NEURODEGENERATIVE PATIENT CARE

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Team

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01.

Initial
POV

We met …

Eleni, a 49 year-old nursing assistant who works at an assisted living facility with a memory care unit

We were amazed to realize …

Even at an assisted living facility, it was difficult for patients and caregivers to communicate needs with one another, especially when it came to Alzheimer's patients

It would be game-changing if …

There was a more **reliable** and **personable** way to gain insight into other people's caretaking process

PROBLEM DOMAIN

Neurodegenerative Diseases dealing with **progressive memory loss** (Dementia, Alzheimer's, etc.)

02.

Needfinding Round 2

SAY

3) Dementia patients usually live in assisted living where they get the care they need

Caregivers often want to talk to others

My wife [dementia patients] would like to talk to others as well

Caregivers sometimes need memories and stories for themselves as well, to remember that dementia shouldn't taint their memory of a loved one

Most patients experience a similar pattern of progression.

I want to know what it's like to go through this - there's no playbook

I want to know what's next (condition wise) - what should I be prepared for

2) They lack independence and privacy when going to doctor visits

"Help me find my car, I don't remember where I parked it."

1) Some states have social service system that offer family members $$ to be a caregiver to dementia patients (~ 4hrs of pay/day)

I often don't know what activities to do with my loved one; I use this website - https://truthfulkindness.com/index-persons-with-dementia-pwd/missy/meltdown/

THINK

Sounds and music are effective when it comes to jogging memories.

I think that a support group is vital for getting through tough challenges

I think that there are special activites that I'm supposed to do with dementia patients - I just dont know what they are

The journey to prep is tedious and demands a lot of emotional support.

2) There is no way to ensure privacy for patient while caring for them

1) The act of caregiving is quite demanding on the giver that they need compensation, but 4 hrs is not enough

3) Are they getting the best support for specific health concerns if a general nurse is overseeing all assisted living residents?

I think music is an effective way to jog my wife's memory or to calm her down

I think that the caregiving process is tough on the caregivers themselves, and sometimes we need a reminder of how things used to be

DO

Long Term Directives:
- Quality of life
- CPR / life support?
- How to handle death?

Get a support group going for family members to help find a community to cope.

1) They get paid a max of 4 hrs of caregiving a day -> is that enough?

I often have to unexpectedly go and support my wife in the middle of calls or classes

Prep:
- Long term care insurance
- Paperwork to sign over banks

Identify where she is in progression of disease and make plans for next steps.

Save momentos. Tape recordings and music playlists. Gather old pictures.

I use Music in order to set different tones and moods

I set up different systems to help her remember things from the day to day - I setup a clendar to help her remember her schedule, important phone numbers, etc.

3) There's a general nurse during all hours of the day to attend to all residents

2) They go in with them when getting checked for various reasons and have to listen to personal convo

I constantly check in on my wife to make sure she's ok - sometimes she'll have injured herself and not say anything about it

FEEL

1) unappreciated for the support I provide

pure happiness when I experience a recollection. the best feeling in the world.

I sometimes feel lost or as if I'm doing the wrong thing when tending to my wide

Heartbroken when having to discuss life support and how to handle death/body with family members.

It must be so hard for my family to see me not recognize familiar.

I feel lonely or isolated as if I'm going through this journey alone

2) invasive of their personal life

Fustrating when asked to identify a mystery face and cannot recognize.

