

Tech for Caregivers

Changing care by centering home health aides in
health technology systems

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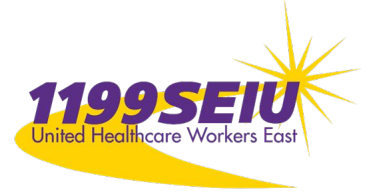
Madeleine Sterling, MD, MPH



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Today's Seminar

- Intro to the home healthcare setting
- Spotlight on **caregivers**
- Empowering caregivers through digital technology

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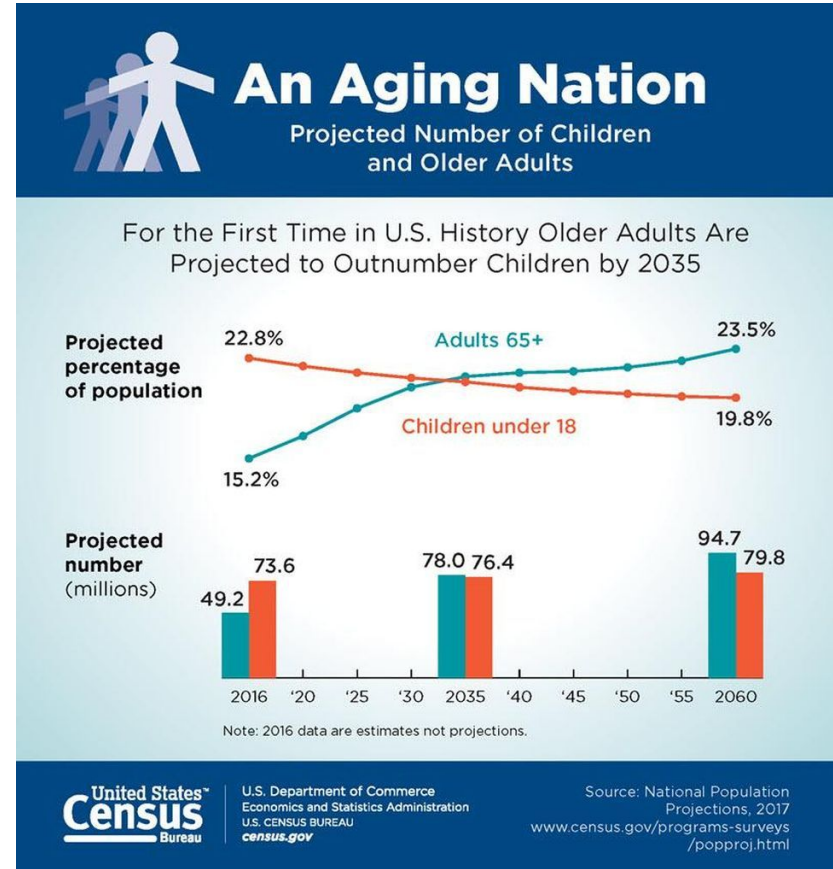
I want to hear from you!

Name, year

What do you know about home healthcare?

Why care about home health?

- More and more people need care in the home.
 - Frail and elderly
 - Acute and chronically ill
 - Differently abled people
 - Adults and children in need of protection



Why care about home health?

