What a healthcare worker wants, what a disabled person needs: Exploring stakeholder design tensions in assistive robotics

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ABSTRACT

While disabled people are typically the primary users of assistive technologies, other stakeholders, such as family members, caregivers, and clinicians, may be closely involved in their care process. Incorporating the perspectives of multiple stakeholder groups into the design of these technologies can however give rise to design tensions, which can be challenging to mitigate. To exemplify these tensions, we report on two case studies from our ongoing work co-designing assistive robots with disabled people and healthcare workers (HCWs). The first included co-designing assistive robots with people with dementia (PwD) and people with mild cognitive impairment (PwMCI), and the second people with cancer (PwC). Within the case studies, we illustrate similarities between the disabled population and HCWs, such as supporting empathy and personalization. However, we also note design tensions, such as within the role of the robot, the services it provides, and the concerns it seeks to address. Finally, we discuss which factors need to be considered by HRI researchers to navigate design tensions throughout the design and development process.

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1 INTRODUCTION

As assistive technologies to support disabled people become more pervasive [1, 2, 6, 15, 17, 21, 24], it is essential that the voices of disabled people as primary stakeholders are heard and incorporated into technology design to ensure their usability, acceptability, and efficacy [13, 30]. However, designing assistive technology that addresses the needs of disabled people could also include incorporating knowledge and perspectives of secondary stakeholders such as their caregivers, and healthcare workers [7, 23]. Each stakeholder group may have different mental models, expertise, cultural backgrounds, contexts, and priorities which, paired with power asymmetries, can exacerbate design tensions. For example, a healthcare provider might want a robot to continually observe a user to monitor their health, but users themselves may have privacy concerns surrounding this [14, 16, 22].

While HRI researchers have explored various methods to incorporate stakeholder requirements into the design process [11, 18, 23, 26], there is limited work on navigating differences in stakeholder perspectives. There is a gap in our understanding of the grounds of tension among stakeholders, and methods of addressing them.

In this paper, we present two case studies which design assistive robots with disabled people. In the first study, we co-designed social robots with people with mild cognitive impairment (PwMCI), people with dementia (PwD), and geriatric care providers (GCPs). In the second, we conducted collaborative design sessions with people with cancer (PwC) and HCWs to design technologies to help improve PwC's experiences in the Emergency Department (ED).

In both studies, we observed tensions between the perspectives of disabled people and HCWs. These tensions spanned specific design choices, to overarching themes about the type of technologies participants felt would best support them. We also observed different design tensions emerge from each study, indicating a need to analyze across contexts. In addition, we identified similarities in how stakeholders envisioned assistive technologies. We analyze these findings to identify potential grounds for tensions in stakeholder perspectives, factors that can contribute to tensions, and general design suggestions for assistive robots.

The contributions of this paper include: 1) Reporting two case studies which co-design robots with three populations historically excluded from HRI: PwMCI/PwD/PwC. 2) Identifying factors contributing towards design tensions in stakeholder perspectives. 3) Suggestions for navigating them. 4) General suggestions for assistive robots based on similar preferences across our stakeholder groups. Thus, this work will help guide HRI researchers to design more inclusive and accessible assistive robots for disabled people.

2 CASE STUDIES

2.1 PwD/PwMCI and Care Professionals

The first case study focused on co-designing assistive robots for people with cognitive impairments [5]. The study investigated how PwD/PwMCI experiences, socio-cultural backgrounds, and interests define their desired assistive robot. We conducted an inclusive co-design process with 13 participants across three populations: three PwMCI, two PwD, and eight GCPs, across two countries (the U.S. and Mexico). The PwD/PwMCI group included three primary Spanish speakers from Mexico, and two primary English speakers from the U.S. Three PwD/PwMCI identified as men, and one identified as a woman. The age range of this group was 60-90 years (M=75.60, SD=13.27). The GCP group included 3 primary Spanish speakers from Mexico, and 5 primary English speakers from the U.S. Seven GCPs identified as women, and one identified as a man. The age range was 23-49 (M=36.62, SD=10.37).

