social life at the moment (Violet).*

While walking outdoors, physical instability and the threat of falls challenged access to services, shopping, transport and independence.

*The streets aren't level, so there's bumps, so it's, and so the doctor was sort of saying to me you've got to get around, you've got to walk that sort of thing. I said I would, but...I've got wobbly legs... (James)*

Uneven footpaths pose a safety risk, particularly to someone with limited mobility and balance. Participants attempted to integrate self-management advice received from healthcare providers, such as daily walking, in environments that were not conducive to safe walking. Even short excursions facilitated by transport assistance were problematic. For example, when attending appointments, one participant explained that he has a small window of opportunity to be mobile each day:

*(My legs) start to stiffen up and lose feeling from very early in the morning. It's an issue even going to an appointment at 1:30 in the afternoon when the clinic is...moving around is getting worse, no doubt about that (James).*

Leaving home provokes anxiety in light of dependence on an elevator because of inability to climb stairs.

*There's the anxiety that maybe when I get back (home), the (elevator) is not working. (James)*

The majority of participants lived alone and as such, continued to undertake daily chores to maintain their households, even when unwell. In the excerpt below, a participant describes his experience of being unwell and falling while taking out the garbage.

*I fell over and smashed my hand...I wasn't doing anything, I was just taking the garbage out, I turned around in the street and I overbalanced, and I had had the flu for about four or five weeks, so I wasn't well, but I had to go and take the garbage out and I fell over. (James)*

The resultant injury was significant, requiring weeks of hospitalisation and further hampering his mobility. Another participant who lived alone described how she has adapted her life to meet her needs in living with a prosthetic leg. Although she described no loss of function, she needed to plan her day differently in light of the pain that resulted from overuse of her prosthetic and the increased time required to undertake usual activities.

*Your time has to be reorganised to suit your activity. You know, whereas I used to rush out the door. (Emma)*

This participant also explained that several cupboards and shelves in her home were out of reach and at times, she considers climbing onto a step stool to reach high shelves, but tries to wait for a visitor or formal (paid) carer to assist her.

### ***The social impact of PAD***

Three female participants discussed being restricted from accessing certain activities outside of their homes due to aspects of living with PAD, unrelated to pain or ability to walk. Due to effects of prescribed diuretics, some participants avoided socialising and being away from home. Another participant referred to the non-specific, unpredictable timeframe of community nursing visits for wound re-dressing hampering her opportunities to be away from her home. Others were able to continue to participate socially. For participants without other

social networks or with significant mobility restrictions, visits by healthcare providers and other homecare services served as opportunities for social engagement. One participant described himself as socially isolated and that the health care team had become part of his social group:

*The other part of it, too, is that all people who come in during the week are, have become my friends...As I said, if I end up with no legs and I lose the community nurses, I'll still have the people from home care, from (NGO), and they provide me with that contact. We'd spend the time, you know, discussing the issues of the world and solving the problems of the world in the time that they're here. They've all become very good friends. (James)*

This participant perceived his health and service providers to be a part of his social network because he spends more time with them during their visits to his home than with anyone else. He perceives these to be good relationships that meet his needs for social interaction.

Two female participants worked from home and were able to return to these roles following hospitalisation. Another two women discussed their informal caregiving roles for their husbands who were living in residential aged care facilities. At the time of the interview, the caregiving role continued for one of these women who was physically able to walk to the facility each day and spend time with her husband. She explained that her daily life is devoted to this caregiving role:

*My life only consists of, I leave here at half past nine and go up to the nursing home, and I stay there all day, I leave at a quarter to five and come back, you know. To me, people say 'Why are you doing that?' and I say 'I have been married to that man for 60 years, I've never had another boyfriend, he's never had another girlfriend', and for me, I just hate being apart from him. (Anna)*

Despite living with one or more chronic conditions, these participants endeavoured to maintain their work and carer roles because they were important and meaningful parts of their lives. This excerpt highlights that being able to walk each day to her husband's care home was an important part of her life.