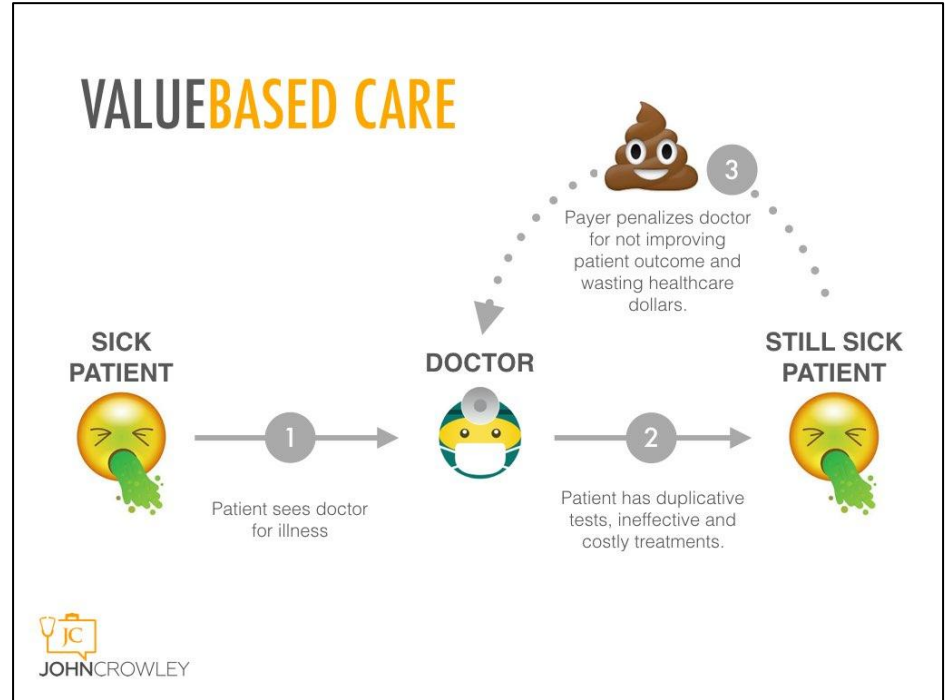
- More and more people need care in the home.
- Patients' at-home experiences can make or break outcomes...



[source](#)

Why care about home health?

- More and more people need care in the home.
- Patients' at-home experiences can make or break outcomes...
- ...and outcomes increasingly dictate how providers are paid
 - e.g., proper at-home post-op care can prevent readmission



The home health experience

- Sets of instructions to follow, medications and supplies to obtain
- Tools for self-monitoring
 - Self-management
 - Remote monitoring
- Peer support
- **Caregivers**



At-home caregiving

- **Formal** (paid, from agency) vs. informal (often family)
- Work under supervision from an RN
- Require certification from the state
- Visit clients' homes, work in shifts (often many aides : 1 patient)



Scopes of practice

Personal care aides (PCAs)

- ADLs
- Household duties
- Meal prep
- Escorts to appointments
- Medication reminders
- Emotional support

Home health aides (HHAs): PCA scope, +

- Monitoring vital signs
- Managing complex diets
- Assisting with prescribed exercise, medical devices (e.g. O2, nebulizer, CPAP), special skin care
- Assisting with dressing change, ostomy care

Advanced home health aides (AHHAs): PCA & HHA scope, +

- Administering routine non-injectable meds
- Injections of heparin or diabetes medications
- Emergency injections (epinephrine, naloxone, glucagon)

Home care work is difficult and poorly paid

- Shift work with long, physical hours
- Difficult, unpredictable, often involves life-or-death situations
- Wages are poor, often minimum or close to it
- Caregivers are often Black / Latinx women