We encouraged participants to create assistive robots, including technology familiarization, ideation on the application context, codesigning robot characters, and co-creating interaction narratives.

Four researchers independently analyzed the data (transcripts and design boards) using a reflexive thematic analysis (RTA) approach [3]. Using reflexive and wisdom design lenses [20], we centered the lived experiences of PwMCI/PwD, and analyzed the role

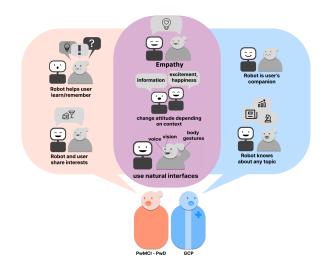


Figure 1: There was contrast between PwD/PwMCI and GCPs regarding the role of a robot. However, they agreed on communication modalities, empathy, and context adaptation.

these experiences play in their current identity. This framing allowed us to gather a more nuanced understanding of how they envisioned assistive robots. Thus, we used RTA as it provides us with greater flexibility in exploring different interpretations and allows us to critically examine our own biases as researchers.

2.1.1 Findings. Robot Role. The analysis clearly showed different perspectives between PwMCI/PwD and the GCP group with regard to the robot's role (see Figure 1). The PwMCI/PwD group wanted a more proactive robot to support their independence, deal with their concerns, and help them reinforce and learn new things. In contrast, the GCP group focused on passive robots to support physical care and provide companionship to people with cognitive impairments.

Although some PwMCI/PwD wanted a robot to support physical independence (e.g., bring food/water, grab items), most envisioned robots to support behavioral and mental concerns such as isolation, depression, memory loss, and irritability. P1 expressed, "Everybody likes to bring up the past for some reason. You know, talk about things that happened in the past through good times and even bad times. I guess if you had a robot that will remember the things you want in the future and bring it up to you, would be nice."

PwMCI/PwD wanted to use the robot to learn something new (e.g., places, people, skills), and to know more about a specific topic or remember things they enjoy. As P4 stated, "[I'd like to meet] new people and [get] to know more about the technology out there. Like the trains under the ground [i.e., subways][...] Logically, we [the robot and I] would both learn about that."

PwMCI/PwD envisioned a robot to help them solve issues in their lives. However, they did not want the robot to solve the problem by itself. Instead, they wanted a robot to support or guide them to solve the situation. P3 imagined, "[The robot] gives me its point of view. I consider myself very stubborn. So the robot could be someone, like an intermediary, to help me to solve [the issue]." P5 explained, "The machine shouldn't think for me, but it should be a machine that helps me to make decisions to solve real-life situations." In contrast, GCPs' perspectives were mainly focused on robots to support the care of people with cognitive impairments. In particular, they imagined a robot could help them deal with care concerns (e.g., physical safety and support, behavioral disorders) and stimulate people (e.g., companionship, socialization) throughout the day.

GCP4 imagined users could "talk to [the robot] or just have a conversation. [...] Something like, 'I'm feeling lonely today. What could you do to make me feel better?' Maybe, 'I can play a song for you,' or 'I can read you a story.' " GCP5 envisioned a scenario where "the senior wanders off. Maybe the robot can be the one who calls the family member like, 'Hey, they're wandering,' 'They're exit-seeking.' Something." GCP6 suggested, "[The robot] can remind them [PwD/PwMCI] to take their medications. Also, reminders like, 'It's time to go to bed,' and, 'You have a doctor's appointment.' "

Empathize with the user's emotional state. Beyond conducting or supporting a specific activity, the robot needs to be aware of a user's current emotional state. Both groups agreed that PwD/PwMCI want to feel understood and empathized with. Thus, the robot could be curious about them (e.g., asking questions about their day, mood, and concerns), and show empathy (e.g., promoting activities that the user is interested in or offering a listening ear). GCP4 thought the robot should "show emotions because if you're not having a good day, you want it to lift your spirits [...] to make you feel better." P3 explained, "It would be nice if [the robot] could recognize that sometimes I don't feel the same way. I don't have the same sense of humor from one day to the next. There may be problems, which one does not expect. And possibly, if [the robot] is patient, it can understand that there is something and help us."

