

Robots for Joy, Robots for Sorrow: Community Based Robot Design for Dementia Caregivers

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Abstract—Many new technologies are being built to support people with dementia. However, they largely focus on the people with dementia; consequently, informal caregivers, one of the most important stakeholders in dementia care, remain invisible within the technology design space. In this paper, we present a six-month long, community-based design research process where we collaborated with dementia caregiver support groups to design robots for dementia caregiving. The contributions of this paper are threefold. First, we broaden the context of dementia robot design to give a more prominent role to informal family caregivers in the co-design process. Second, we provide new design guidelines that contextualize robots within the family caregiving paradigm, which suggest new roles and behaviors of robots. These include lessening emotional labor by communicating information caregivers do not want to hear (e.g., regarding diet or medication) or providing redirection during emotionally difficult times, as well as facilitating positive shared moments. Third, our work found connections between certain robot attributes and their relationship to the stage of dementia a caregivee is experiencing. For example, caregivers wanted their robots to facilitate interaction with their caregivees in early stages of dementia, yet be in the background. However, for later stages of dementia, they wanted robots to replace caregiver-caregivee interaction to lessen their emotional burden, and be foregrounded. These connections provide important insights in to how we think about adaptability and long-term interaction in HRI. We hope our work provides new avenues for HRI researchers to studying robots for dementia caregivers by engaging in community-based design.

I. INTRODUCTION

People are living longer than ever before, reshaping how we think about aging. Rather than viewing aging as a problem to be fixed, many are now adopting the perspective that gerontologists have held for decades - aging is a normal phase of life to be supported holistically [33], [38]. A variety of stakeholders, including clinicians, community members, and technologists, are exploring ways for older adults to live at home for as long as possible, which is a shift away from the residential nursing care paradigm [4].

The challenge facing many of these efforts is that they are not sustainable. As people age, they face increasing mobility and sensory challenges, and sometimes cognitive ones. Many people need support with activities of daily living (ADLs), such as grooming, eating, and mobility, as well as cognitive functioning tasks (instrumental ADLs (IADLs)), such as problem solving, scheduling, financial management, and medication management. Currently, caregivers shoulder the majority of this support burden. However, they are frequently older themselves, and experience physical strain, cognitive burnout, and financial devastation with the enormity of the task [43], [49]. Dementia caregiving can be particularly challenging.

Dementia is an umbrella term to describe a group of symptoms that mark a clinical diagnosis in the noticeable decline of mental abilities. It is irreversible, and its effects can be progressive, static, or can fluctuate [22]. People with dementia experience difficulties in IADLs, and report a reduced quality of life (QOL) relative to older adults without cognitive impairment, due to increased neuropsychiatric symptoms, and reduced functioning [70]. Each case of dementia is unique, and there are no known cures to slow or stop its progression, which is difficult and stressful for families.

Caring for someone with dementia is difficult because of the emotional diligence required over an indefinite duration, adapting to their loved one becoming a stranger. As the caregivee’s cognitive abilities decline and memory fluctuates, it becomes difficult to redirect their agitation and repetitive questioning. Caregivers feel guilty about having to take away aspects of the caregivee’s autonomy and independence.

While professional caregivers are an important stakeholder group in technology design, full time family caregivers shoulder an even higher burden of dementia care, yet are underrepresented in technology co-creation [27]. Informal caregiving work in the home has long been devalued (and unpaid), in contrast to paid jobs [10]. 75% of the care for people with dementia is provided by unpaid family caregivers who are commonly female spouses or adult children [11]. Our work gives this group a more prominent voice in HRI design.

In this paper, we aim to make previously invisible caregivers visible in the robot design process by engaging with dementia caregiver support groups. We conducted a six-month long, community-based design process with a multi-faceted approach including ethnographic observation, individual interviews, and design workshops to understand everyday dementia caregiving. We primarily collaborated with dementia caregivers as well as other community stakeholders, including social workers and geriatric nursing students, to give a voice to dementia caregivers within the robot design process.

The main contributions of this paper are threefold. First, we co-designed robots with informal dementia caregivers. They are a unique user group due to the extensive emotional labor in taking care of a loved one with degenerative memory impairments - losing shared memories and identity, in addition to a range of other comorbidities. Although caregivers have been identified in HRI contexts before as important stakeholders, we are unaware of projects where caregivers actively participated in the design process to create new robots. Second, we provide new design guidelines that contextualize robots

within the family caregiving paradigm, which suggest new roles and behaviors of robots. For example, robots can further engage in lessening emotional stress (e.g., robot can serve as the “bad guy” when restricting unhealthy food intake or administering unwanted medication), or accentuating positive shared moments (e.g, helping a caregiver/caregiver couple dance to a Jukebox Robot).

