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Background

- Heart failure with preserved ejection fraction (HFpEF) is a complex syndrome to diagnose and manage and it represents the fastest growing heart condition worldwide
- Prior studies suggest patients are unaware of their HFpEF diagnosis
- Patient unawareness of their diagnosis impedes their ability to perform self-management tasks and negatively affects health outcomes in HFpEF
- There is a critical need to develop a HFpEF patient-centered intervention to foster patient understanding of HFpEF as a condition to improve HFpEF health outcomes

Theoretical Framework

Fear
Surprised by diagnosis
Denial of diagnosis
Confusion
Not given enough information
No encouragement from medical field
Inadequate mental health support
Fragmented care

Impact of receiving initial diagnosis

None of the study participants - aware that they have HFpEF

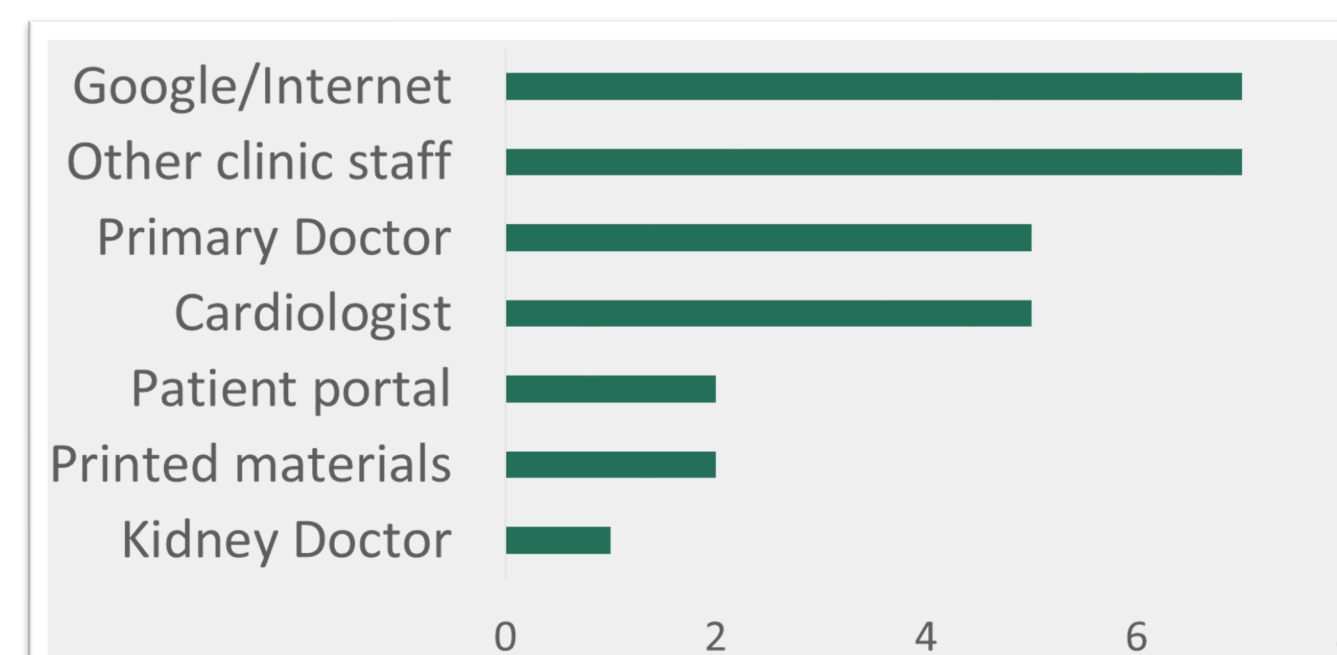
"I really don't know nothing besides I think [I have] an enlarged heart and I take medicine for it. But what caused it I do not know."

