Global Perspectives on Medicine, Rehabilitation and Robotics
Webinar Series
April 17, 2024, 5pm-6:00pm CAT, 11am-12:00pm EST
Towards Home-based Stroke Technology for All

Understanding Stroke Rehabilitation from a Clinical Perspective

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Considering Home-Based Stroke Technology for Diverse Populations

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Considering home-based stroke technology for diverse populations

GPMRR Seminar: 4/17/24

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“A stroke … blocks blood supply to part of the brain or when a blood vessel in the brain bursts” - Center for Disease Control

~80% of Cases Lead to Motor Disability
Rathore et. al. 2002

25-45% are Able to Return to Work
Wilz et. al. 2009
McLean 2007
Vestling et. al. 2003

Leading Causes of Lifelong Disability
Virani et. al. 2020
Underserved Hispanic Stroke Survivors (USA)

- Increased Incident Rate of Stroke
- Worse Cognitive & Functional Outcomes
- More Stroke at Younger Ages
Underserved Hispanic Stroke Survivors (USA)

- 2 times increased incident of stroke (Sacco et. al. 1998)
- 1.48 increased rate of stroke after adjusting for Age & Sex (Gardener et. al. 2020)
Underserved Hispanic Stroke Survivors (USA)

Worse Cognitive & Functional Outcomes

- 48% worse stroke symptoms (as measured on NIH Stroke Scale)
- Worse cognition
- Less capable of performing activities of daily living (Lisabeth et. al. 2014)
Underserved Hispanic Stroke Survivors (USA)

- 2.04 times more likely to have an ischemic stroke from ages 45-59 (Morgenstern et. al. 2004)
“It was difficult for me because, as I told you, I could not enjoy my pregnancy because of so many worries, and then he got the stroke, the premature child. It all happened in the first year of marriage.” - Caregiver
“And when he goes out with me, it's a little bit complicated because he's very tall and I'm very small, people told me that I was going to fall with him, but thank God that didn't happen.” - Caregiver
“Because the doctor told me to find a job where I could sit pretty much the whole eight hours…It’s gonna be hard for me to find a job like that.” - Stroke Survivor

“But I look for help..for food…because the money that Social Security gives me isn't enough for everything.” - Stroke Survivor
Definitions

**Stroke Technology** - anything that aims to improve quality of life and bring people with stroke to the most functional, independent state possible

**Informal Caregiver** - person whose chosen career was not to serve as a caregiver, however, despite this they are performing a caregiving role for a stroke survivor
How can we design appropriate stroke technology for medically underserved stroke survivors and their informal caregivers?

What are the challenges, needs, and goals of medically underserved stroke survivors and their informal caregivers?
Need Finding

Survey

- Daily Life Post & Pre Stroke
- Interpersonal Interactions
- Medical Care
- Personal Goals
Interview Details

- In-person, Phone, or Zoom
- 13 Stroke Survivor
  - 4 Spanish
  - 9 English
- 10 Caregivers
  - 4 Spanish
  - 6 English
Stroke Survivor Eligibility

- Hispanic/Latino OR Non-private Insurance OR Uninsured
- Have difficulty doing the things you would like to do your hands, arms or legs because of the stroke
- Unable to perform basic ADLs, prepare food, drive, or groom themselves alone
- Live in the U.S.A.
- No other sensorimotor conditions (ALS, MS, Parkinsons)
- No severe aphasia
Methods: Grounded Reflexive Thematic Analysis

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Methods: Thematic Analysis

Broader Theme

Factors that discourage stroke technology use

- Cost is limiting factor for stroke technology access
-缺乏功能技术，缺乏吸引使用
- Stroke survivors have difficulty using technology
- Stroke technology is difficult to set up
- Stroke technology is expensive
- Stroke technology is easy to set up

Factors that encourage stroke technology use

- Stroke technology is helpful to help improve independence
- Stroke technology is easy to use
- Stroke technology is useful to help improve independence

The stroke survivor and caregiver feelings about a technology affect whether or not a device will be continually used

Codes
Methods: Thematic Analysis
Stroke Survivor Themes

● Emotional Obstacles Inhibit ADLs
● Emotional Experience Influences Technology Adoption
● Stroke Technology Can Cause More Problems
● Family/Loved Ones Facilitate Positive Outcomes
Emotional Obstacles Inhibit ADLs: Grappling with Ability

“Because… physically I'm not up to snuff… I should be able to just get up and get going. It's harder now. So I just stay in bed and watch TV. Because sometimes it's just easier to just lay in bed instead of crying.” - Stroke Survivor

Loss of Independence
Altered Physical & Cognitive Ability
Isolation
Emotional Obstacles Inhibit ADLs: While Actively Performing Activity

Fear of Getting Hurt  Perception of Others  Frustration, Shame, & Loss of Motivation

