

# Caring for Alzheimer's Disease Caregivers: A Qualitative Study Investigating Opportunities for Exergame Innovation

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Northeastern University



Brandeis  
UNIVERSITY

# Rise in Informal Caregivers of Alzheimer's disease

**Around the clock**, live-in, primary caregivers to family members with Alzheimer's disease (AD)

Spouses, Children, Grandchildren, and even Extended Family

Average length of care from **8 - 10 years**

# Caregivers face numerous Burdens to Health:

Isolation

Little support

Chronic stress

Decreased physical activity (PA)

Increased health problems (e.g., insomnia, mood disorders)

Burden on caregiver health impacts the **Caregiver (CG)**  
AND the **Care Recipient (CR)**

**Physical Activity (PA)** is critical for improving cognitive, physical, and psychological health.

Previous interventions target reducing stress and depressive symptoms

Few interventions designed to increase physical activity among caregivers.

**Physical Activity (PA)** is critical for improving cognitive, physical, and psychological health.

Our intervention seeks to promote the wellbeing of caregivers by

- + increasing PA and

- + creating a community of caregivers

- = support for **PA** + increase **social connectedness**

## **Exergames:** Software tools where Physical Activity drives game play forward

- Repeated demonstrations of efficacy + acceptability in older adults
- Improved strength, balance, flexibility, socialization, and positive mood

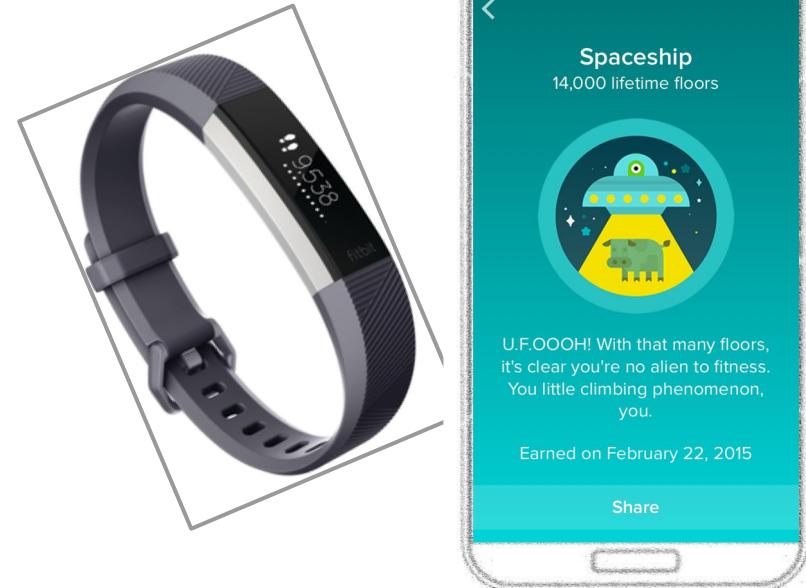
### However

- Play is restricted to **one setting**  
(e.g., by a video game console)
- Require **expensive equipment**  
(e.g., video game console)



## Pervasive exergames:

- Play is not restricted to one setting
- A myriad of user activities may serve as input
- Do not require expensive equipment



Design a **pervasive exergame** to increase physical activity and social connections for AD caregivers using participatory design methods.

# Participant Overview

**Recruitment:** through two partner organizations that work with AD Caregivers, Craigslist, and local AD Caregiver support groups

## 14 Caregivers

- Gender: 10 female, 4 male
- Age: 50 years old (SD=13, range 30-77)

They cared for a **spouse** (n=4), a **parent** (n=7), and **other family members** (n=3)

*Other: Grandparent, great grandparent, sister's mother-in-law*

# Method

## Semi Structured Interviews

- Caregiver role
- PA barriers
- Social Connection barriers

## Participatory design activities

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## Participatory design activities

- Inspiration Book

(spades)

1 Name of the Game: **playing cards**

How often do you play this game (circle one answer)?  
Once a year or less | A few times/year | Many times/year

When was the last time you played this game? \_\_\_\_\_

2 What specific actions and behaviors do you enjoy in this game (e.g., shuffling and dealing cards in a card game, buying properties in Monopoly, stacking shapes in Tetris)? **I like shuffling and dealing cards.**

3 Type of Feature | What features make the game fun, and why?

Sensations	<b>FEEL Cards</b>
Fantasy	<b>EXPERIENCES ON CARDS (FACES)</b>
Stories	
Challenge	<b>BET your opponent, people</b>
Social	<b>play with other</b>
Explore	
Self-Expression	
Pastime	<b>HOURS of PASSING TIME</b>