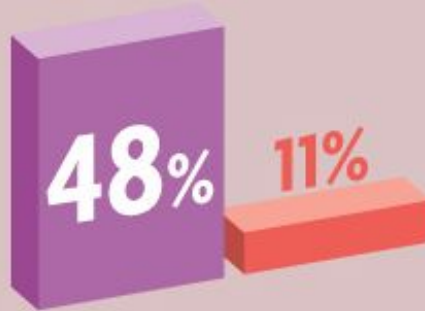


Despite this, the job is only growing



\$20,820

Median annual salary of a home health aide⁽³⁾

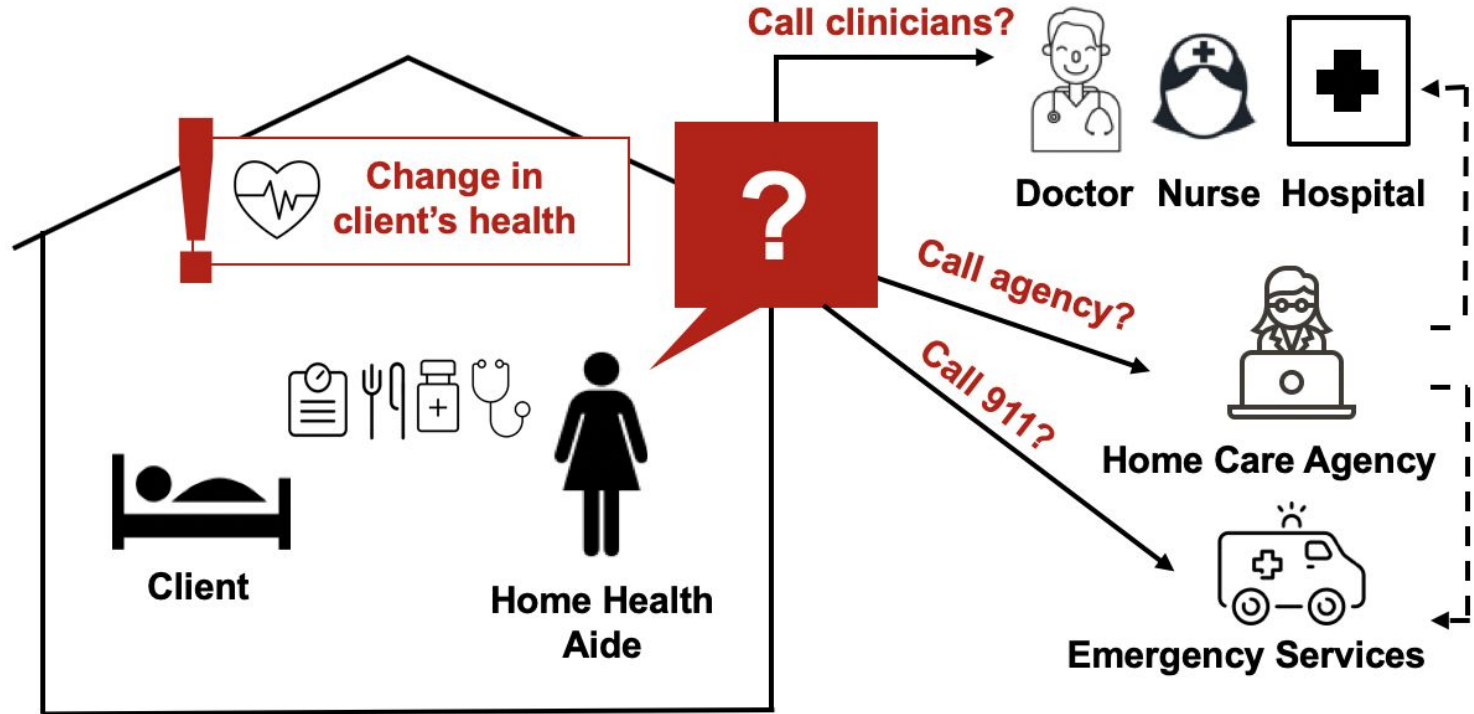


48% Job growth outlook for 2012-2022, much faster than the average 11%⁽³⁾



73% Percentage of national home healthcare expenses that are paid by taxpayers. That makes it a \$42.5 billion industry.⁽²⁾

Home health for patients with heart failure



OUR THESIS

Aides are underutilized and de-prioritized in the current healthcare system.

Integrating their perspectives into clinical care would help us better understand + treat patients.

Thoughts?

Human-centered design

Understand the problem

- Interviews
- Focus groups
- Observations
- Contextual enquiries
- Surveys

Prototype + test solutions

- Wireframing
- Paper prototyping
- MVP builds
- Beta testers
- Interviews
- Focus groups
- Observations
- Surveys

Deploy and evaluate

- A/B tests
- Clinical trials
- Interviews
- Focus groups
- Observations
- Contextual enquiries
- Surveys

Our work

Understand the problem

Interviewed and held focus groups with aides, nurses, coordinators, and agency leadership over 2018 and 2019.