However, we found cultural differences in cues and attitudes a robot should use to empathize and motivate users. P1, a primary English speaker from the U.S., expressed, "I wish [the robot] would be supportive of me right now. You know, motivate me, get through this [some activity] [...] So it can be supportive to do or achieve something.". Meanwhile, P5, a primary Spanish speaker from Mexico, imagined a robot that is "disciplined. [The robot] should guide me when it sees that I am doing something wrong."

2.2 People with Cancer and Healthcare Workers

Next, we describe our second case study to co-design technologies to improve the experience for PwC in the ED. Towards this, we conducted two studies. First, we conducted co-design sessions with 9 HCWs (5 physicians, 3 advanced practice providers, and 1 nurse) with 7 to 27 years of experience working with PwCs. 4 HCWs identified as male and 4 as female, the rest declined to state their genders. Their ages ranged from 36 - 68 years (M = 48.75, SD = 10.75). In the second study, we conducted similar co-design sessions with 2 PwCs. Both PwC identified as women, and both declined to state their ages. All participants were proficient in English. We did not collect ethnicity-related information in this study.

2.2.1 Study Overview. In the first study with HCWs, we conducted two phases of co-design, primarily exploring technologies that could support cancer-related pain assessments. We first conducted hour-long interviews with HCWs to understand the ED space, and identify how robots and technologies could support HCWs in the ED. We analyzed this data to develop preliminary storyboards and initial design prototypes for a social robot that performs cancer pain

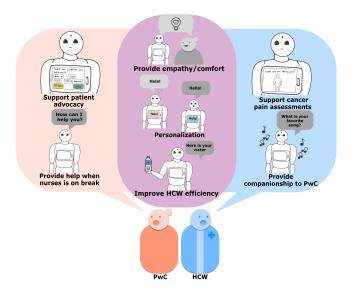


Figure 2: A summary of similarities and contrasts in stakeholder perspectives in Case Study 2.

assessments. Then, we conducted an hour-long session to co-design a social robot that supports HCWs and PwCs by performing cancerrelated pain assessments at regular intervals. We also discussed the ethical implications of such robots, bias in pain assessments, and the notion of robots bearing witness to human pain.

In the second study with PwCs, we conducted a single 45 minute co-design session to design technologies that would improve patient experiences in the ED. We found it significantly harder to recruit PwCs due to severe illness, treatment-related travels, and exacerbations of symptoms of our recruited participants.¹

In both studies, we conducted one-on-one sessions with participants, guided by a semi-structured interview script. Two researchers analyzed the data (interview transcripts and storyboards) through RTA methods as described in Section 2.1.

2.2.2 Findings. Perceptions of Cancer-Related Pain Assessment: In our study with HCWs, we received overwhelmingly positive reactions towards technologies to assist with cancer-related pain assessments. This was primarily because HCWs said cancer-related pain is multifactorial, and therefore difficult to manage in a timely manner. Most HCWs also felt that once the pain was initially managed, it was difficult to check on the patient again due to the chaotic nature of the ED. As HCW1 explained, "It makes doctors feel a LOT better to even just drop by a patient's room and let them know that they are there for them." Therefore, HCWs designed social robots that would perform periodic pain assessments.

Most HCWs also wanted the robot to have empathic capabilities to provide some level of comfort to the PwC in pain. HCW3 stated this was so "the patient can feel that they haven't been forgotten." HCW7 discussed, "[The robot] is inherently going to bear witness to suffering. We are using the robot to make the suffering better."

In contrast, both PwCs in our study said they had very positive experiences with pain management. Neither participant preferred technologies to support pain management, and instead envisioned technologies for patient advocacy, supply delivery, and to support HCW efficiency. PwC1 explained, "I love technology, but I don't see the vision for it here [pain management support]." As a result, the technology designed by PwCs were not as centered around compassion and empathy as the HCWs robots for pain management.