Third, our work found connections between certain robot attributes and their relationship to the stage of dementia a caregiver is experiencing. For example, caregivers wanted their robots to facilitate interaction with their carees in early stages of dementia, yet be in the background. However, for later stages of dementia, they wanted robots to replace caregiver-caregiver interaction to lessen their emotional burden, and be foregrounded. These connections provide important insights in to how we think about adaptability and long-term interaction in HRI.

II. BACKGROUND

A. Dementia Caregiving as Invisible Work

Dementia caregiving is emotionally and physically stressful [11], [27]. Caregivers are often overwhelmed because in addition to daily self-care activities and managing a carees’s health regimens, they are also required to learn new strategies of communication. Caregivers tend to de-prioritize their own mental and cognitive health, despite the fact that health professionals recommend maintaining a healthy lifestyle [31].

Despite the necessity of supporting caregivers, both they and their work are undervalued and invisible. Most caregivers of people with dementia are *informal caregivers*, commonly unpaid family members caring for their spouses or parents [5], [9]. In the United States, 15 million informal caregivers provide 18 billion hours or an estimated \$220 billion, of unpaid care per year with few support services or resources. [5], [27], [76]. Justifying explicit responsibilities and duties can inform better coordination of care, such as through design of supporting technologies [23].

B. Technology to Support Caregivers

Most support for dementia caregivers has been limited to computer-mediated solutions with mobile or desktop interfaces [2]. Most address caregiver education, rather than attempting to reduce caregiver burden [71]. Other approaches include creating virtual support systems, connection to home care workers, and connections to clinicians [6], [20], [51]–[53].

Prior work in robotics technology for dementia has primarily been geared towards assisting the person with dementia themselves rather than the caregiver, though they do provide indirect benefits. For example, researchers have explored socially assistive robots (SARs) [18] to support aspects of physical and cognitive therapy to alleviate cognitive decline and promote socialization [3], [8], [16], [17], [25], [25], [44], [69]. Robots can initiate mental stimulation to help people with dementia remain active and combat irritability, agitation and depression [50]. For example, Jack and Sophie [8] and NAO [47], [72] have been used to improve communication between

caregivers and a people with dementia, making overall caring easier. Telepresence robots like Giraff help people with dementia communicate with caregivers remotely [44], [48].

The affordances of a robot makes it a medium well-suited to provide support to older adults in their homes [65], [78]. They can support engagement, facilitate interactive presence [68], provide contextualized and socially situated cues, and can support interaction in a range of new ways that extend interventions into the physical world beyond the current state of practice in mHealth (e.g., phone apps). For dementia specifically, the landmark 2017 Lancet Commission report [42] outlines multiple ways in which technology, including SARs, can support older adults with dementia and other stakeholders, and specifically highlights supporting caregivers.

The HRI community affirms the importance of including caregivers in robotics to support their well-being [19]. However, caregivers have not, to our knowledge, been invited to the robot design process as co-designers (as in [35]). As a result, we have chosen to collaborate with family caregivers to make their work visible in the technology design process by engaging with the local dementia care community

III. DESIGN PROCESS

The first step of our design process was to build relationships with members of local community centers before initiating our design workshops. These connections supported trust building, to create a safe environment for expressing ideas as we progressed into facilitating formal design workshops. The core of our design methodology included curating one hour design workshops to further engage with family caregivers [62], [79]. We hoped to create an open space for caregivers to share their experiences and personal challenges with dementia caregiving. Participants were given an opportunity to envision various robot designs by choosing a scenario, discussing strategies they currently employ, and brainstorming potential technology related solutions. Through a hands-on activity with physical prototyping, caregiver participants were guided in designing robots for the home. We describe this process below.

A. Building Connections: Community Engagement

It is imperative for researchers to understand the implications of the community they are working with along with the stakeholders involved, rather than walking in with a technology hammer. Therefore, on this project, we engaged in a six-month long, community-based, participatory design process. To learn more about dementia and dementia caregiving, we immersed ourselves in a series of educational seminars and virtual workshops. After this initial effort, we engaged in observations of people with dementia, their caregivers, and professionals at memory care centers, and attended weekly support groups sessions for firsthand insight. In parallel, we began building rapport and fostering relationships with three different dementia day care centers in the local community. With permission from both the group facilitators and participants, our team attended these weekly sessions to learn from the lived experiences of caregivers. For an expert opinion on