[2,3]

Prototype + test solutions

Prototyped a tablet tool giving aides data collection, communication and education capabilities.

Showed it to aides, nurses and coordinators; gathered reactions. [1]

Deploy and evaluate

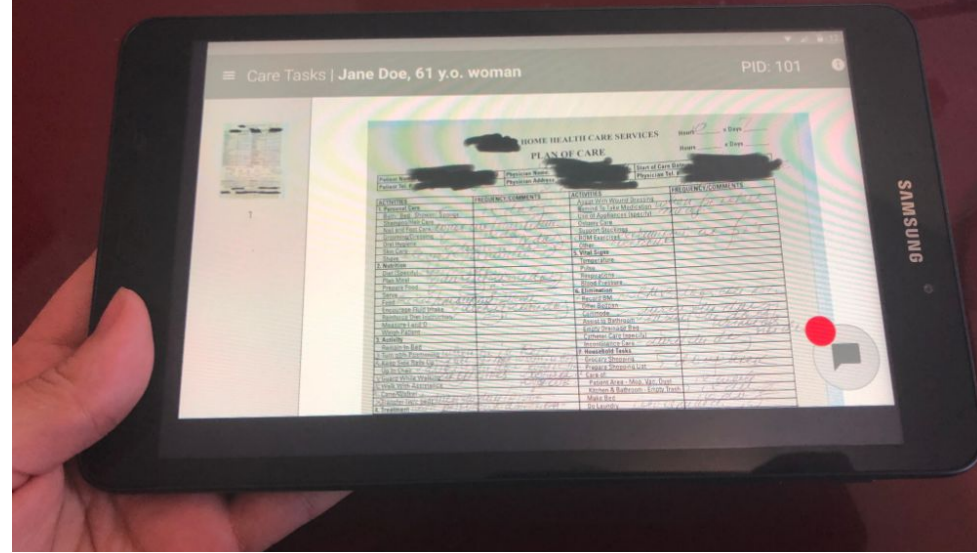
Clinical trial in the works

Re-designing to center aides

Prior work [2,3] distilled **3 key needs**:

- 1) Better tools for collecting the myriad information aides observe about patients every day
- 2) Better mechanisms for communicating with other stakeholders: agency coordinators, nurses, clinicians, family members, etc.
- 3) Better access to educational content (e.g., video CPR tutorials)

1) Better tools for collecting the myriad information aides observe about patients every day



Care Tasks | Jane Doe, 61 y.o. woman PID: 101

HF MONITORING
Leg and ankle swelling? +1 to +2 +3 or higher
 None observed

ALL VITALS

PERSONAL CARE
Confusion? Yes None observed

Feeling dizzy, lightheaded, or faint? Yes None observed

ACTIVITIES
Fall? Yes None observed

NUTRITION
Energy level? More tired or fatigued than usual Normal

TREATMENT
Sleep? Increase in the number of pillows needed Normal

NON-PERSONAL CARE

Care Tasks | Jane Doe, 61 y.o. woman PID: 101

HF MONITORING
Continue monitoring the patient.
 None observed

ALL VITALS

PERSONAL CARE
Confusion? Yes None observed

Feeling dizzy, lightheaded, or faint? Yes None observed

ACTIVITIES
Fall? Yes None observed

NUTRITION
Energy level? More tired or fatigued than usual Normal

TREATMENT
Sleep? Increase in the number of pillows needed Normal

NON-PERSONAL CARE

Care Tasks | Jane Doe, 61 y.o. woman PID: 101

HF MONITORING
Contact your supervising nurse or call 911.