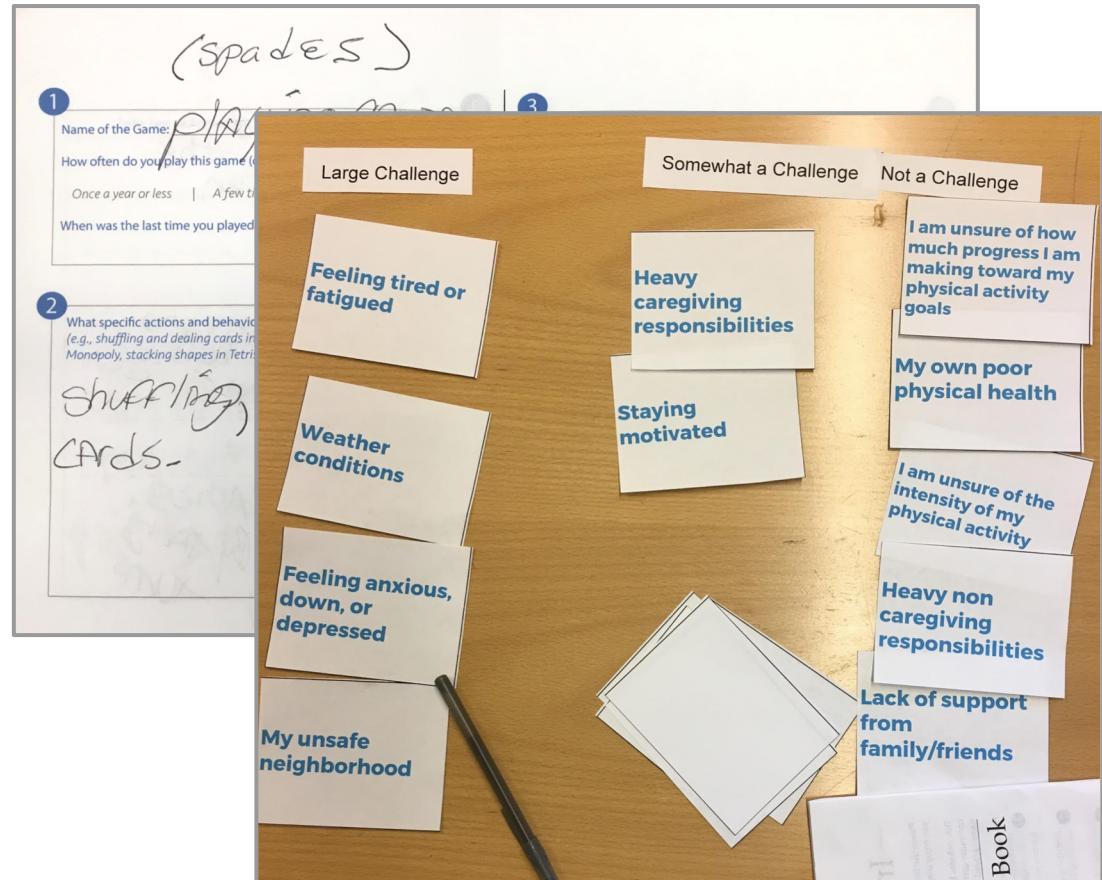
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## Participatory design activities

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- **Cardsorting: PA barriers**



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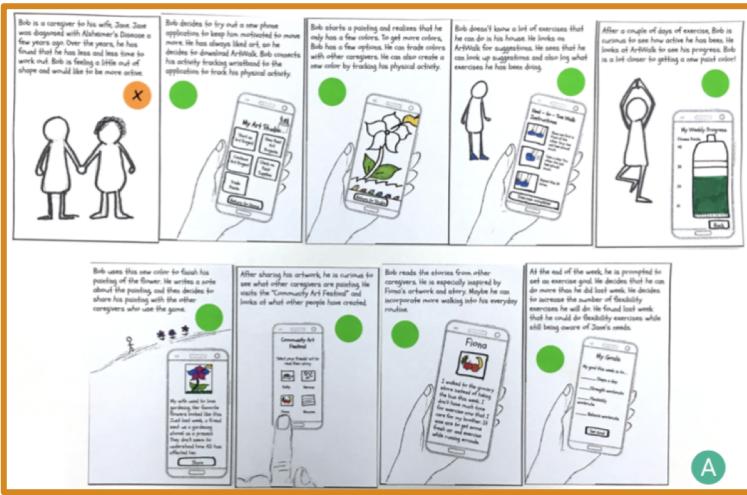
## Participatory design activities