Acceptance: As dementia is unpredictable and progressive, caregivers must accept a lack of control, and take it one day at a time.	Anger: Caring for dementia brings frustration for being in the situation and towards the caregivee.	Autonomy: Emotional attachment to the caregivee makes it more difficult to deprive them of personal freedoms.	Coping: Each caregiving experience is different so finding a personal coping process that works can be difficult.
Denial: Unfamiliarity and shock of experiencing dementia symptoms makes it difficult for caregivers to realize that they must seek help.	Education: The gravity of change calls for consistent openness to learning and education of what they are experiencing.	False Hope: It is easy to get caught up in getting back caregivee memories. This takes away energy from care and perpetuates denial.	Identity: As caregiving is an all consuming experience, people tend to lose themselves in the process.
Internalized Emotions: Caregiving brings emotional uncertainty throughout each dementia stage. Feelings of guilt, helplessness, and remorse can lead to depression.	Isolation: The stigma of dementia does not encourage sharing of problems with others.	Physical Labor: Most caregivers are older adults, and the physical labor of caregiving demands strenuous burden.	Reassurance: Caregiving is individualized and unique, requiring constant reassurance on normality of experience and ways of caring.
Reminiscence: Caregivers want to go back to how things used to be.	Responsibility: Caregivers attribute caregivee decline to their quality of care, blaming themselves and not the disease's progression.	Support: Caregivers need the community around them to empathize and understand their experiences, to feel they are not alone, with physical help from others for respite.	Self-Care: Caregivers prioritize caregivee needs, neglecting their own health. They often do not know when to take time off and feel guilty engaging in selfcare.

Fig. 1: Major themes most dementia caregivers in our cohort encountered.

the complexities of dementia caregiving, we interviewed five social workers who acted as coordinators or directors of the dementia day care centers we visited.

Following several months of engagement with the dementia care centers, we were able to better understand the community ecosystem of dementia caregiving as a whole and recognize its various stakeholders. From our initial phase of research, observation, and interviews, we built an affinity diagram of our main findings. We used grounded theory to identify the emerging themes showing the needs of family caregivers of people with dementia from our data [7]. We identified 16 major themes we found most caregivers of dementia encountered, which are summarized and defined in Fig. 1.

B. Scenario Creation

To enrich the participatory design process, we employed scenario-based activities, a fundamental part of interaction design practice [14]. We structured each of our scenarios by components of user, need, and limitation in terms of “caregiver [C]” and “person with dementia [D]”. We synthesized the aforementioned themes to inform the needs reflected in the scenarios. We took this initial draft of scenarios back to the social workers for feedback, and consulted with a clinical psychologist to ensure scenarios were not emotionally charged or a trigger to caregivers. The final scenarios included: worrying about leaving a caregivee in the care of another for extended periods of time, having to prevent a caregivee from driving, getting a caregivee to bathe, answering repetitive questions, and attending to caregiver self-care.

C. Prototyping Tool Creation

One objective of the workshop was for caregivers to build physical prototypes. Since most participants were older adults, we paid specific attention to the accessibility of materials assembled for the design workshop, including using large fonts and supporting an ease into ideation processes. They also had limited time, so we provided pre-cut shapes to the participants constructed from balsa foam covered in Envirotex hard shell.

1) *Interaction, Morphology, and Functionality:* We focused on how robots can interact with caregivers in their specific environments and situations. While the curated scenarios provided contextual information to ground the participants’ ideas, they were not technologists, and had limited experience

with robots. Therefore, we crafted suggestions of possible features to better afford the functionalities they envisioned the robot to have. These functionalities were decomposed into several tasks, modalities of interaction, and devices of executing desired features. This was informed by technology preferences reported in the literature [66], as well as based on our observations described in Section III-A. Based on these, we formed different groups centered around themes of affect, home care, learning, reminders and scheduling, connecting, self-care, monitoring, and caregivee self-care. For the purposes of the workshop, these tasks were visually represented through icons with labels that the participants could easily attach onto their robot design (See Fig. 2).

D. Design Workshops

We conducted a series of design workshops at two caregiver support groups, one memory care facility, and at a caregiver’s home. We had 13 family caregivers of people with various types of dementia, 11 female, 2 male, whose ages ranged from 62 to 85 (mean age was 70 years old). 10 caregiver participants were spouses, the others were adult children. Most caregivers lived with their caregivees, though one lived an hour away, and one rotated care with another family member. We also had 3 geriatric nursing students participate in a workshop, whose ages ranged from 27-35 (mean age was 31 years old).

After giving informed consent, learning about the workshops, and having an opportunity to ask questions, participants formed groups of two or three and began the design activity. To capture caregivers’ perspectives on robot design, we introduced a set of current technologies to provide them with background knowledge and gave them a chance to familiarize themselves with current technology, particularly robotics. These included: petlike robots, cleaning robots, telepresence robots, social robots, smart speakers, and wearables.

We empowered participants to be bold and share a large quantity of their ideas, regardless of their plausibility or quality (as in [33]–[35], [37], [38]). A facilitator was present at all times to answer questions and record ideas. This process was particularly important for older adult caregivers, some of whom had limited grasping abilities due to arthritis and limited mobility [41]. The facilitator also simultaneously categorized participants’ ideas into themes, making it easier for them to reflect and choose one idea to prototype.