ALL VITALS
140 lbs MONDAY 10:00 141 lbs TUESDAY 10:00 141 lbs WEDNESDAY 11:00 140 lbs YESTERDAY 11:00 Weight Enter today's weight

PERSONAL CARE
100/70 WEDNESDAY 8:58 PM 110/70 WEDNESDAY 9:12 AM 100/70 WEDNESDAY 5:23 PM 100/70 TODAY 9:21 AM BP Enter latest blood pressure

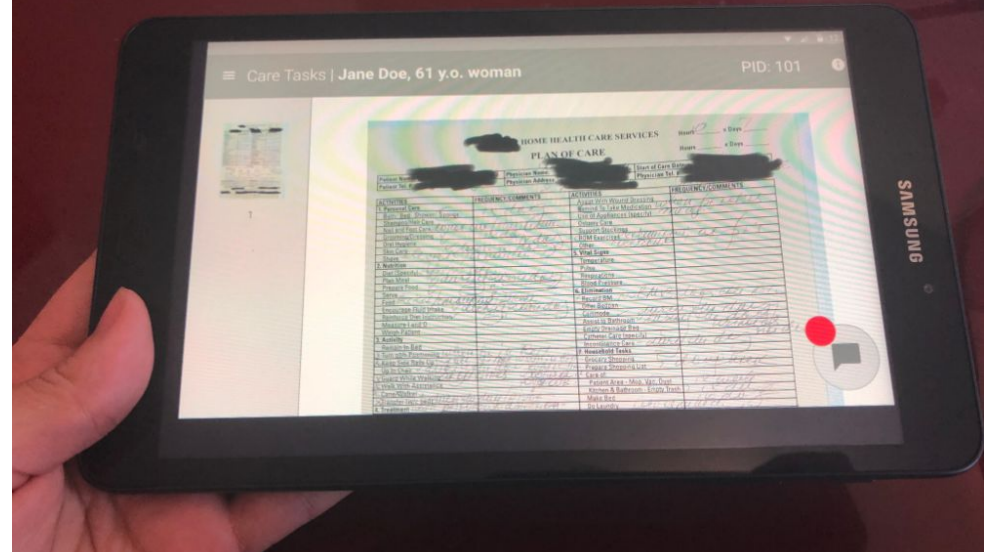
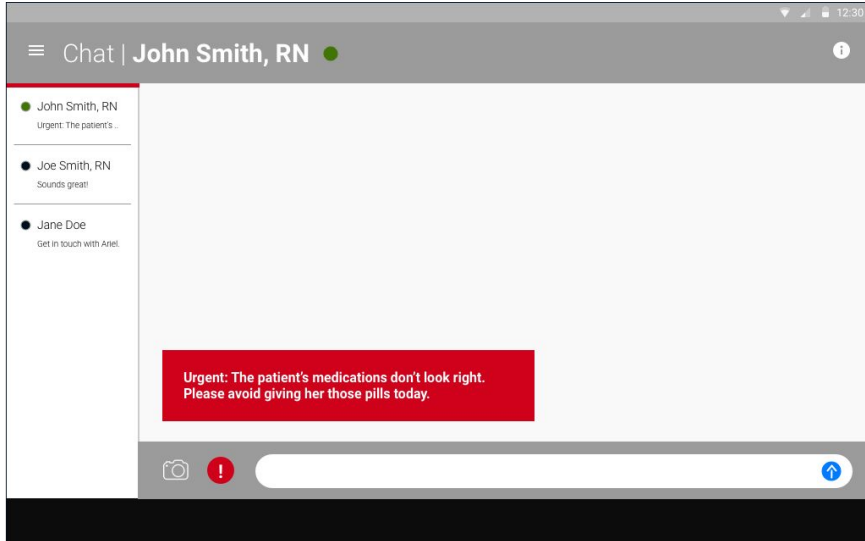
ACTIVITIES
Shortness of breath?
 Yes, and won't resolve Yes, and not able to lie down Yes, with activities
 None observed