Uncertainty of heart condition and its management

Patient-reported needs

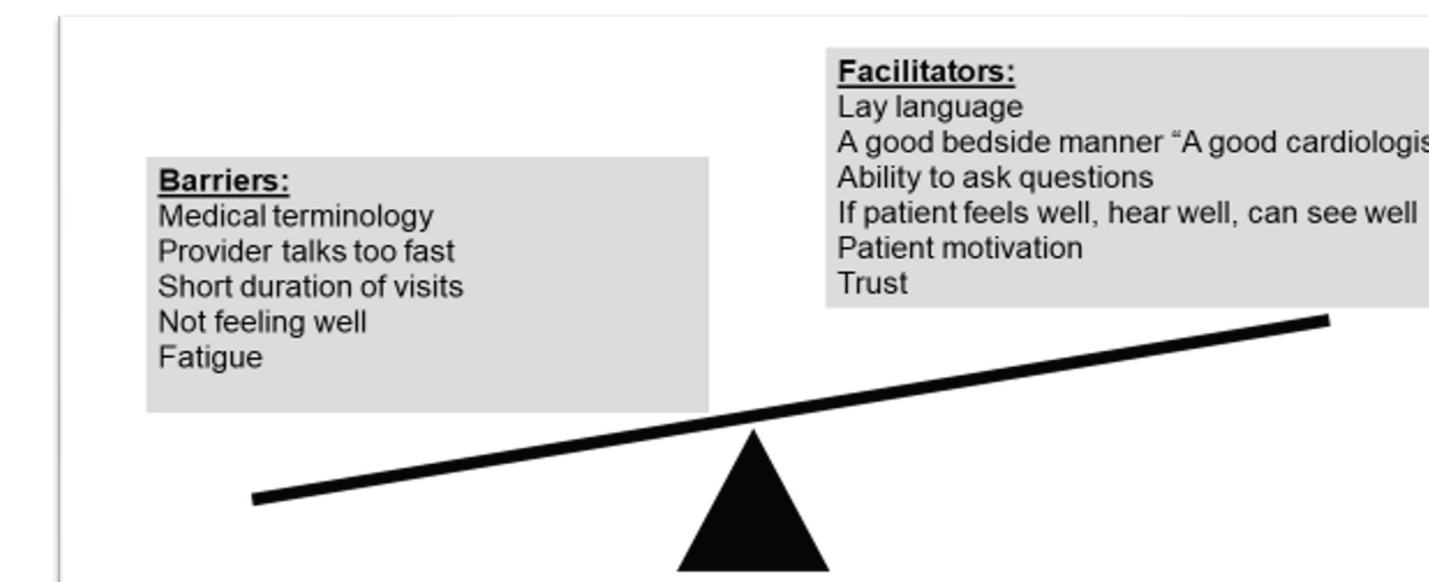
Informational/health counselling
Mental health support
Instrumental support

Frequency-ranked sources of learning about HF



Insufficient experiences with learning about HF

Barriers and facilitators of patient learning about HFpEF



Project Aims

- Explore patient understanding of HFpEF
- Elicit patient-reported learning needs to inform intervention development

Study Design

- A qualitative study of adult patients with stage C (symptomatic) HFpEF
- Oversampled patients from underserved populations

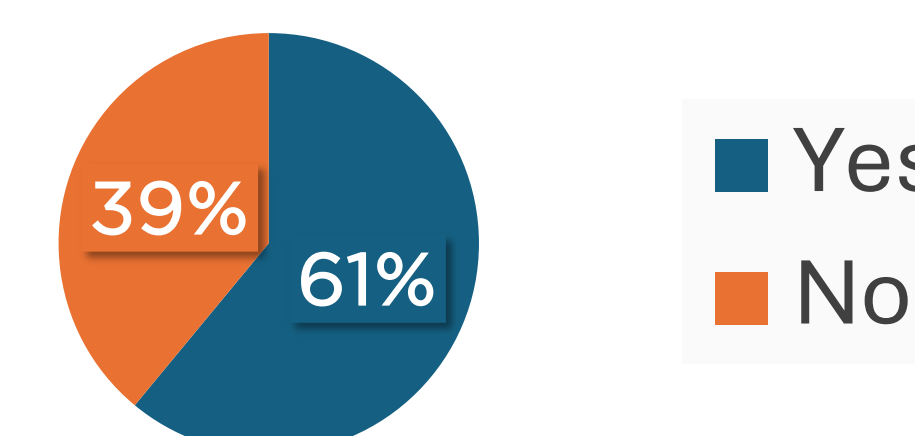
Data collection and analysis:

- Participants pre-screened using ICD-10 codes in electronic medical records (EMR)
- Diagnosis of HFpEF confirmed in chart review, including ECHO and other imaging data
- Semi-structured interviews following interview guide
- Patients were asked to describe 1) their heart condition, as they understand it; 2) where they currently learn about their heart condition; 3) what they want to learn more about; and 4) who can help them learn more
- Qualitative inductive thematic analysis

Outcomes

Study Participants		n=21
Age (years), mean \pm SD		60 \pm 15.1
Race		
Black		13 (62%)
White		8 (38%)
Sex		
Female		14 (67%)
Male		7 (33%)
High School Education or above		15 (72%)
Duration of HF (years), mean \pm SD		3.85 \pm 2.5

Aware they have been diagnosed with HF?



Key Messages

- Current level of HFpEF understanding among patients is low
- Patients report inadequate support at the time of receiving HFpEF diagnosis
- Patients use internet to learn most frequently, but online information is confusing
- Future intervention should be timed at the initial diagnosis and include informational, instrumental and mental health support

Community Impact

- Identified future HFpEF intervention targets based on patient's preferences:
 - More information about signs, treatment and prognosis of HFpEF
 - Learning how to prevent further deterioration
 - Patient condition monitoring (wearable devices)
 - Improving patient-provider communication: in-depth and more empathy
 - Mental health support
- Community partners in the future intervention development:

References