Mutual Benefit through Technology: We observed crossempathy in both studies. In our HCW study, participants placed themselves in the shoes of PwCs while envisioning technologies, whereas in our PwC study participants envisioned technologies that they felt would support HCWs' workflow.

HCWs were mindful that patients may come in with different mental and emotional states and therefore any technology interacting with PwCs would have to be mindfully designed to be accessible to all PwCs. HCW2 stated, "We do occasionally get sexual assault victims, and they're not comfortable with men in the room. Certain religious preferences may not be comfortable with someone of the opposite sex in the room." Most HCWs also suggested that the robot be able to communicate verbally, and in multiple languages (at least English and Spanish) to promote inclusiveness and provide additional comfort to majority of patients in our local EDs.

PwCs indicated that supporting HCWs' workflows would ultimately improve the care they received. PwC2 imagined, "This could help increasing the efficiency of nurses. Nurses have to work highly efficient, highly accurate." PwC1 wanted to support patient advocacy by helping HCWs make correct diagnoses, by designing a monitor near the patient bed that would provide data and statistics for probable diagnoses based on patient symptoms. PwC2 also raised cultural considerations to ensure acceptability for patients. In addition, PwC2's personal ethical and spiritual values led them to favor less humanoid robots, stating, "I am a strong believer in God, and nobody can create a human but God. So it's better to make them [robots] look like more a robot."

HCWs felt that technologies for cancer pain management could also help alleviate pressure they experience when patients suffer. HCW6 explained, "We as healthcare professionals get distressed when we feel someone is suffering alone. [...] It is very difficult being a witness, especially in what I do."

On the other hand, HCWs were also conscious that any robot or technology would only act as a healthcare extension, and would not replace the HCW or their responsibilities towards patients. HCW1 explained, "There needs to be a disclaimer that the robot is a healthcare extender." HCW2 stated, "Physicians and nurses shouldn't lose an important part of their job/ humanity"

3 DISCUSSION

Empathy and Personalization: Despite the differences we observed across stakeholder groups, empathy and personalization emerged as a core similarity. In both studies, stakeholders designed technologies to maximize the comfort of end users, focusing on personalization and compassion. In Case Study 1, stakeholders wanted robots to support PwMCI / PwD through cognitive stimulation, motivation, and companionship. They envisioned these abilities through personalizable behaviors that convey empathy to users.

Similarly, in the second case study, stakeholders wanted technologies that supported both HCWs and PwCs either through cancerrelated pain support or through patient advocacy. Both stakeholder

¹We recruited 9 PwCs over one year. Only 2 were able to participate in the full study.

groups were concerned about ensuring their robots were accessible to users of differing cultural backgrounds and catered to the individual needs of end users. HCWs also envisioned personalization and empathy cues for the cancer pain assessment robot.

We also observed that all stakeholders favored interaction interfaces that closely resemble how humans communicate with each other, particularly voice interactions. This could also be a way of maximizing end-users' comfort while using these technologies.

These findings indicate that a fundamental component of any assistive technology is its ability to comfort users via personalization and empathy. Although stakeholders' opinions may vary on how to achieve this [19], researchers should explore their integration into assistive technologies. Differences in cultural backgrounds may also arise; thus, researchers should consider tailoring different robot aspects (e.g., appearance, features, interaction, personality) accordingly to improve acceptance and engagement.

Navigating tensions in stakeholder perspectives: Differences in stakeholder perspectives arose on many levels in our studies. These differences manifest on overarching themes such as the issues stakeholders choose to design for, or on more specific themes such as the role of technology within a particular context. For example, in Case Study 2, HCWs and PwC envisioned completely different technologies and use cases to support them in the ED. In Case Study 1, GCPs and PwMCI/PwD had differing perspectives on whether they wanted a more active or passive robot for cognitive support.