“Well, the right side of my body being severely compromised. I find it difficult occasionally to think about other people observing my lack of ability as it were and seeing me moving in an awkward way. I find that somewhat troubling and annoying…” - Stroke Survivor
Emotional Experience Influences Technology Adoption: Negative Feelings

“...I bought him a stand up walker… but it just didn't feel right to [him]. And so they're much taller. And one of the things he hated about it was how big and obvious it was. I mean, that's a big part of people with disabilities. It just doesn't look that cool.” - Caregiver
Emotional Experience Influences Technology Adoption: Positive Feelings

“...it's a puzzle games, it's so easy and simple... it has a tutorial...those apps are easy for me to use but other apps.. the tutorials are too long...I would just turn it off...” - Stroke Survivor
Stroke Technology Can Cause More Problems

Skin Irritation
Fatigue-Based Issues
Posture Issues
Balance Issues

“...position of the handles are straight back. They're not adjustable, and I have to hunch over like a little old lady looks to use it, which makes no sense because this is supposed to help my body” - Stroke Survivor

Stroke survivor: “I like being able to stand upright, so I don't like walkers for that very reason.”

Caregiver: “They kind of tip you forward, don't they?”

Stroke survivor: “Among other things.”
Family/Loved Ones Facilitate Positive Outcomes

“...she [daughter] gets me to draw, manual activities, like cutting figures…I also like to have the children guess what… is drawn there…they have to identify what it is and put it where it goes. They are very simple things, but for me they are very fulfilling…” - Stroke Survivor
Summary of Stroke Survivor Themes

- Emotional obstacles inhibited ADL
- Emotions evoked affect technology use
- Stroke technology can cause further issues
- Family is a powerful motivator
Caregiver Themes

- Appreciation of Technology that Accounts for Safety
- Unable to Prioritize their Own Health
- Very Few Technological Options for Caregivers
Appreciation of Technology that Accounts for Safety

Curating Physical Environment  Supervision  Supporting Activities

“I prepare everything for him. I even walk with him to the shower and I stay in the shower until he finished because I'm afraid he may fall…” - Caregiver

“…we have one of those little emergency gadgets… in case he feels bad, he falls, whatever emergency, he presses that button and that's how the emergency paramedics can come in to assist him. Many things can happen in a minute…we leave for thirty minutes or ten minutes. In that time something could happen....” - Caregiver
Unable to Prioritize their Own Health

Physical Health
- Safety Concerns
- Lack of Time

Mental Health
- Worrying
- Social Isolation
- Cognitive Load

"I think caretakers a lot of times don't take care of their own health as well as they might otherwise because they're so focused on someone else's health. I don't know. I don't know how to fix that." - Caregiver
Very Few Technological Options for Caregivers

“You know what? I really don't use any tools on my end, as far as the calendar on my phone.” - Caregiver
Summary of Caregiver Themes

- Appreciate technology that accounts for safety
- Caregivers unable to prioritize their own health
- Very few technologies available for caregiver-based support
Well-Received Stroke Technology

- Positive Feelings
  - Empowering
  - Safe
  - Enjoyable

“Oh, God, yes. I don't know why we didn't do it [Alexa] sooner... it's brilliant. It brings him so much joy. That kind of a voice control device where he can ask questions like what the temperature is. What, who, how old an actor was when he died? What the feeding habits of juvenile wolves are? He loves that and then he listens to music on it too. It's been a game changer. I wish we've gotten a lot sooner.” - Caregiver
Less Well-Received Stroke Technology

“We have one [robotic glove]... we never used it because... hand balled up a lot... hard to get into something. So we never actually tried it again... I brought it up to his OT and they wanted to check it first before we use it, but so far it's not something that we've used but we do have...And they [OT] wanted to make sure... the action of the robot wasn't always going inwards because he already naturally goes in... make sure it wasn't like extra of this [finger flexion].” - Caregiver

- Concern for use
- Difficult to use
- Forgotten
Takeaways

- Emotional component of daily life plays a role in activities and technology use
- Informal caregivers, particularly family are incredibly important motivators and supporters of physical and emotional needs
- Informal caregivers are incredibly overwhelmed
- There is minimal technology for caregivers
- Stroke technology should not create more problems
- These burdens are great within an already burdened and underserved population
Opportunities for Future Discovery

- How can we draw from existing powerful motivators to improve the experience and emotions evoked while using stroke technology?
- How can we create technology to encourage the mental health of both the caregiver and the stroke survivor?
- How can we design technology to help caregivers care for their own health?
Motivate the Process

- Currently stroke technology design focuses on improving physical and cognitive functionality
- Should create technology to support positive emotional responses when people use them
- Motivation through not only the goal of getting better in the future but also the positive experiences with the tools used to reach that goal
Thank You

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