NUTRITION
Chest pain or pressure? Yes None observed

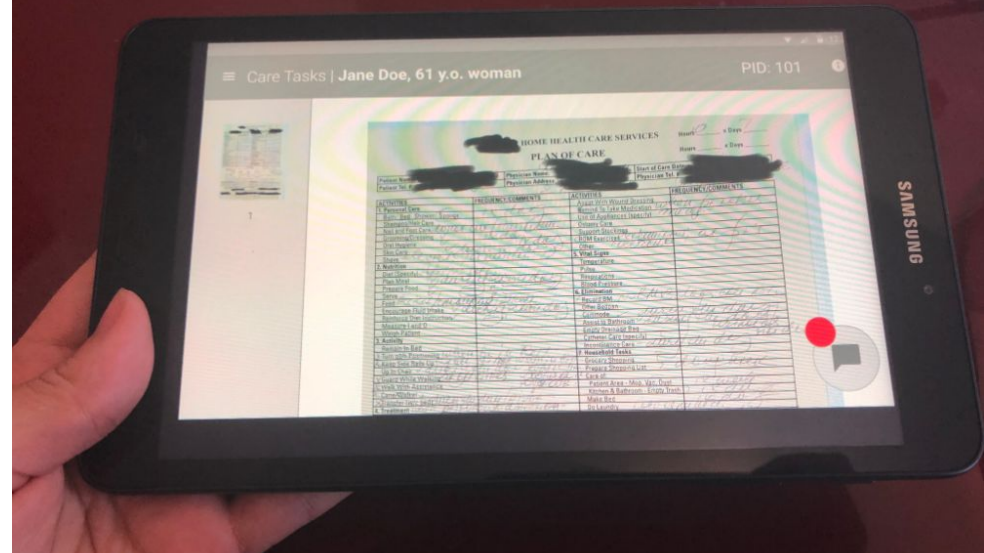
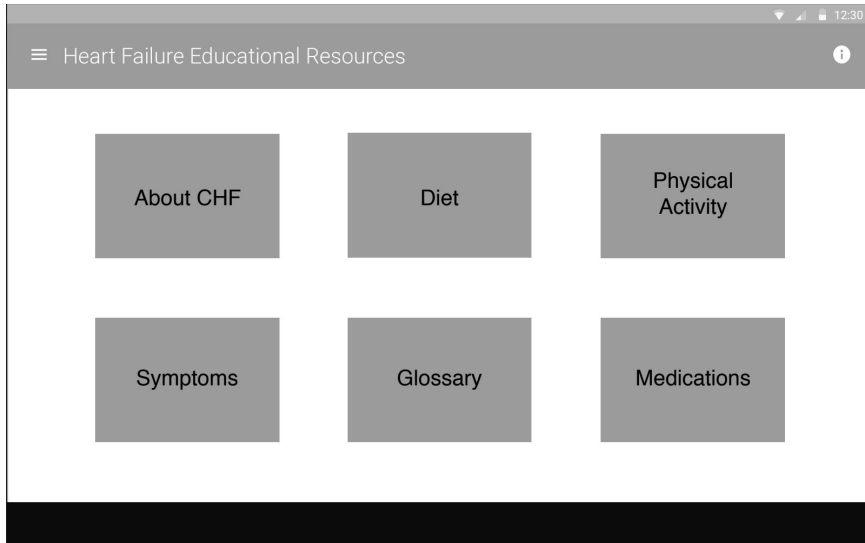
TREATMENT
Leg and ankle swelling? +1 to +2 +3 or higher
 None observed

NON-PERSONAL CARE

2) Better mechanisms for communicating with other stakeholders



3) Better access to educational content (e.g., video CPR tutorials)



Findings

- Aides saw the data collection features as a way to gain leverage when dealing with their employers

“This would protect me, because once [my task] is in, it’s recorded. There’s no ‘you didn’t call’. It would be my backup, my paper trail.”