***Patient, provider, and systems factors shape self-management in PAD***

*Psychosocial factors affect an individual's willingness and ability to self-manage*

Individual-level factors influenced participants' ability to self-manage their PAD. Two participants discussed mental health issues. A female participant explained that she often felt anxiety about the need to increase her physical activity and reduce her weight. Her doctor advised that she should increase her walking, but she struggled with fatigue.

*He has said to me that I need to do a certain exercise and I should not sort of think oh yea, I am walking, and not sort of want to push myself. I have to push myself more. A lot of times, because I get so highly stressed, anxiety really around that. When you think about a cat chasing his tail in circles, that is how I get with anxiety. It is really bad. And I have a hell of a lot of weight and that is something I should be working on, but a lot of time, I just want to rest. (Kathleen)*

Another participant described his experience of depression following a series of stressful life events that changed his living circumstances.

*Basically, I was on a, a downward spiral...back (a few years), I found myself temporarily homeless so I ended up moving from (suburb) to here and I was temporarily in two homeless shelters...I got to the stage where I was by myself, um, I had little or no contact with anyone else, I hadn't been back to where I came from at (suburb) so, I didn't have the, the money, I didn't have the confidence. (James)*

He went on to describe the physical impact of his self-neglect during this difficult period:

*So I was just drinking too much, but I wasn't drinking socially, I was always drinking by myself. So eventually what happened, basically my legs dried out and I stopped going to the doctor, I left my doctor, I didn't go to a new doctor, I stopped taking my medication, so...I wasn't deliberately trying to suicide but I knew what was going to happen. I was either going to die or I was going to fall over and you know, we'll see what happens. (James)*

He explained that he was at a low point where he refrained from medications and seeking health care, despite needing it. He withdrew socially and from his own self-care. Ultimately, he credited being put in contact with his current healthcare team after an injury for facilitating his recovery. These relationships with his health care team facilitated his resuming self-care and self-management.

*Complexities of clinical conversations highlight importance of patient-provider communication in PAD and self-management*

The majority (n=6) of participants revealed a limited awareness of having PAD or not identifying with the term. Some cited not remembering whether they had been told of this diagnosis or had only a vague recollection and understanding of the condition.

*Interviewer: At what point did anyone mention, or did they, peripheral arterial disease?*

*Participant: Ah, not that I recall...ah, they could have (Kevin)*

The following participant had a leg amputation after unsuccessful attempts to restore circulation. This participant could not recall specific PAD management instructions nor exercise advice given after rehabilitation following the amputation.

*I think somebody gave me some – no they didn't. Not on how to manage with your leg. I mean, no – once you can walk, you can manage. Well, I don't remember any information. Maybe it was given to my children or something. (Emma)*

Advice from other healthcare providers, not specifically involved in PAD management, was mentioned. One participant recalled a specific exercise recommendation from his orthopaedic surgeon.

*Knee Dr asked me if I have been doing much up and down. He tells me to walk 30 minutes 3 days a week, but I do enough walking around the house here, I am up and down like a yo-yo. (Kevin)*

Perceived conflicting or seemingly incongruous exercise advice led to confusion for participants. For example, a participant recalled hearing that her 'blockage' was minor and did not yet warrant surgical intervention. She received advice from her health providers that she needs to walk, but she also needs to rest and elevate her foot. She was confused by this seemingly conflicting advice.

*I've been told that, um, on one hand I shouldn't stand for long periods of time, but on the other hand I should walk. You know, get a bit of walking in and not sit still the whole time... (Violet)*

When asked if her health professionals had given her an idea of how much she should be walking while her wound is recovering, she said they did not. Just as there was reported ambiguity around exercise and rest advice, another participant was confused by perceived incongruous wound care suggestions:

*A doctor did mention that some time ago, just do it in the shower, hold your leg under the shower... I was just surprised that it's the three of them including the doctor told me that, he said it's as good as anything. And then some nurses told me to go into the*

*sea, and the majority – and my GP, said not. So, I didn't, but I was thinking about it last time we went because it was very hot, and a few of them have said put it in the sun, and I don't know whether that's the right thing or not, but sometimes I do. I can't see that it's doing any harm. (Sharon)*

Whether from a single healthcare provider or from various multi-disciplinary team members, participants described receiving advice that caused confusion. Clarity and consistency of information and recommendations was desired to facilitate self-management.