I feel like I'm missing out on vital pieces of info when it comes to resources and support

I feel like I could be doing more to help out my wife

3) uncertain of the type of support provided by assisted living facilities

I am constantly worried about my wife and if she's safe or not

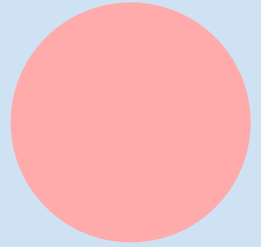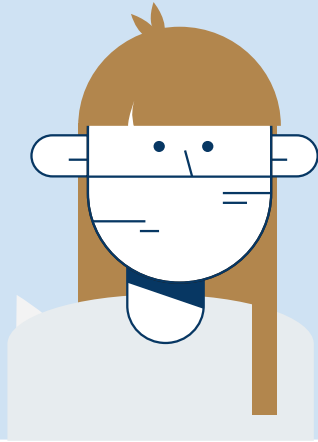# INTERVIEWEE #1

Katie
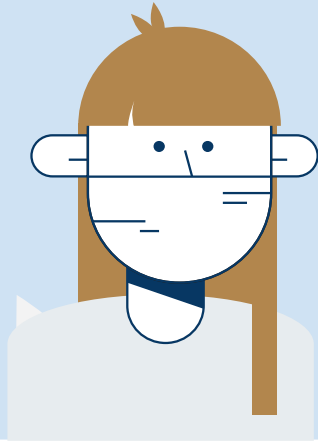
- ❖ 63 year-old woman from Seattle, Washington
- ❖ Diagnosed with Mild Cognitive Impairment
- ❖ Recruited via Reddit
- ❖ Zoom

INSIGHT

Katie

Surprise:

"Whenever I feel my mood is volatile, I'll listen to my favorite song or look at my favorite memory to make me happy"

POV #1

We met ...

      Katie, 63 year-old diagnosed with Mild Cognitive Impairment

We were amazed to realize that ...

      she is able to recall experiences better when hearing a song or shown a photograph over verbal storytelling

It would be game-changing if ...

      there is a means to automate the capture and customization of sensory experiences in one's life

INTERVIEWEE #2

❖ 59 year-old German teacher at Goethe Institute in Atlanta, Georgia

❖ His wife was diagnosed with Alzheimer's a few years back

❖ Primary caregiver to his wife

❖ Zoom

Wolfgang

INSIGHT

Contradiction:

"I've been directed to numerous online resources, but I still feel lost when it comes to what I can do to help my wife."

Wolfgang

POV **#**2

We met …

> Wolfgang, a 59 year-old German teacher whose wife was diagnosed with Alzheimer's a few years back

We were amazed to realize …

> that even though he had access to a plethora of resources, he still felt helpless and lonely when it came to navigating the caregiving process
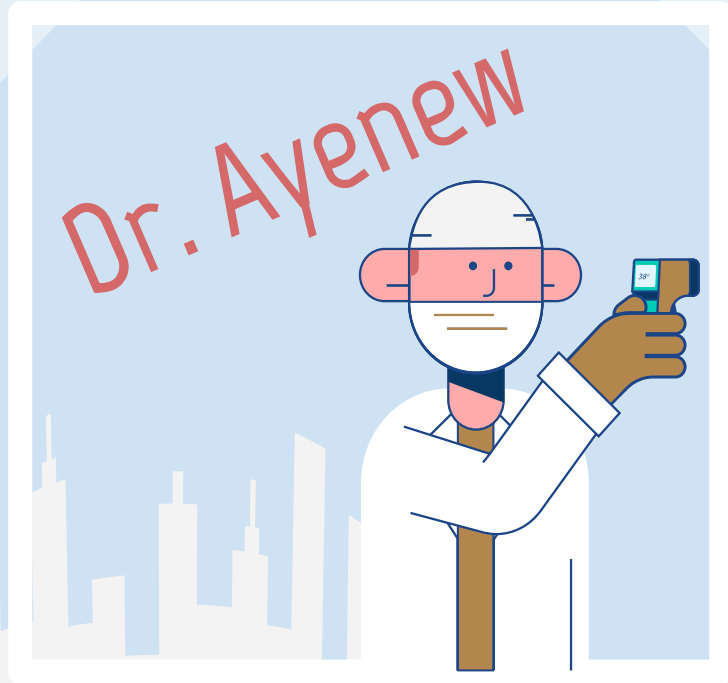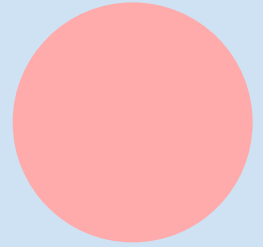
It would be game-changing if …