- Inspiration Book
- Cardsorting: PA barriers
- **Cardsorting: Game Design**

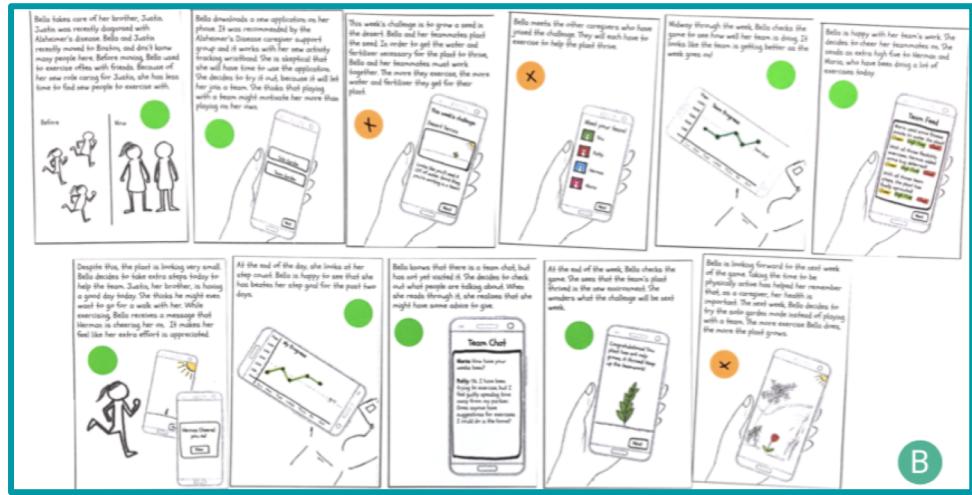


# Storyboards

## ArtWalk



## Gardening

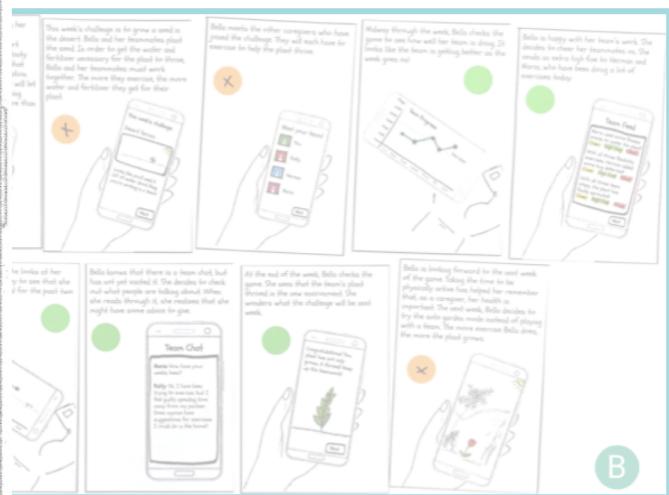


# Storyboards

## ArtWalk



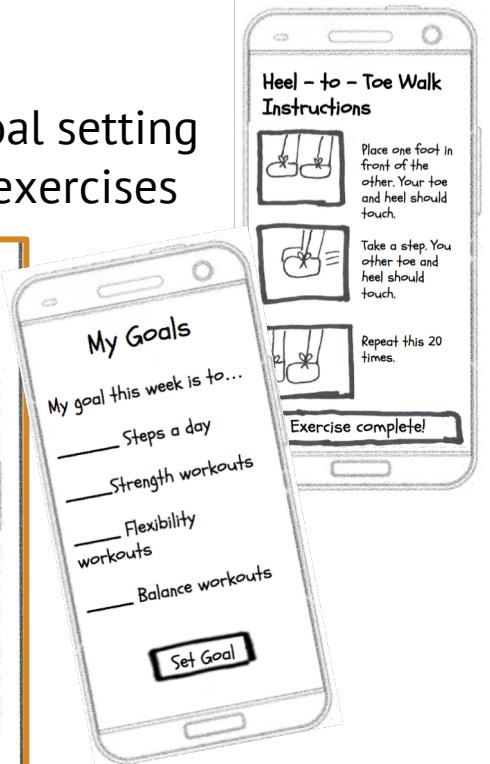
## Gardening



# Physical Activity Features

## ArtWalk

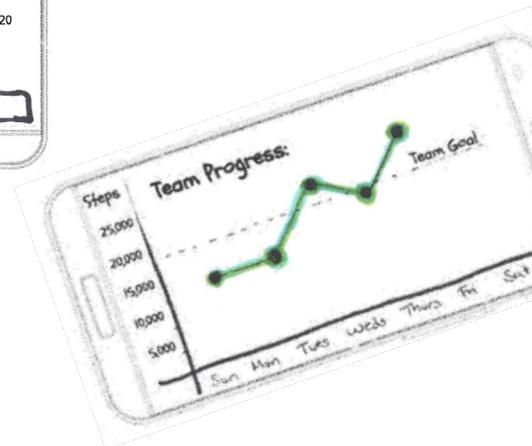