“A bed sore progresses. I’ve made several calls, it’s growing, it gets worse and worse. This would document my persistence.”

Findings

- Aides saw the data collection features as a way to gain leverage when dealing with their employers
- Nurses and coordinators were concerned aides would abuse the chat features

“If I know these aides, everything would be red.”

“One of the first things we tell aides is to buy a little book from the 99-cent store so they have all their addresses in that book. A lot of aides don’t comply with that. When they start working and you tell them something, they just tear off a sheet of paper and write it down, but they don’t save it. **So by texting like this it seems a little more permanent, I should say.**”

Findings

- Aides saw the data collection features as a way to gain leverage when dealing with their employers
- Nurses and coordinators were concerned aides would abuse the chat features
- Everyone was concerned about patients' reactions

“If this were to get piloted, people would need to be informed, meaning the patients. They can get funky. They can feel like you’re spying on them.”

“The biggest complaint we get from clients is that aides are always on their phones. ‘She don’t do nothing, she just sit on her phone all day, texting texting.’ So I don’t know how I would explain it to the clients. They’d be sneaky, they’d be telling the patients ‘Oh, I’m texting my supervisor...’ “

Findings

- Aides saw the data collection features as a way to gain leverage when dealing with their employers
- Nurses and coordinators were concerned aides would abuse the chat features
- Everyone was concerned about patients' reactions
- Aides themselves were mixed on whether the new features would help or hurt them

“Some people want to go, follow the care plan and that’s it. Stuff like this would seem like extra work.”

“Some [aides] don’t even know how to write and read in Spanish. How are they gonna be writing and reading in English?”

“You’d have something to anchor you and take away your anxiety – ‘oh my god, heart failure, what is it, what do I do’. This gives you a foundation.”

Next Steps

- What information from aides would be useful for clinicians? How does this vary by clinician, e.g. traveling nurse vs. PCP vs. discharge nurse vs. surgical team?
- How can chat communication be built to adequately respect clinicians' time while getting aides the answers they need?
- How can a pilot like this be designed to prioritize safety, comfort and privacy for both aides and patients? What do we do when these priorities are at odds?

Next Steps

- What information from aides would be useful for clinicians? How does this vary by clinician, e.g. traveling nurse vs. PCP vs. discharge nurse vs. surgical team?
- How can chat communication be built to adequately respect clinicians' time while getting aides the answers they need?
- How can a pilot like this be designed to prioritize safety, comfort and privacy for both aides and patients? What do we do when these priorities are at odds?
- **(In reality: Redoing everything due to COVID)**



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Recap

- You should care about what happens to your patients in the home
- You should care a lot about what their **at-home caregivers** are facing
- Thoughtful elicitations with relatively uncomplicated technologies can help us imagine a better care system

Cited works

1. Emily Tseng, Fabian Okeke, Madeline Sterling, and Nicola Dell. **"We can learn. Why not?": Challenges and Opportunities in Designing for Equity for Home Health Aides.** *ACM Conference on Human Factors in Computing Systems (CHI 2020)*. <https://doi.org/10.1145/3313831.3376633>
2. Fabian Okeke, Emily Tseng, Benedetta Piantella, Mikaela Brown, Harveen Kaur, Madeline R. Sterling, and Nicola Dell. **Technology, Home Health Care, and Heart Failure: A Qualitative Analysis with Multiple Stakeholders.** *ACM SIGCAS Conference on Computing and Sustainable Societies (COMPASS '19)*. <https://doi.org/10.1145/3314344.3332487>
3. Sterling, M.R., Dell, N., Piantella, B. et al. **Understanding the Workflow of Home Health Care for Patients with Heart Failure: Challenges and Opportunities.** *J GEN INTERN MED* 35, 1721–1729 (2020). <https://doi.org/10.1007/s11606-020-05675-8>