> there was a more reliable and personable way to gain insight into other people's caretaking process

INTERVIEWEE #3

Dr. Ayenew
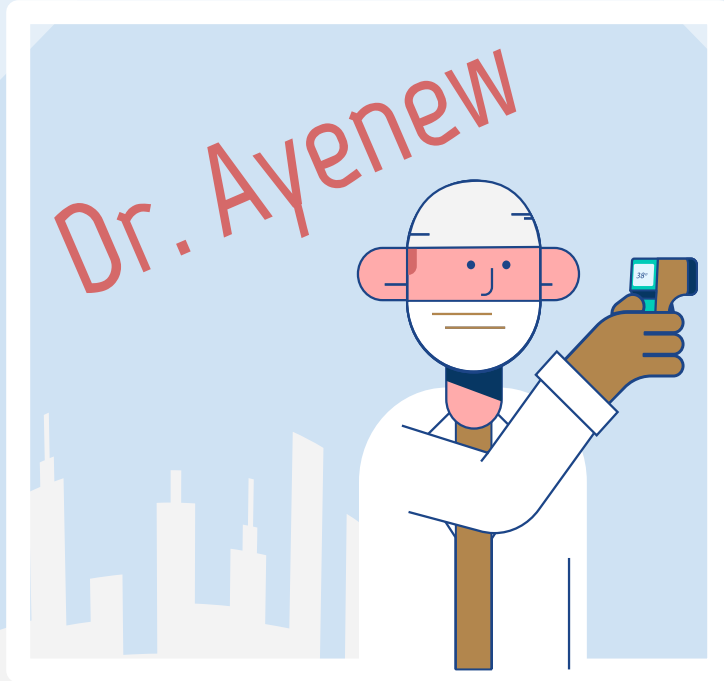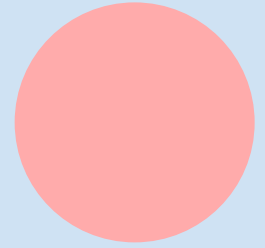
❖ A clinical doctor who has been practicing for 20+ years
❖ Treats patients over the age of 50
❖ Zoom

INSIGHT

Tension:

"Even when a patient with neurodegenerative disorder has a caregiver, the caregiver usually has another job, and thus can't guarantee care around the clock"

POV #3

We met ...

    Dr. Ayenew, a clinical doctor who has been practicing for 20+ years treating patients over the age of 50

We were amazed to realize ...

    that he gets patient messages via MyChart (an online healthcare portal) in the middle of the night, most of which he can't attend to promptly
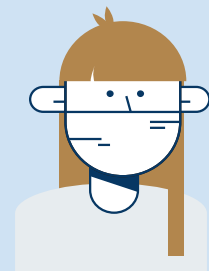
It would be game-changing if ...

    there was a way to attend to patient needs 24/7 for those not in assisted living, especially during the caregiver's off-hours

03.

HMW,
Solutions,
Experience Prototypes

Katie

How might we convert stories into sensory media?

Automate creation of storyboards that synthesize photos and sounds to recreate a "memory."

Visual and auditory stimuli are more effective than oral storytelling.

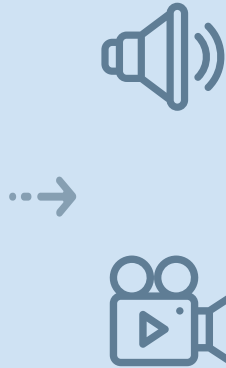Automate creation of storyboards that synthesize photos and sounds to recreate a "memory."

Visual and auditory stimuli are more effective than oral storytelling.