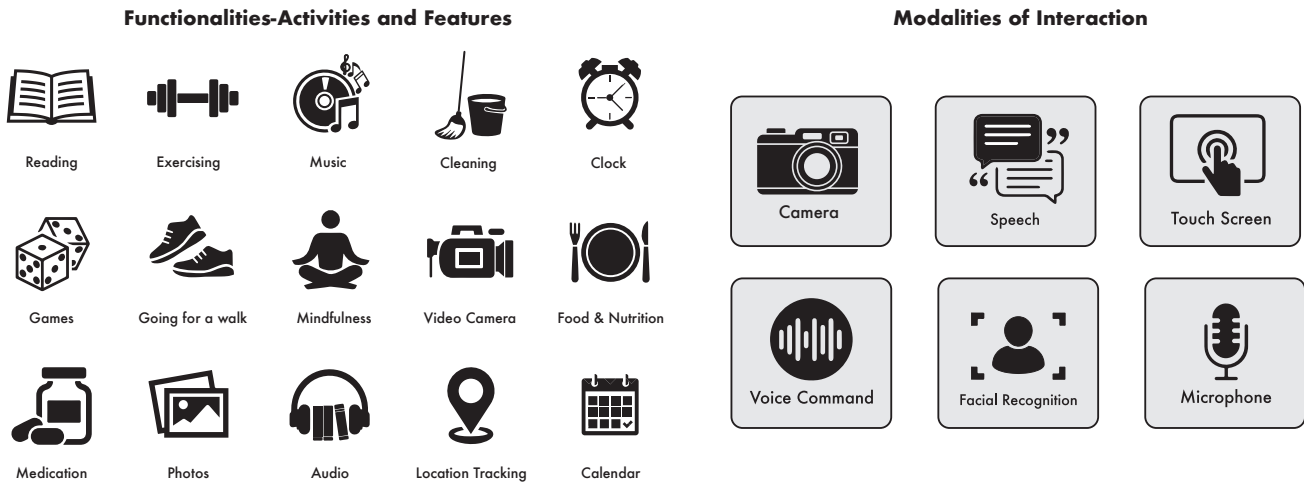


Fig. 2: The modality and interaction cards caregivers used to design robots. These were derived from the literature and themes frequently heard in our interactions with the community.

The ideation phase of the workshop enabled participants to explore robot design possibilities to meet caregiving needs. We found it helpful to direct participants in a guided ideation process, given they were new to design thinking. Participants chose a scenario card (See Section III-B), and the facilitator guided participants through a series of questions. Participants then discussed personal accounts relating to the scenario, what types of strategies they have used, and described how they would incorporate these strategies in a robot.

Next, to determine the physical characteristics and appearance of the robot, participants were instructed to use the prototyping materials. They received basic shapes and abstract pieces made from industrial foam to visualize their ideal robot structure. On top of these structures, they could attach various features and functionalities they envisioned the robot performing. Finally, they chose cards representing which modalities of interaction they preferred the robot to have. When participants finished building their prototype, they described the robot and their design decisions. The facilitator led the group through several reflective questions to understand why participants chose the given morphology and interactions, as well as to identify intended user groups, communication modalities, and contextualization of use.

We assigned each participant a pseudonym to anonymize their information. This helps preserve each participant’s individuality. The pseudonyms came from a social security database [1] based on the birth year of each participant.

IV. FINDINGS

A. Intended purpose and functions of robots

Overall, the diversity of experiences of caring for dementia prompted participants to produce robot designs for a range of purposes (See Fig. 3).

1) *Robots for Joy:* Participants designed robots that engaged the caregiver, caregivee, or both in positive activities. For example, Judy’s husband hides his dementia, and she actively tries to keep him preoccupied so he does not feel bad about himself. When he listens to the jukebox, he relaxes

and focuses on the moment. Since Judy and her husband met, they have always enjoyed dancing to a jukebox. They have many memories dancing together, and they continue to enjoy listening to the jukebox they have at home.

However, when Judy is not present, her husband cannot remember how to operate the jukebox, which makes him feel frustrated. Inspired by the jukebox that uplifts their spirit during tough times, Judy designed *Jukebot*. A robot that would play music, display lyrics, and encourage them to get up and dance would be invaluable. It was designed to be shared and allow both the caregiver and the caregivee to engage in an activity they love together, and “get the party going.” Having the affordances of a classic jukebox would be reminiscent of a time with good memories.

2) *Robots for Repetition:* People with dementia often ask the same question repeatedly, which can be frustrating for caregivers. For example, Linda, who now takes care of her mother full time, expressed how it took almost a year to learn how to navigate and get used to answering repetitive questions. Linda mentioned how “in a car ride of barely ten minutes, [Linda’s mother] asks where we are going more than twenty times,” and said the repetition constantly wears her down.