Participants' orientation towards giving and receiving information to and from health care providers featured. Participants occasionally stated that they had not shared new or ongoing symptoms with their healthcare providers. For example, a participant who had an amputation chose not to share with his provider that he was experiencing the same symptoms in his remaining leg.

*I still have pins and needles in this foot. But I'm not going to tell the doctor about it at the moment. I just don't feel like doing it. It's not hampering me. If it hampered me, then I would do something. (Curt)*

He explains that he chose not to disclose this information to his healthcare provider because it was not currently a problem, thus his care-seeking was informed by degree of physical symptoms or functional deficit. Another participant posited that not receiving information about PAD from her doctor may have been because she had had several health issues and had not asked for information about them previously.

*No, they probably thought I didn't appear interested. Honestly, I never ever, I just believe what the doctor says. I don't query them, because I don't feel I know anything, and I've had so many major things wrong, but they've fixed me up, you know, and they*



*sort of said afterwards, 'Oh we didn't think you would survive that', and I say 'Well ok, don't tell me about it'. (Anna)*

In this excerpt, the participant initially attributes her providers not talking to her about PAD as their perception that she was not interested. Her reasons for not seeking out information involve perceiving herself as less informed than her providers and having had multiple medical problems. She also alludes to emotional difficulty in hearing about the severity of her condition. These two examples highlight the complexity of these clinical conversations and the possible need for psychological approaches to help people cope with adverse health.

*Overcoming provider- and systems-related barriers to care: integrated care and transition planning facilitate wellbeing*

Participants' accounts revealed that health care professionals both facilitated and impeded referrals and care integration. One participant explained that a nurse flagged the need for a specialist referral, but this was not enacted immediately by her physician:

*One of the nurses – I think she was the case manager, suggested I have a Doppler test, and she rang my GP and organised a referral...she was very keen on me seeing a vascular surgeon. Well, my GP didn't agree. He said he didn't think it was at that stage... Finally, when I went back a few times and told the nurses; he (GP) sent me to a vascular surgeon... They sent the results to my GP and they got lost, and so we had some trouble getting them re-sent...I had the Doppler done in July, and it wasn't until September – he straight away gave me a copy and it wasn't until then that I knew.*

*(Sharon)*

The delay in transferring test results to her general practitioner (GP) was attributed to a breakdown in health information management systems. The delays described here reflect obstacles to getting a referral, receiving test results, and planning treatment.

Another example of the importance of communication between patients, providers, and systems involved facilitating homecare for a patient who was returning from hospital home without a carer. The participant perceived that he was discharged prematurely and without necessary links to supportive services, which he attributed to a systems flaw. He admitted his resistance to receiving services initially, but feels it is important for providers to ‘push’ the patient to accept homecare services as a patient safety measure, again reflecting the complexity of clinical care conversations.

*Whereas in my situation, there wasn't anyone to go home to so, so my room wasn't adequate, and it was contributing to (my) being sick. (James)*

After returning home without support, he became unwell and had a fall upon which he was re-hospitalised. While in hospital, he was linked to a social worker and a case manager who arranged a variety of health and social services including support from non-government organisations. The case manager helped to advocate on his behalf to extend his homecare services, change his accommodation, facilitate transport assistance to appointments, and provide devices to facilitate the patient’s independence and maintain or establish social networks. He attributes these positive changes to the persistence and insistence of the social worker who facilitated his integrated services and supports.

Despite these improvements facilitated by care integration, he noted policy-level initiatives that have challenged his access to needed support. One example is the funding gap due to his age and disability status.

*For example, up until this year, um, I've been going to the podiatry at (Hospital X)...I was going to the clinic the other day and he said oh, we can't look after you anymore because you're only 63 and you're on a disability pension and you're now looked after by the Disability Insurance Scheme... so that's an issue; from the start, I wasn't old enough or, and/or I wasn't disabled enough.(James)*

Another gap in support involves transport assistance to appointments. He explained that although he receives a taxi voucher to travel to and from his hospital appointments, the person who helps him get between the taxi and Dr's office or up the elevator to his apartment is not entitled to a travel subsidy.

