What's in a Name? A Mixed Methods Study of Patient Knowledge, Understanding, and Experience with Peripheral Artery Disease Education

Maggie A. Reilly[1], Cassandra Iroz[1], Megan Alagna[1], Alexander Lundberg[2], Emily H. Ho[3], Andrew W. Hoel[1], Ashley Vavra[1], Julie K. Johnson[4], Karen J. Ho[1]

[1]Department of Surgery, [2]Department of Emergency Medicine, [3]Department of Medical Social Sciences, Northwestern University Feinberg School of Medicine, [4]Department of Surgery, University of North Carolina

Introduction

- Peripheral artery disease (PAD) is a chronic disease that leads to increased risk of cardiovascular death, walking impairment, and leg amputation
- Patient knowledge of PAD is low compared to patient knowledge of other cardiovascular diseases

Aims:

- To quantify awareness and knowledge of PAD and understand the patient experience of PAD education using mixed methods

Methods

- In this convergent parallel mixed methods study of patients with PAD, participants completed a paper survey:
  - Demographic information, PAD knowledge, Awareness of diagnosis
  - Assessment of functional health literacy (FHL) using the Short Test of Functional Health Literacy (S-TOFHLA)
- Participants were scored as "Adequate" or "Low" FHL
- Multivariable linear regression was used to identify factors associated with PAD knowledge scores
- Semi-structured interviews were conducted and transcripts analyzed with inductive and deductive coding using a constant comparative approach
- Quantitative & qualitative data were integrated to develop overarching themes

Table 1. Adjusted multivariable linear regression of factors associated with increasing knowledge score

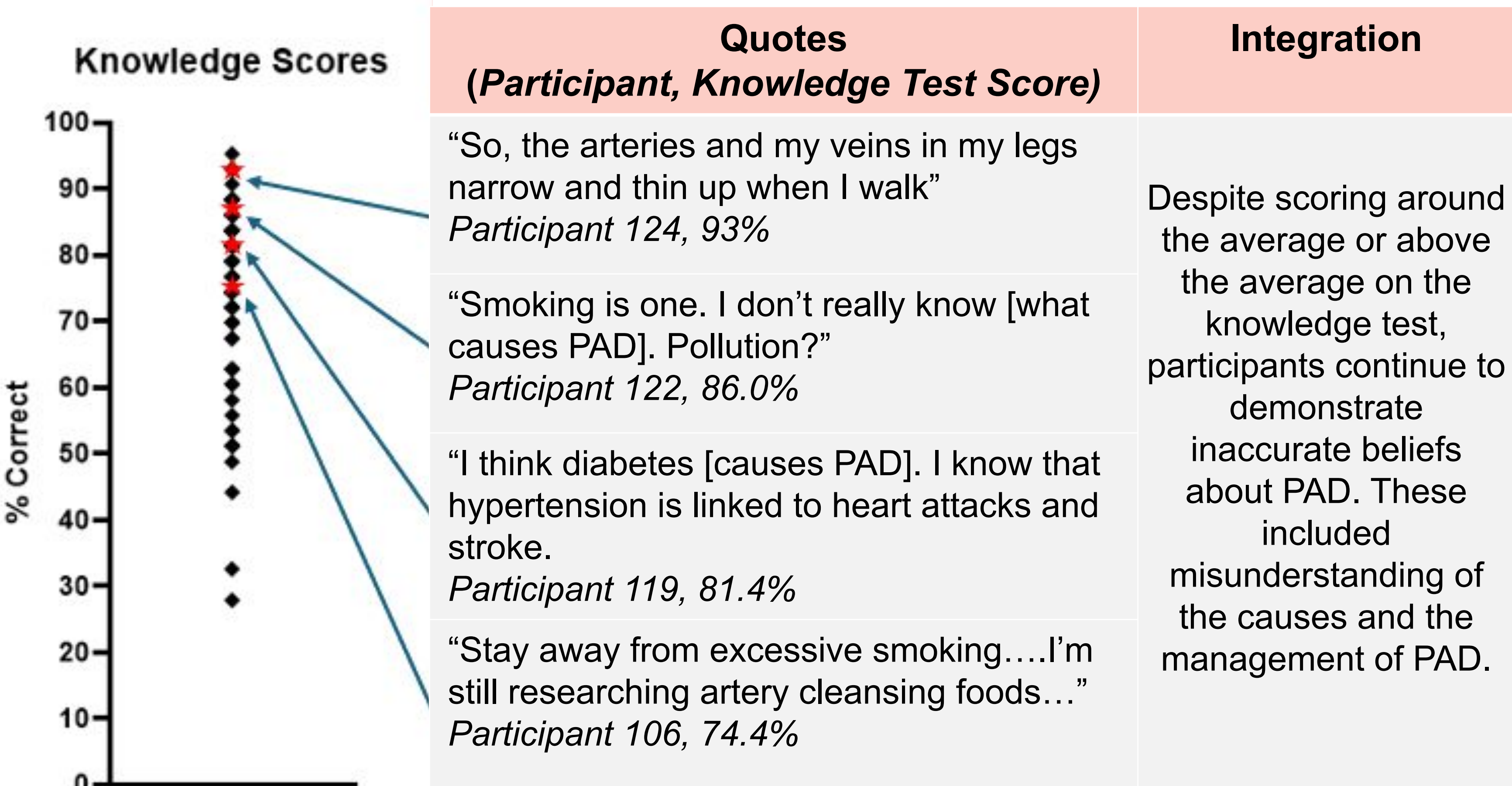| Demographic/ Socioeconomic Factors	Percent Difference in Score	95% Confidence Interval	P Value
Non-White Race	-7.2	-0.2-0.02	0.10
Functional Health Literacy Low FHL **Adequate FHL**	REF **14.0**	**0.02-0.2**	**0.023**
Annual Income Unsure/Prefer not to answer <$49,000 $50,000-100,000 > $100,000	-7.2 -0.7 1.1 REF	-0.2-0.05 -0.1-0.1 -0.07-0.2	0.24 0.91 0.43
Aware of PAD diagnosis	**10.5**	**0.01-0.2**	**0.037**
Ambulates independently	6.6	-0.02-0.1	0.12