To address issues like the one Linda encounters, five out of ten robots were primarily designed to alleviate stress from repetition. Several caregivers wanted to reduce the exhaustion of repetitive questioning by applying the concept of “Alexa”. For example, Mary created the *Answerbot*, which would be able to pick up on keywords from her husband’s banter, and provide responses. Mary said, “I want the robot to match the brain of a person with dementia”. Thus, the robot Mary designed would respond and keep up with the conversation of the caregivee to maintain engagement.

Similarly, *G.I. Joe Robot* and *Amigo Robot* were designed to provide constant verbal redirections of repetitive questions and provide alternate conversation topics to distract the caregivee. These diversions could entail an assortment of activities and hobbies the caregivee enjoys. Robots like the *iCare Robot*, designed by the geriatric nursing students, was intended to

Robot Name	Design	Role of Robot	Stage of Dementia	Foreground/Background	Features & Activities	Mobility	Interaction Modalities	Morphology
Amigo Robot		Redirection; wellness for caregiver	Early	Foreground	Location, Mindfulness, Music, Television	Stationary	Voice Commands, Recording	Smart Home Assistant
Answering Robot		Answering repetitive questions	Middle	Foreground	Conversation	Stationary	Voice Command, Speech	Smart speaker
Food Delivery Robot		Regulating nutrition	Middle	Foreground	Delivering food & managing intake	Mobile	Speech, Voice Command	Semi-humanoid
Exercising Robot		Facilitating exercise	Middle/Later	Foreground	Exercising	Mobile	Speech, Voice Command	Semi-humanoid
G.I. Joe Robot		Redirection and distraction	Middle	Foreground	Humor, music, photos, television,	Mobile	Camera, facial recog., speech, voice command	Zoomorphic
iCare Robot		Help with ADLs	Any	Foreground	Administer food, playing music, telemedicine	Stationary	Speech	Zoomorphic / Portable speaker with screen and ears
Jukebox Robot		Joy, sharing time together	Early	Foreground	Displaying lyrics, encouraging dancing	Stationary	Facial recog., speech	Humanlike; Jukebox
Monitoring Robot		Settling arguments and conflict	Later	Background	Calendar, location tracking, medication, video camera	Mobile	Facial recog., location tracking, motion detection, recording	IoT; Camouflaged with environment
PillPack Robot		Managing medication	Any	Background	Calendar, clock, medication storage, video camera	Stationary	Facial recog., speech, touch interface, voice commands	IoT / Medical Cart
Rosie the Robot		Counseling caregiver	Later	Foreground	Engage in conversation, facilitate games	Mobile	Facial recog., speech, voice commands	Humanlike; Maid

Fig. 3: The robots participants designed varied in their roles, appearance, and abilities. They supported a range of activities, including: redirection, medication management, practicing mindfulness, listening to music, and playing games.

automate repetitive, tedious tasks caregivers have to engage throughout the day. The robot provided caregivers with daily schedule reminders, queued up tasks, and generated instructions for tasks around the house.

3) *Robots for wellness:* With the diet of a person with dementia irregularly fluctuating, caregivers need a means of tracking a caregiver's food intake and ensuring they have access to meals. This need was addressed with the *Monitoringbot*, designed to keep a record of the caregiver's meals. Similarly, the *FoodDeliverybot* was designed to physically bring the caregiver a balanced meal.

Along with diet, caregivers described medication management as a challenge. *PillPackbot* was designed to ease this burden and improve medication adherence by prompting and delivering medication to the caregiver. This robot helps automate the mundane tasks of organizing multiple medications with different doses and frequencies. Participants also expressed they wanted confirmation that medicines have been taken, and assurance the medications are safely stored.

Many with dementia experience co-morbidities. As explained by Kenneth, who cares for his wife, memory changes are a small part of caregiving, because she is also going

through cancer and diabetes. As Kenneth's wife's dementia advances, it has become difficult for her to exercise and accomplish basic ADLs like going to the restroom by herself. She is not motivated to be active, and was recently diagnosed with diabetes. Kenneth designed *Exercisingbot* to provide motivation to be active and facilitate physical therapy exercises.

Recently, Kenneth's wife stated her stomach was not feeling well. After a long period of discomfort, popsicles were the only food she enjoyed, and she wanted to have more than ten per day. Kenneth wanted to stop her, but had difficulty doing so, as popsicles brought her so much joy as she experiences dementia, cancer, and diabetes. Thus, Kenneth envisioned a robot that can firmly regulate her food intake. The robot delivers popsicles if she wants them. However, after delivering it several times, the robot firmly says "You finished two popsicles today and this is the last one. You can have more tomorrow." In that way, Kenneth does not need to argue with his wife, and can just mildly say "Maybe this is it today. We can have more tomorrow!" The robot takes the role of a bad guy, and Kenneth can be the good guy.