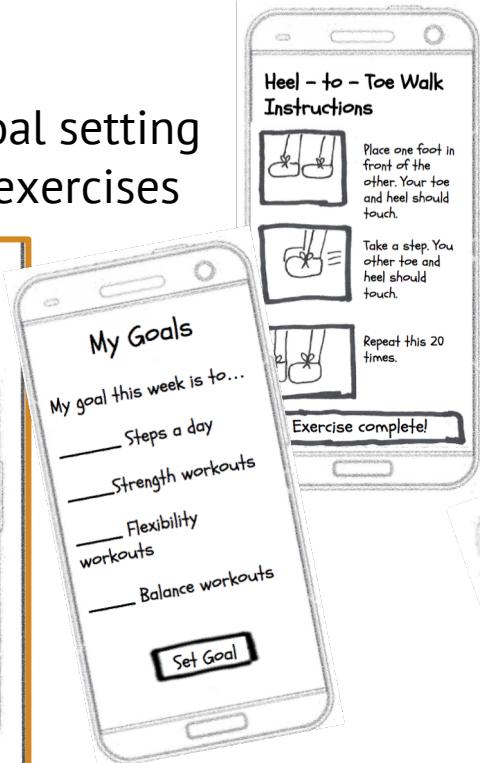
- Solo game
- User-driven goal setting
- Repository of exercises



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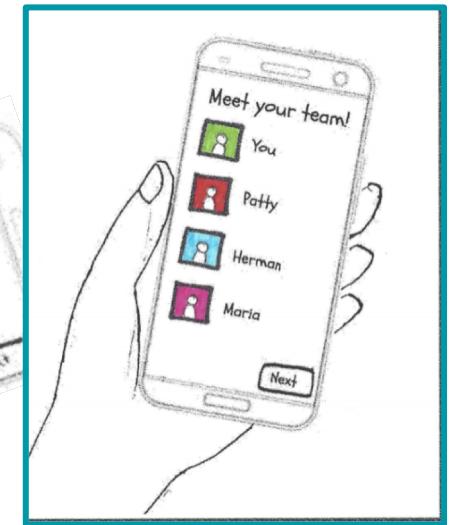
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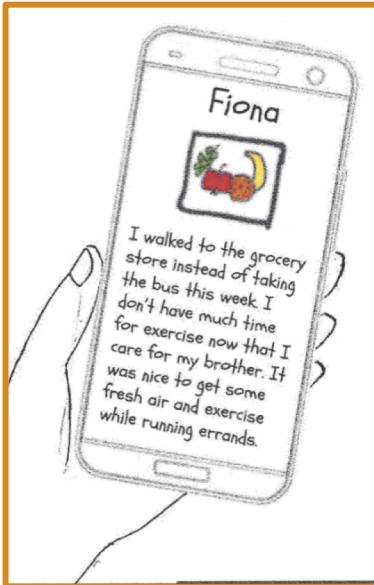
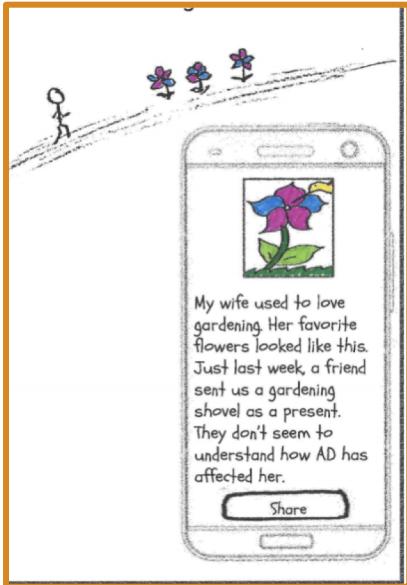
- Teamwork
- Competition against the game
- Collaboration with a team