Bold indicates P < 0.05

Table 2. Themes in Patient Interviews about PAD Knowledge

Theme	Illustrative Quote (*Participant Number, Age, Knowledge Test Score, S-TOFHLA Score*)
Participants are not aware of their diagnosis of PAD	*"I don't think [my doctor] ever mentioned PAD as a diagnosis. I think she maybe had said, "It seems like there may be blood restrictions in your legs."* Participant 125, 70 years old, 88.4%, Adequate FHL
Participants do not understand terms "peripheral artery" or "peripheral artery disease"	*"I have no idea… I know there's arteries. Your vessels, I guess, right? And the vessels are full of blood. Yeah, I can't say [peripheral artery disease]. I can't even pronounce it."* Participant 122, 63 years old, 86.0%, Adequate FHL
Participants have continued knowledge deficits about PAD	*"I enjoyed learning about the PAD, because I really want to know, like, is it life-threatening and stuff like that? I want to know how to stop the pain…Does it go away? Does PAD go away?"* Participant 108, 42 years old, 51.2%, Adequate FHL
General lack of knowledge about PAD – patient and provider-related – leads to delays in diagnosis and treatment	*"I thought I was being treated. I had a sore on my heel and then I noticed spots coming up on my leg…And at no time did anyone mention that it could be [PAD], that I need to see a vascular surgeon…By the time she mentioned it, it was too late. The tissues were dying and there was nothing else they could do."* Participant 119, 76 years old, 81.4%, Adequate FHL
Trust in a physician promotes engagement in care	*"Most doctors just don't want to hear it. They wanna throw drugs at you and excuse me, they got the waiting room with 20 people. They're way overbooked. My doctor is absolutely wonderful…he really answers my question."* Participant 107, 85 years old, 86.0%, Marginal FHL

91 participants:
51.7% had chronic limb-threatening ischemia & 17.6% had major amputation

Figure 1. Joint Display of Participant Knowledge Scores with Qualitive Examples of Persistent Incorrect Knowledge of PAD.

Knowledge Scores	Quotes (*Participant, Knowledge Test Score*)	Integration
	"So, the arteries and my veins in my legs narrow and thin up when I walk" *Participant 124, 93%*	Despite scoring around the average or above the average on the knowledge test, participants continue to demonstrate inaccurate beliefs about PAD. These included misunderstanding of the causes and the management of PAD.
	"Smoking is one. I don't really know [what causes PAD]. Pollution?" *Participant 122, 86.0%*	
	"I think diabetes [causes PAD]. I know that hypertension is linked to heart attacks and stroke. *Participant 119, 81.4%*	
	"Stay away from excessive smoking….I'm still researching artery cleansing foods…" *Participant 106, 74.4%*	

Principal Findings

- While 21.3% had poor FHL and 24.4% were unaware of their PAD diagnosis, the average knowledge score was 79.1% (Figure 1)
- Poor FHL and not being aware of PAD diagnosis were independently associated with lower PAD knowledge (Table 1)
- Qualitative analysis of 20 interviews revealed four themes (Table 1)
- Data integration yielded three overarching mixed methods themes: (1) Not understanding the name of the disease led to further knowledge deficits; (2) the knowledge test was not a sensitive assessment of patient understanding of PAD; and (3) physician trust led to engagement with treatment regardless of disease knowledge

Conclusions

- Patients have incorrect beliefs and difficulty understanding the terminology associated with PAD despite a high average knowledge score
- Knowledge scores may not adequately reflect understanding
- Future research will focus on optimizing patient education, identifying strategies to appropriately gauge patient understanding, and assessing associations between knowledge and behavior in PAD

Karen Ho Lab   NQUIRES

@karenholab   @MaggieReillyMD