B. Communication with the robot

Caregivers discussed a range of modalities for interacting with their robots, including voice interaction and face recognition. All participants selected voice interaction as the most natural, due to its ease of use, as well as its potential for engaging their caregivees and providing stimulation. Also, they wanted their robots to have the voices of people that caregivees were already familiar with, such as caregivers or doctors, to build trust between robots and caregivees. Facial recognition was the next most popular communication method. Caregivers wanted the robot to provide reminders and instructions upon detecting the caregivee. Robots with tracking features were prompted to have motion detection for a caregiver to keep track of a caregivee's actions in their own home. Caregivers also wanted to add touch interfaces to their robots, since they were familiar with iPads and other tablets.

C. Robot morphology

Each robot's morphology varied depending on the participant's perception of robots, which was influenced by media / Hollywood robot depictions [54], and thus often reflected humanlike attributes and capabilities. The functionality of the robot was closely tied to morphology. For example, *Food-Deliverybot* was designed with mechanical hands to facilitate exercise, while *Rosie the Robot* had hands to deliver food.

Each caregiver wanted their robots to have different degrees of humanlikeness depending on their robot's function. For example, a participant designed the *Exercisingbot* with robotic arms since the robot was expected to physically demonstrate yoga postures. The participants who designed it also emphasized the importance of humanlike hands to mimic more feelings of human touch and warmth.

Some robots were designed with the face of a person the caregivee knows. For example, the face of a doctor, so the robot could serve as an authority figure for the caregivee. In situations where the caregiver could not be physically present, the robot could depict the face of the caregiver.

Physical attributes of each robot were personalized and catered to the robot's intended user and functionality. Caregivers created robots that were tailored to what they envisioned their caregivee would easily assimilate to. For example, Linda expressed how her robot should not be "terminator-like" and should be "warm, fuzzy, and welcoming," as her caregivee really liked nature and animals. Several caregivers designed the robot's morphology based on memories of icons they were familiar with. For example, when it came to naming the robot Linda built, she immediately jumped to the thought of the 1964 action figure "G.I. Joe". The participants who designed *Rosie the Robot* were making an all purpose robot which referenced the 1962 TV show, *The Jetsons* where Rosie appeared.

D. Robot roles

1) *Robot as the bad guy*: Caregivers designed robots to serve as a neutral third party, communicate facts and information the caregivee may not want to hear, and make caregivees do things they do not want to do. Caregivers wanted someone

else to be the "bad guy" so they do not have to shoulder all responsibility and deal with emotional burden alone. For caregivers who have difficulty getting caregivees to take medicine, having the *PillPackbot* administer medication would reduce stress. Sandra said that managing her caregivee's pills is one of the most difficult tasks, since he does not enjoy taking medicine. She often mentions his doctor to help, e.g., "The doctor says that it is important to take those pills!" Thus, she wanted her robot to have the voice of her caregivee's doctor, who can play a role of a bad guy as an authority figure. Another example was Kenneth's *FoodDeliverybot*, which takes charge of managing a caregivee's diet and intake. The robot helps caregivers from having to refuse their caregivees what they enjoy (e.g., popsicles).

2) *Robot as the facilitator*: With the progression of dementia, caregivers have to be more involved in caregiving, and must increasingly support caregivees with many IADLs, and often ADLs. As caregivers struggle to take care of themselves and their own health concerns, a robot to help facilitate daily tasks could be very valuable. For example, *Exercisingbot* was designed to motivate caregivees to stay active and carry out the strenuous task of directing physical therapy exercises. Similarly, robots like *G.I. Joe Robot* and *Rosie the Robot* were designed to facilitate games, and *Amigo Robot* was to provide verbal instructions to caregivees when the caregiver was away.

3) *Robot as the counselor*: When beginning to take care of someone with dementia, caregivers are bombarded with immense pressure and are vulnerable to emotional breakdowns. It takes time to navigate the frequently changing behavior patterns of a person with dementia. Caregivers are often unaware of who to contact, or what resources to utilize. It becomes difficult for caregivers to accept their situation and admit they are struggling and need help. For example, Nancy designed *Rosie the Robot* because her husband with dementia gets angry when she is not physically with him. *Rosie the Robot* would intervene when it detected Nancy's husband speaking to her in an angry voice. Nancy wanted her robot to remind her that her husband's anger is not because of her poor care toward him, but because of his dementia. The robot can provide strategies of how to deal with emotions, or suggest a break. *Rosie the Robot* was designed to council the caregiver upon request. Similarly, the robot could serve as an outlet for the caregiver to vent, reflect, and calm down.

V. DISCUSSION

Here, we present guidelines for designing robots for dementia caregivers, discuss challenges we faced when conducting community-based research, and discuss some ethical issues.