## **Discussion**

An ongoing limited awareness or understanding of PAD by patients who have the condition has been discussed in the literature for decades<sup>21</sup>. In the current study, patients lacked understanding of how the condition developed, mechanisms that lead to exacerbations and how these can be managed. In some cases, participants did not recall or denied being informed that they had PAD. Prioritising other health conditions or specific symptoms may be a reason why participants did not recognise having 'peripheral arterial disease' or 'PAD'. Participants expressed confusion around seemingly incongruous instructions from health care providers regarding self-management strategies. These findings highlight the importance of patient-provider communication as well as health literacy and the role of the health professional in ensuring a clear and consistent message is conveyed regarding diagnosis and management.

Low health literacy is associated with higher health care utilization and costs<sup>22, 23</sup>. The majority (78%) of Australians aged 60–74 have less than adequate or the lowest health literacy skills<sup>24</sup> and this is similar to older people in the USA<sup>25</sup>. Studies have shown that

physicians' use of medical terms, combined with patients' limited health vocabulary, can result in confusing communication<sup>26</sup>. Patients may not understand the context, detail, or significance of their diagnoses and perceived simple instructions may be quite complex to someone with low health literacy<sup>27</sup>. Information and recommendations provided by health care practitioners must be clear and consistent to facilitate self-management. Upskilling health care practitioner communication skills to meet the needs of patients with peripheral arterial disease, who may have low levels of health literacy, may assist in facilitating self-management.

Health care providers also need to appreciate the context within which their patients are living to tailor the instructions for self-management, for example, providing a prescription for physical activity that is clear and achievable. Considerations should include a person's dwelling, proximity to services, whether a carer is available to provide support, and presence of co-morbidities and how these may effect eligibility for services. These factors highlight the complexity of clinical conversations. Further, clarity and consistency of recommendations is required to avoid confusion and patients' need to integrate information. A person-centred approach, whereby an individual's needs, preferences, and priorities are central to care provided will likely facilitate open reciprocal communication between patients and providers. In addition, engagement of the patient and carer, if available, with a multidisciplinary team, led by a case manager may assist to ensure understanding and achievement of health care provider recommendations.

Experiences of social isolation as a result of experiencing painful or otherwise limiting PAD symptoms have likewise been reported in the literature<sup>21</sup>. While research has explored what patients' perceive are the ways in which PAD impacts on their family members, the current study adds the experience of individuals who live alone and do not have informal carers.

Challenges in accessing services and fulfilling basic instrumental activities of daily living

may emerge for individuals with PAD even when they live in close proximity to health care and other services.

The imperative for integrated healthcare and ‘joined-up’ care for these individuals cannot be overstated. An integrated approach places the patient at the centre, ‘wraps’ the services and supports around them and involves teamwork across disciplines, including general practice<sup>28</sup>. Inter-professional collaboration for community-based chronic disease management can result in comprehensive care planning and coordination of services<sup>29</sup>. An integrated approach with a dedicated multidisciplinary team to support patients with peripheral arterial disease will facilitate self-management<sup>21</sup>. Upskilling multidisciplinary team members, including general practitioners, in recognition, communication, management, and timely referral can clarify and enable the assessment and treatment pathway for patients.

### **Limitations**

We interviewed a small number of individuals each only once regarding their experiences. A more comprehensive account of living with the condition would include repeated data collection to ascertain progression and management of the condition over time. Further, we did not include participants who were not conversant in English and did not assess health literacy in participants. We acknowledge that these participants may have had more advanced PAD than has been reported in the few other qualitative reports of living with this condition, given descriptions of the impact of wounds and amputations. One of the recruitment sites was a wounds clinic and as such, the impact of having a wound may have superseded identification with PAD. Although we explored perceptions of individuals living with PAD, future research should explore the perceptions and experience of health care providers who work with patients with PAD to ascertain their thoughts about interactions with this population.

## **Conclusion**

Greater attention to awareness-raising and clear and consistent communication with individuals who have PAD is imperative. Health care providers also need to consider the context within which their patients are living and their need for various communication strategies to ensure understanding. Incorporating multidisciplinary teams with case managers may facilitate integrated care for individuals with PAD who have multifaceted needs.

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