EXPERIENCE PROTOTYPE #1

In the fable of the dragon tyrant, the story starts off with a dragon that eats the villagers and terrorizes them. He does this over and over again, and the villagers realize that they need to feed him to keep him complacent. So they ship x number of people to him everyday. One day, a scientist makes a breakthrough to kill the dragon, but the king turns him down. The king eventually comes around to his senses and approves. At the end, we hear a touching scene of how they should've started earlier. The dragon still dies, and they realize that they have a whole new world ahead.

The story begins with a dragon perched on top of a tall mountain top overlooking a village. No matter what the village did, the dragon was unstoppable. It would just eat villagers upon villagers. So, to make the dragon happy, the village decided to sacrifice a cart load of people to the dragon every year. Even though it was morbid, it meant that the dragon was satisfied and wouldn't wreak havoc on the town every single day. And this continued for hundreds of years. So much so, that the dragon became a part of everyone's life. A necessary evil to the population. But one day, a scientist went to the king's court room with a proposal. He had figured out a way to make a weapon that pierced the dragon's scales, and could kill it. The king, scared that any action could anger the dragon, and scared that the missile wouldn't work, said no. After a few years, the king kept thinking back on this proposal, and decided it was worth a shot. He assembled all of his finest scientists and made it a national priority to secretly build the weapon to take down the dragon. While the weapon was being built, people were still being sacrificed to ensure that the dragon wouldn't grow suspicious. Finally, the day came, when the missile was complete. But on that day, they still had to send the last cart, so that the dragon wouldn't grow suspicious. The relatives and friends of those on this last cart were heartbroken - if only they'd started the project a day earlier, their friends wouldn't have perished. The last cart went, and the dragon ate them all. Later that day, in prime weather conditions, the missile was launched, and the dragon was no more. Now, the population would think about what a post-Dragon life looked, and what it meant for them.

We picked a short story, and showed person 1 a video version and version 2 an audio-only version

We asked them the next day to summarize what they remembered about each story

RESULT

Visual participant latched on to details while audio participant focused only on the plot

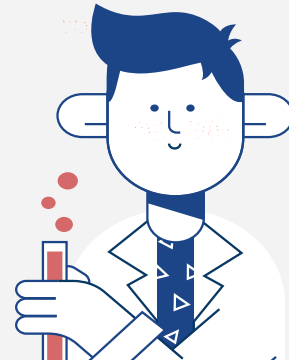Visual stimuli was found more interesting and engaging than audio only.
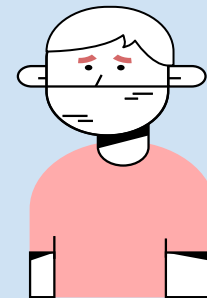
Surprise:
Audio participant took longer to remember fewer details

New Learning: Visual required greater focus and attention span

<u>**Validity:**</u>
Person who watched the video version produced a much more detailed summary than audio only.

How might we use peer support to guide and inform the caretaking process?

Wolfgang

SOLUTION

A centralized network for caretakers to share physical resources and emotional support throughout the caregiving process.

Caregivers are willing to speak to caregivers they don't know about their intimate circumstances

ASSUMPTION

SOLUTION

A centralized network for caretakers to share physical resources and emotional support throughout the caregiving process.

Caregivers are willing to speak on intimate circumstances to others they don't know

ASSUMPTION

EXPERIENCE PROTOTYPE #2

Would Caregivers be **willing** to join a Discord **Support Group** with others they have **never met before**, with the intention of **sharing stories and experiences**?

r/dementia · Posted by u/Low_Battle_6127 4 hours ago

Caregiver Support Discord Group

Hello everyone! We've spent the last few weeks talking to caregivers to people who may be undergoing cognitive decline, and we learned that a lot of them don't have others to talk to who are going through the same thing. We'd like to make a Discord server to help connect people and foster more intimate conversations, and we were wondering who'd be interested!

If you'd like to participate, please fill out this Google Form:
https://docs.google.com/forms/d/e/1FAIpQLSeFvsWnMVHYIitAGNs8ET2uIAKD9GT0Re43Als8mgeRAZrPFA/viewform

Thank you so much!

