

Learning from patients and communities about long COVID: A pilot intervention in primary care



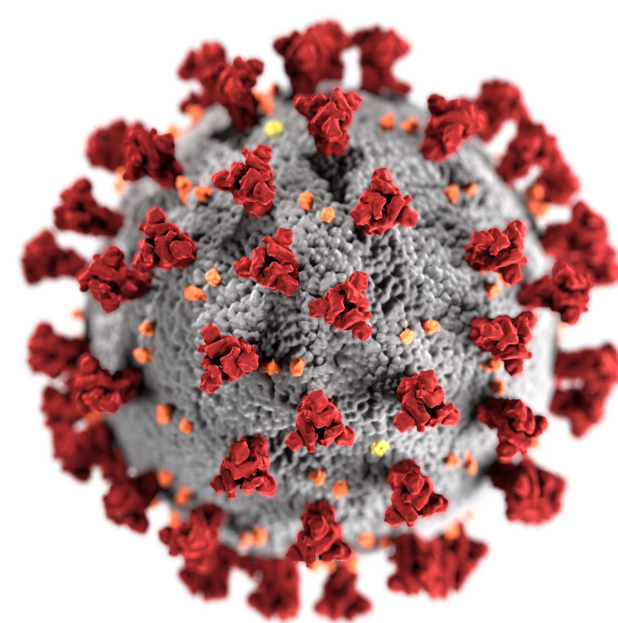
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Background

10-30% of people experience persisting long COVID symptoms after acute COVID infection



Patients and clinicians both struggle to understand and respond to this chronic phase of the pandemic

Project Objective and Design

How might we create an educational intervention to increase the capacity and confidence of primary care clinicians caring for people with long COVID?

25

interviews with people with long COVID

15

interviews with mental health, community health workers, lawyers, physicians, nurses

2

pilot groups of residents and clinicians

Intervention Components

Catalyst film

From interviews with people with long COVID and those who care for them, we created a 15-minute film with emotional testimony and actionable strategies for clinicians caring for people with long COVID

Patient Experiences with Long COVID



Resource sheets

We developed and distributed resource sheets for clinicians and patients

SUPPORTING PATIENTS WITH LONG COVID

COMMITMENT TO PATIENTS

- "My doctor's ability to keep coming up with things to try and reminding me of the small successes has really helped."
- As a clinic, we are committed to, as appropriate:
 - Screening patients for Long COVID and documenting prevalence
 - Adding Long COVID to the visit diagnosis and to the patient's problem list
 - Following up with patients about their Long COVID symptoms and trajectory
 - Being candid with patients about what we know and don't know about Long COVID
 - Asking patients about what they are trying at home or with other health practitioners

DIAGNOSTIC CRITERIA FOR LONG COVID (POST ACUTE SEQUELAE OF COVID)

Long COVID is diagnosed clinically. Criteria include a history of COVID infection (either documented, or classic symptoms and history of exposure) and continued symptoms weeks to months after the acute infection resolved.

Diagnostic approach:

- Careful history with documentation of the dates of acute infection
- Assessment of physical, and psychological symptoms and energy level
- Use of objective measures as much as possible
- Targeted lab and imaging based on primary symptoms (i.e., chest pain is primary symptom, then an EKG and echocardiogram is indicated)

TIPS TO SUPPORT EMPLOYMENT NEEDS

"My doctor says... you need to take time and when you feel badly, you need to use your FMLA." So, that kind of gained our trust back a little bit.

- Encourage patient to apply for Family Medical Leave (FMLA) to protect employment while recovering
- Tell patients Long COVID is a disability under the Americans with Disability Act (ADA), which means they will be able to get workplace accommodations
- Document Long COVID thoroughly to support accommodations

TIPS TO SUPPORT DISABILITY NEEDS

"I know now there's some talk of certain long COVID things being covered as a disability... how that will work, you know, legally, well, since I never had a positive test?"

- Document COVID infection date
- Add "Long COVID" or "sequelae of COVID infection" to diagnosis and problem list
- Clearly document all relevant symptoms
- Describe the patient's limitations tying their symptoms to concrete activities of daily living (e.g. driving, grocery shopping, cooking)
- Thoroughly document patient follow-through on health behaviors recommendations and healthy living suggestions

LONG COVID RESOURCES

INFORMATION

National, reliable sources for COVID-19 information

- cdc.gov/coronavirus
- JAMA Network

FINANCIAL SUPPORT

- Local Dane County resources
- City of Madison Community Resources
- Resource Navigator Program - Center for Patient Partnerships

INSURANCE

Student advocates provide free advocacy for patients facing life changing health events