# Social Connectedness Features

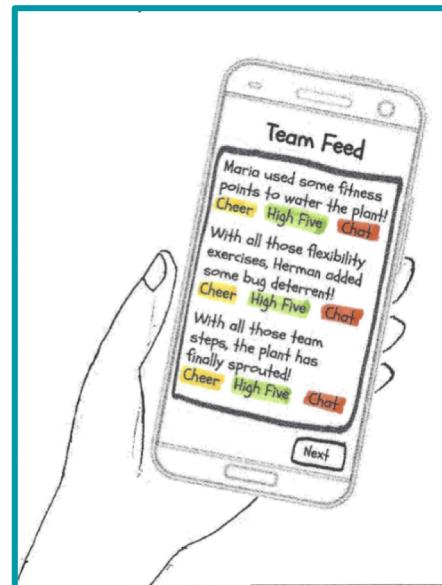
## ArtWalk

### Story Telling



## Gardening

### Team Chats



# Findings

**Caregiver constraints impact attitude toward technology for PA**

Caregiver preferences for technology-supported social connectedness

## Locational Constraint:

The need to be **physically present** with the care recipient meant long hours spent in the home.

*“... if he’s having a bad day, and he’s tired, he’ll literally sit in the same chair from after his milkshake, like 10:00 to 2:00, and I’m bored to death, but it’s not like I can go anywhere or do anything.”*

## Temporal Constraints:

**Frequency** of caregiver responsibilities.

*“I’m kind of on a [...] a stopwatch with her. You know, I hit the button, go. Come back, stop.”*

## **Unpredictability** of caregiver responsibilities.

- Uncertainty of the *disease progression*
- Unpredictability from *Day to Day*

*"I have tried changing my routine so that I get him through his morning rituals and then go meditate, and sometimes that works and often it doesn't, so I'm struggling with my own access to meditation time."*

# Caregiver-Tailored and Goal Setting

Interventions grounded in goal-setting theories are more likely to yield positive health outcomes.

# Caregiver-Tailored Goal Setting

**Goal Difficulty.** How does the unpredictability of caregiver responsibilities impact perception of goal difficulty?

**Goal Proximity.** How do caregiver constraints impact goal proximity?

# Findings

Caregiver constraints impact attitude toward technology for PA

**Caregiver preferences for technology-supported social connectedness**

# Story-Telling

- Informational support from other caregivers.

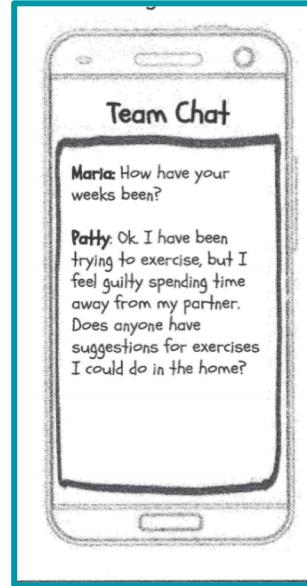


# Story-Telling

- Informational support from other caregivers.
- Low-Pressure Social Connection to other caregivers.



VS



# Story-Sharing

Sharing stories with other family members

*“... if you talk to her [care recipient], she would seem normal...to my son, oh it’s just old age grandma, whatever.*

*No, you don’t understand. Take her for a day and you’ll see what it’s like.”*



# Support Low-Burden Social Interactions

How to support social connectedness among caregivers with low-burden social interactions?

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**Scaffolded Storytelling:** to ease the process of sharing one's experiences.

# Building Trust through Shared Experiences

## Relationship to the person with AD

*“Talking to this woman [granddaughter caregiver, same age as P8] was really good and made me understand that it would be valuable to talk to somebody who’s also a daughter. Like it’s different. And it’s different when you’re 80 and when you’re 53. It’s a different dynamic.”*

## Stage and Symptoms of AD

*“I think it could be potentially dangerous or misleading to compare [symptoms]. Really with Alzheimer’s, each person’s situation is very unique.”*

# Design for Strategic Connections

Little work in social health applications has explored techniques to help users strategically connect with others.

# Design for Strategic Connections

Helping users identify strategic connections among caregivers with important shared traits

# Takeaways

- Support Caregiver-Tailored Goal-Setting
- Support Low-Burden Social Interactions
- Design for Strategic Connections

Full Paper @ [bit.ly/ADCaregiver](http://bit.ly/ADCaregiver)

*“Play it as it comes, because **everyday is different.**”*