We posted on r/dementia, putting out an **open call** for those who'd **like to join** a caregiver **Discord** server

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Dementia Caregivers Support Group

Thank you so much for taking the time to fill out this form! We're looking into creating a Discord server for more intimate community building amongst caregivers, and we'd love for you to join!

First Name? (Write N/A if you'd like to be anonymous)

Your answer

Last Name? (Write N/A if you'd like to be anonymous)
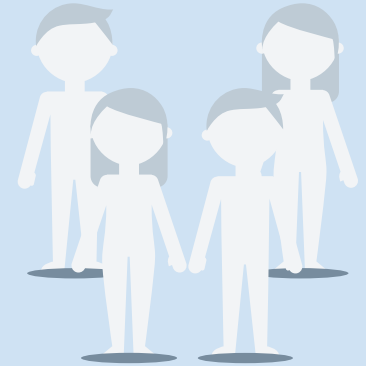
Your answer

Reddit username?

Your answer

Would you like to be added to a Discord Group to meet and learn from other caregivers?

○ Yes!
○ No
○ Other:

We directed them to a **Google form**, asking if they'd join, and if they would like to **share stories**

We received **4 'YES'** responses in **10 hours**.

RESULT

Open to sharing personal topics, even to strangers.

Surprise:
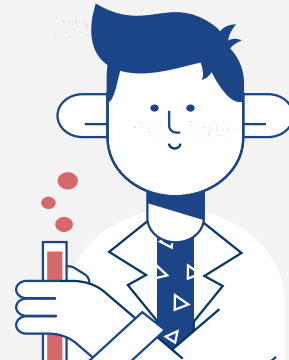They felt comfortable enough to deanonymize themselves
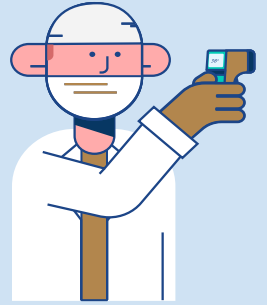
New Learning:
Most comfortable if it only involved other caretakers

More hesitant to initiate contact though many sought community

Validity:
Numerous caretakers were willing to join a support group.

How might we increase accessibility to assistance when a caregiver is unavailable?

Dr. Ayenew

SOLUTION

A digital assistant that substitutes for a caregiver, monitoring the patient and providing them timely reminders in a non-overwhelming way

People have difficulty remembering daily tasks without the assistance of an automated system

ASSUMPTION

SOLUTION

A digital assistant that substitutes for a caregiver, monitoring the patient and providing them timely reminders in a non-overwhelming way

People have difficulty remembering daily tasks without the assistance of an automated system