Identify whose voices to include: In both studies, we included the disabled population we were designing for as primary stakeholders, and HCWs as secondary stakeholders. To identify relevant stakeholders to include, researchers could refer to existing literature exploring technology to support disabled populations that identify key stakeholders via expert advice, surveys and engagement with the disabled community and their lived experiences [26, 27, 34]. In our studies, since we were envisioning robots as extensions to the care team, we chose to include HCWs as secondary stakeholders.

Identify whom to prioritize: While including a wider variety of stakeholders can bring multiple perspectives to light, it is clear that this can also raise more design tensions among stakeholders that researchers then need to balance. In the case of knowledge asymmetries such as HCWs vs disabled people, research indicates that caregivers and disabled people may approach disability from different perspectives [28]. Researchers could find value in evaluating whose perspectives to prioritize when tensions arise, or identify ways to balance both perspectives through design decisions. While we cannot make specific recommendations based on our studies, we defer to literature in disability theory and accessibility research [29, 30] to use as guidelines while making such decisions.

However, we note that sometimes stakeholders' perspectives neither conflict nor align. In these cases, researchers could incorporate all perspectives that add value to the experience of end-users. For example, in Case Study 2, PwC envisioned technologies to address their immediate needs, and clinicians envisioned pain assessment robots that provided compassion and comfort to patients in pain. In this case, providing comfort and compassion could be complementary robot behaviors that enhance the direct services it provides.

Sample sizes and addressing cross-empathy: Another challenge in sensitive settings is identifying what sample sizes are sufficient to gather diverse perspectives from disabled populations while not being extractive of them [33]. These challenges can be addressed by following best practices in the research ethics, design justice, and critical access studies literature to balance the harms and benefits of imposing on these populations [4, 9, 10, 12, 31, 32]. Researchers may also include proxy stakeholders [8] to bring out the voices of underrepresented populations. Thus, adequate representation should be capable of capturing disabled populations' interests without imposing new burdens on them. Adequate representation could also potentially address the effects of cross-empathy that we observed in Case Study 2, where participants of one group tried to envision technologies to support the other group. While all caregiver participants had the best intentions, the ideas they came up with were not necessarily representative of the needs of the disabled population.

Factors for Consideration: While it is difficult to generalize where stakeholders differ or align, we present potential factors that could inform how stakeholders envision assistive technologies. These factors indicate that context affects how stakeholders envision assistive technologies and may lead to tensions.

Health condition. In both our studies, the type and criticality of health conditions affected what stakeholders wanted from the robot or technology. For example, PwMCI/PwD wanted robots that were cognitively stimulating and engaging. Meanwhile, PwC wanted technologies that could provide prompt services as requested (e.g. deliver items, provide statistics of diagnoses) to help them navigate uncertainty in their condition. In either case, HCWs and disabled people expressed differences in the role a robot could take to best support their particular health condition.

Period of interaction. We observed that the period of time over which users would interact with the technology affected the sociability of the technologies they envisioned. In Case Study 1, GCPs and PwMCI / PwD envisioned robots with a larger social presence to cognitively support users over longer periods of time. In Case Study 2, HCWs and PwC were not as concerned about the social aspect of the robot and focused more on the services it could provide during a PwC's stay in the ED. Thus, the expected duration of interaction could lead to tensions regarding the types of interactions stakeholders envision occurring between users and a robot.

Location of deployment. The location where the technology would be deployed affected the physical design of the technology. Particularly, technologies for safety-critical spaces such as the ED called for a higher emphasis on safety aspects to be embedded into their design [25]. Robots designed for safer spaces such as homes provided more room to ideate on appearance. Stakeholders may have varying degrees of familiarity with different locations, leading to tensions in how to design technology for those spaces.

4 CONCLUSION

We discussed tensions that arose between HCWs and disabled people in two case studies designing assistive robots for healthcare applications. Based on these insights, we provided suggestions to guide HRI researchers in bridging these tensions throughout the design and development process. These contributions will help ensure that disabled populations' needs are centered, and secondary stakeholders' expertise are incorporated into robot design, to ultimately promote more inclusive, ethical, and accessible design of assistive robotics for disabled people.

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