A. Design Guidelines for Dementia Caregivers

1) *Redirection*: Redirection to a new topic is a frequent strategy employed by family caregivers and its importance was reflected in the robot designs. Some designs indicated the robot should seamlessly change the subject as a distraction to what the person with dementia wants to do. A robot can be used as a means of scapegoating in difficult situations for a caregiver. For example, *JukeBot* can redirect to a fun activity either for

Design Component	Caregiver	Caregiver	Design Guideline
Redirection	Loss of short term memory causes repetitive questioning	Is exhausted, wants a break from continually answering the same questions	Robot should provide means of redirecting caregivers conversation into a positive distraction
Integration	Responds more positively to stimuli that resonates in retrograde memory	Needs easier method of keeping person with dementia engaged	Robot morphology should be reminiscent of user's salient memories
Familiarity	Difficulty learning new things	Difficulty breaking routines and incorporating new habits	Interactions can be embedded within technology stakeholders are already familiar with
Trust	Trusts and wants to interact with few people	Cannot always be physically present	Robot should reflect existing relationships and embody familiar characteristics
Adaptability	Dementia constantly fluctuates, changing daily behaviors	Cannot predict abilities and tendencies	Robots should adjust [human likeness, interactivity, function, autonomy] depending on dementia stage and severity
Personalization	Heterogeneity of dementia experience requires individualized care	Needs to learn to identify effective caregiving strategies	Robot should be able to learn with stakeholders, and customize itself based on end-user feedback
Visibility	Can detect changes in their environment	Needs to cautiously manage technology based on purpose of usage with caregiver	The degree of fore-/backgrounding of the robot should be determined by function

TABLE I: Robot design guidelines, addressing caregiver and caregiver needs.

the person with dementia individually, or in a triad between robot, caregiver, and caregiver.

Redirection is a new design concept for robots. Although a number of robots can verbally communicate with older adults [30], they tend to focus on delivering or accepting factual information. Compared to existing robots for older adults that can verbally communicate, caregiver participants envisioned robots to understand the behaviors of people with dementia (e.g., repetitive questions or agitation) and wanted them to redirect caregivers to more positive interactions.

2) *Familiarity and Integration:* Since caregivers and caregivers are unfamiliar with new technologies, their robots should be integrated into what they already know. This echoes a reminiscence therapy method that addresses the importance of past experience. For example, the therapy includes the discussion of past activities, events and experiences with another person or group of people [77]. Dementia caregivers integrated existing objects their caregivers are already familiar with into their robot designs, to provide them comfort. (e.g., Diane wanted her husband to receive messages on the TV, which he already spends a lot of time watching, which she reflected in *Amigo Robot*). These findings align with other work in HRI addressing the importance of familiarity by integrating existing objects into robot design. For example, DiSalvo et al. [15] designed the Hug, a pillow-like robot to increase its familiarity to older adults.

3) *Trust:* To build trust between robots and people with dementia, caregiver participants envisioned robots that would have characteristics of people caregivers trusted. For example, *Amigo Robot* has Diane's voice, and an image of her face to help her husband feel safe and engender trust. Prior work in HRI has explored how to engender trust between humans and robots [13], [60], [61], [75]. Most researchers expect robots can build trust through their behavior (e.g., honesty [28]), and decreasing task failures [40]). In our study, we found that people with dementia engender trust in robots if they resemble people they are already comfortable and familiar with.

4) *Adaptability:* Dementia is a progressive disease and at each stage there are new challenges for caregivers. There are

unique fluctuating patterns of progression in each individual case of dementia. Predictability of behavior is almost impossible, and stages could plateau for years, or suddenly digress. Hence, robots should adapt to the behavior of the person with dementia and be able to aid in new situations. For those in earlier stages of dementia, caregivers wanted a recreation robot like *Rosie the Robot* to facilitate human-human interaction. While in later stages of dementia, caregivers wanted respite by having the robot interact with the caregiver.

This aligns with other work in HRI stressing the importance of adaptability in assistive robot designs. For example, Heerink [26] argues that robots need to be self-adaptive and autonomously change their performance based on understanding users' contexts. At the same time, robots need to leave room for older adults to have a sense of control and decide the level of autonomy they want for themselves. In our work, we found that dementia stage should be an important factor when considering robot adaptability.

5) *Personalization:* Robots should be able to customize their own behavioral responses based on user feedback. Similar to our findings, others in HRI explored personalization in terms of a robot's appearance, interaction modality, or level of autonomy [39], [45], [67]. We too found that participants personalized their robots based on the caregiver and caregiver's preferences. For example, when Diane and Nancy designed *Amigo Robot*, they wanted the robot to display a picture of them, so that their caregiver, who sometimes stays at home alone, feels more comfortable communicating with the robot. More than half of participants also wanted their robots to employ their (the caregivers') voices, which would help people with dementia pay more attention to the robot.