ASSUMPTION

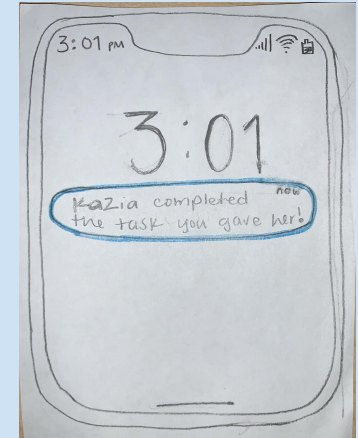# EXPERIENCE PROTOTYPE #3

Set a new task for the patient
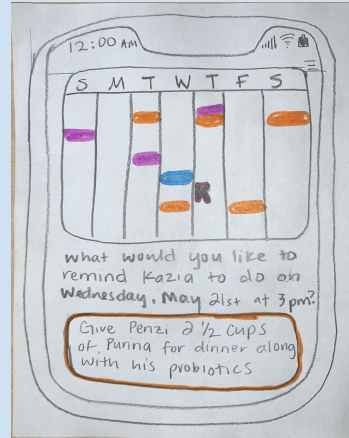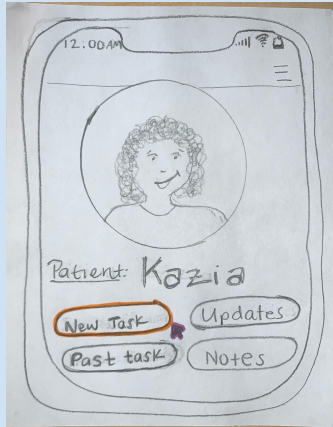
Select date & time of the task. Include task details
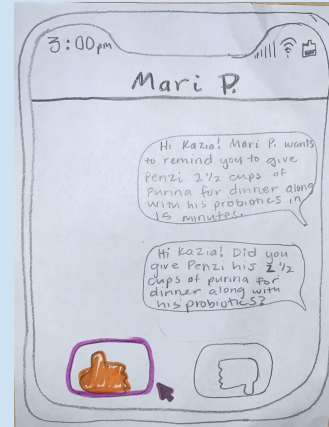
Send reminders to patient on schedule time. Collect feedback (i.e. thumbs up for completed)

Care Provider gets real time task updates

RESULT

Appreciated simplicity and ease of use of app

Responsibility to create reminder is on the caregiver
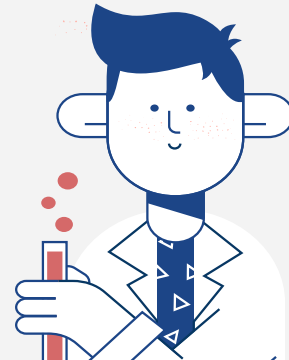
Surprise:
Preferred pop-up reminder over text/message

New Learning:
Needs more human touch

<u>**Validity:**</u>
Automated reminders ensured that tasks were completed.

KEY LEARNINGS

01.

Certain senses trigger memory recall more than others

02.

While caretakers are eager to join support groups, they are hesitant to make the first move

03.

An automated system delivers adequate care but requires more of a human touch
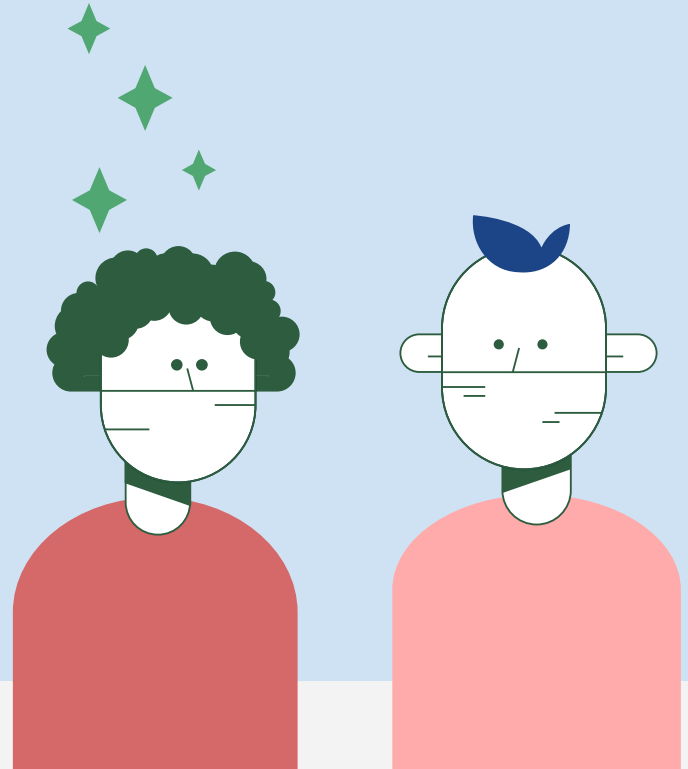
SOLUTION AND NEXT STEPS

Solution

Combine aspects of multisensory memory with automated digital assistance to improve the caregiver - patient experience

Next Steps

Generate design ideas with task flows and test concept videos.

THANKS!

Any Questions?