- Health Justice Clinic - Center for Patient Partnerships

DISABILITY

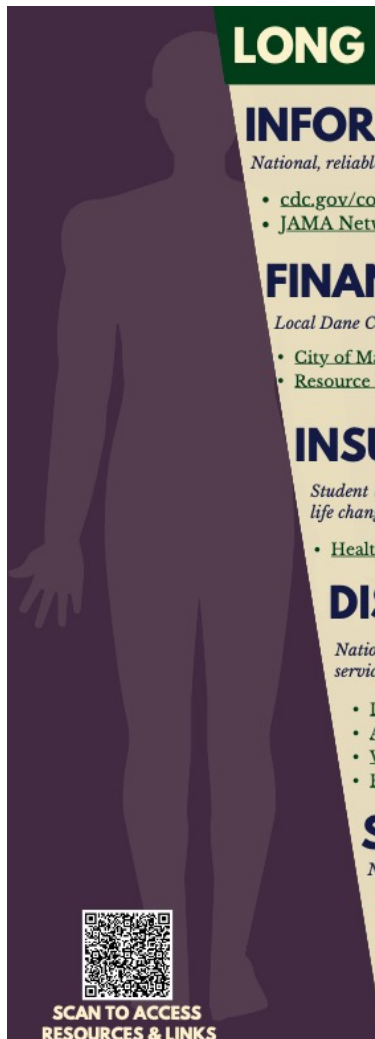
National and local organizations offering free or low cost services and advocacy

- Legal Action of Wisconsin
- Aging and Disability Resource Centers
- WI State Bar Attorney Referral Services
- HHS.gov - Long COVID as a Disability Resources

SUPPORT GROUPS

- National online groups
- Facebook - Long COVID Support Group
- Long COVID Kids

If you have any questions or would like to speak to a clinician at Northport Dr. clinic, please call 608-241-9020



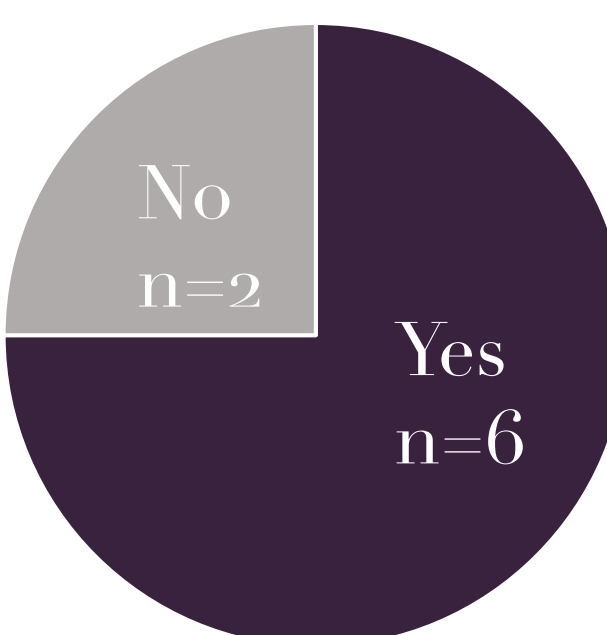
Facilitated discussion

We screened the film and overviewed the resource sheets in facilitated discussions with family medicine residents and faculty, measuring pre and post outcomes



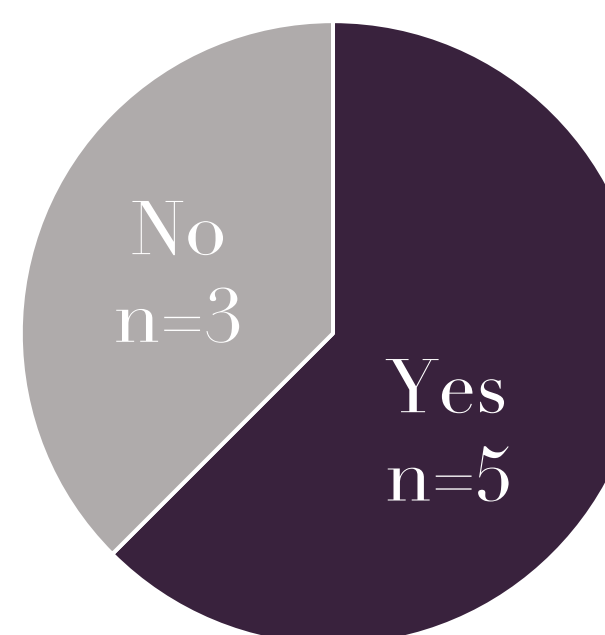
Outcomes

Changes in clinicians' ideas about long COVID since date of intervention



"I'm more aware that this syndrome is something that my patients might be dealing with but not necessarily vocalizing this concern to me."
"I think about asking about it more at routine patient appointments."

Changes in clinicians' approach to helping people with long COVID



"I discuss it more often and provide resources more often."
"Better documentation in my notes."

Conclusions and Relevance

1. We demonstrated how close partnerships can facilitate the development of a patient experience intervention in the US healthcare context.
2. Discussions during the pilot intervention helped us refine the intervention. For example, clinicians confirmed that they would like having paper copies of resource sheets to distribute to patients along with an EMR dot phrase for adding to after visit summaries.
3. Though many clinicians in this pilot had not had a lot of experience with long COVID, we had robust discussions at all intervention sessions. Post evaluation survey results revealed changes in ideas about long COVID and how to best help people managing it.

Intervention available at



healthexperiencesusa.org /Long-COVID



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