6) *Humanlikeness:* Participants found the humanlikeness of robots to be an important design factor, though they widened the spectrum of humanlikeness beyond prior work in HRI. For example, researchers often rely on the Uncanny Valley [46] to guide their designs regarding an appropriate level of humanlikeness [12], [21], [57], [58], [73]. However, they often consider humanlikeness as an one-dimensional concept (e.g., robots that are too humanlike indicate a zombie-like

appearance). In this study, we found the participants determine robots' humanlikeness based on their complex situations. This includes caregivers' preferences on robot designs, the dementia stage of caregivees, and expected functions of robots. The humanlikeness was derived not only from the robots' morphology but also from their interaction modality.

For example, *Amigo Robot* has a shape of a cylinder similar to a smart speakers, but it uses real human voices (of caregivers) and follows the caregiver's speech patterns. HRI researchers should consider humanlikeness in multi-dimensional ways, particularly considering the preferences and situations of caregivers and people with dementia. These findings align with other work in HRI, c.f. [36].

7) *Visibility*: Participants determined the level of robot visibility based on its function. When caregivers wanted robots to take an active roles in persuading people with dementia to do something, they designed robots with more human-like features. For example, robots that were built to support behavior change in people with dementia (e.g., regulate their food intake or encourage exercise) had a stronger human-like morphology, with humanlike torsos and faces. On the other hand, robots that focused mainly on functional features with limited social interactions (e.g., display or share information) were expected to have a subtle, machine-like morphology. Our finding on visibility aligns with existing HRI findings on visibility in terms of foregrounding/backgrounding. For example, Hoffman et al. designed a peripheral conversation companion robot that stays in the background, to not interfere human-human communication flow [29].

B. Challenges to Community Based Research

Working with caregivers of dementia from ethnically diverse backgrounds poses its own set of challenges. Communities hold different perceptions of aging that relate back sociocultural values on taking care of older adults and even gender roles in caregiving. We noticed that caregivers had different opinions on participating in support group programs. Those reaching out for help and resources were predominantly caucasian, whereas Latinx caregivers tended not to. This contrast was also emphasized in our interviews with social workers.

There are other challenges when working with people with dementia and their informal family caregivers. During the course of our study we experienced: people with dementia hiding from their loved ones, wandering behaviors, and even mistakenly using our research room as a bathroom.

Furthermore, our research had several time limitations. It was generally restricted to early mornings because of sundowning (the increase of confusion of people with dementia as the day progresses). The time we had with caregivers was very short because their participation was dependant on availability of respite care. However, despite these challenges, we encourage HRI researchers interested in dementia care to engage in community-based research. This process allows robot designs to be more situated within society.

C. Robot Ethics

Our results raised many interesting ethical questions, which are ripe for exploration in future work. First, with regard

to how people with dementia and their caregivers perceive robots in terms of humanlikeness, Riek et al. [53], [55], [56] discuss how humanlike robots can potentially induce Turing deceptions in people with cognitive impairments. (e.g., when one does not know if they are interacting with a person or a robot). Thus, it is important for stakeholders to consider tradeoffs of how a robot might be perceived - perhaps more trustworthy by appearing or sounding like a caregiver or doctor, versus its potential to be deceptive to a person with dementia. It further could be used as a vehicle for unwitting manipulation [24], [55], [59], [63]

The idea of robots serving as bearers of emotional labor in caregiving is another ethically challenging topic. On the one hand, it may reduce burden on caregivers, who suffer a high rate of burnout and negative effects on their own health. However, this process of robot foregrounding in later stages of dementia has the potential to displace human contact, which can be deleterious to caregivee well being (c.f. [64]).

VI. CONCLUSION

One of the biggest lessons from our participants is that attitudes to correct people with dementia never work. For example, when a person with dementia asks "Please bring me home. I want to go home" to a caregiver when already at home, answering "This is our home!" does not really help. Instead answering, "Oh. That is a good idea. But it is too dark outside and I do not think driving at night will help us. How about staying here for today?" works better for both caregivers and caregivees. As a person with dementia can still detect and relate to emotions, they can easily feel the frustration and stress of their caregiver, commonly lifelong partners or children. Therefore caregivers try to avoid correcting caregivees and argumentitive discourse.

Rather, the best way to deal with these types of challenging situations is by accepting the difficulties, and finding ways to live everyday as one did before - sometimes feeling joy, and sometimes feeling sorrow. Considering their daily life experiences, participants envisioned robots for joy to cherish their happy moments, and robots for sorrow to better manage their challenging moments. This aligns with recent critical aging studies that criticize technology designs which follow a deficit model of aging, characterizing aging as a series of losses and problems to fix [32], [33]. Following these arguments, this paper addresses the importance of reflecting the perspectives of people with dementia and their caregivers into the robot design process. We employed a community based design approach to reflect multi-dimensional aspects of their lives into robot design, rather than to overly focus on problems coming from dementia.

As described in previous HRI research, robots offer great potential to support people with dementia [48], [74]. Integrating the perspectives of family caregivers, often invisible in the actual technology design process, enables rethinking robot roles in dementia care. We hope this work provides a new approach to studying robots for dementia by working with a community.

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