Designing Accessible Telepresence Robots for People with Chronic Illnesses

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Abstract

Telepresence robots have the potential to support people with chronic illnesses (PwCI) by enabling remote participation with greater physical and social agency than traditional videoconferencing. However, these robots can be cognitively exhausting to use. This is exacerbated by PwCI's need to constantly weigh the potential benefits and risks of participation due to fluctuating symptoms. In our work with PwCI, we explore how we might design telepresence robots that minimize the health consequences of remote participation. To do this, we leverage *pacing*, a self-management strategy PwCI use to balance activity and rest. Ultimately, our research helps advance the accessibility of telepresence robots by foregrounding the embodied and sociopolitical dimensions of PwCI's episodic disability while challenging the social norms of rest/productivity.

CCS Concepts

• **Computer systems organization** → **Robotics**; • **Human-centered computing** → **Interaction design**; **Accessibility**.

Keywords

Human-Robot Interaction, Telepresence Robots, Chronic Illness

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1 Introduction

Chronic illnesses (CIs) are long-term health conditions that affect hundreds of millions of people worldwide [1–3]. They often have no definitive cure and require lifelong management.

A major challenge for many people with chronic illnesses (PwCI) like Long COVID is intense fatigue. This is exacerbated by diverse symptoms such as tachycardia, brain fog, and sensory sensitivities [4–7]. Symptoms fluctuate daily, or even hourly, resulting in episodic disability that disrupts PwCI's ability to participate consistently and meaningfully in everyday activities. This inconsistency leads to social stigma and ableism towards PwCI, as it conflicts with dominant norms of productivity and continuous engagement [8, 9].

In recent years, there has been an increased demand for telepresence technologies that provide remote access to work, education, and social life, while allowing PwCI to manage symptoms and follow flexible schedules from any location [10–15]. Telepresence robots, in particular, offer mobility and manipulation capabilities that can support forms of remote participation not possible with videoconferencing alone [11, 16–19]. However, these robots can be exhausting to use, as they require users to learn unfamiliar control systems, multitask, and remain constantly aware of themselves, others, and the surrounding remote environment [18, 20–24].

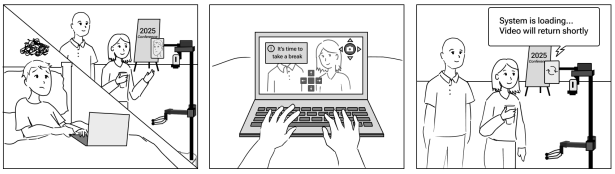


Figure 1: Through long-standing collaborations with PwCI, we co-designed telepresence robots that support pacing, through features such as timers and autonomous assistance. PwCI also envisioned robots as a social buffer, helping to reduce the guilt and social disapproval often associated with taking breaks or resting.

For PwCI, such challenges can be especially burdensome, as they also have to engage in *consequence calculus*. This means assessing their current health status and whether the anticipated benefits of an activity (e.g., social connection) outweigh potential consequences (e.g., symptom exacerbation) [25]. The need for consequence calculus shows that telepresence robots must be designed to minimize fatigue by accommodating the fluctuating nature of CI and the potential health impacts of their use. Yet, current telepresence robot designs do not (yet) account for this, placing the burden of managing access on disabled users instead [11, 13, 15, 26].

Thus, in our work, we explore the design of accessible telepresence robots for PwCI to support more sustainable forms of remote social participation. Drawing on the concept of consequence calculus, we consider how these robots can help offload the responsibility of managing the physical, cognitive, and emotional consequences of participation in relation to fluctuating symptoms. To do this, we leverage *pacing*, a self-management strategy commonly used by PwCI to balance periods of activity and rest [15, 27–29].

Contributions to HRI: First, we introduce *pacing* as a design framework for accessible telepresence robots. Second, through ongoing, multi-year collaborations with people with Long COVID, we identify design considerations for telepresence robots that support pacing. Second, we draw from principles of disability justice to examine the socio-ethical implications of designing autonomous assistance in these robots. Finally, by supporting PwCI with pacing, we challenge prevailing normative assumptions about rest/productivity. In doing so, we expand the understanding of what it means to be present when exhausted during remote telepresence.

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2 Envisioning Pacing in Telepresence Robots

We conducted participatory research with 8 people with Long COVID (PwLC) to explore how they envision telepresence robots that enhance social inclusion while supporting pacing [15]. The study focused on two key questions: 1) *how do participants imagine using mobile telemanipulator robots (MTRs), which support both mobility and manipulation, to engage in remote social interactions?*, and 2) *how might these MTRs be designed to support pacing practices and promote well-being during teleoperation?*

Methodology: Our study involved remote robot teleoperation, an interview on pacing strategies, and an ideation activity during a 1-hour Zoom session to gather feedback on telepresence robots and their design. Three researchers analyzed the transcripts using Reflexive Thematic Analysis [30]. To avoid *techno-ableism* [31], we situated PwCI's perspectives in critical disability studies [32, 33].

Findings: All PwLC agreed that "pacing…[is] the way of life". They also noted that while MTRs reduce the physical exertion of going to activities (e.g., offices, museums), they can be cognitively exhausting. To mitigate this, PwLC suggested how MTRs might help them balance activity with rest during telepresence. For instance, the robot could monitor their symptoms and provide break reminders or autonomous assistance with its controls. Some also wanted the robot to act as a buffer and help navigate social pressure when the user needs to step away and rest (Fig. 1). Others wanted to offload the effort of displaying social cues onto the robot.

Many PwLC recognized the challenges of integrating pacing features within telepresence robots. They were uncertain about communicating fatigue to the robot, and how it would adapt to fluctuating symptoms. For instance, while some were comfortable with the robot monitoring their symptoms to support pacing, others expressed discomfort and wanted assurances of confidentiality.

Participants were also cautious about robots providing autonomous assistance as they wanted to maintain their sense of agency over the robot's actions, especially in social contexts. Others were concerned that failures in the robot's autonomous assistance could force them to redo tasks, which would be frustrating and exhausting.

Lastly, participants voiced concerns about the stigma of using MTRs, fearing ridicule or misunderstanding, which can be emotionally exhausting. They wanted the robot design to look mechanistic/functional rather than human-like, and to be as unobtrusive as possible in both appearance and behavior in social settings. Despite such concerns, they stressed the importance of being visible to others via such robots, as "[otherwise,] people [aren't] seeing us".

Discussion: Drawing from our findings and critical disability studies, we developed several design considerations for pacing-aware, accessible telepresence robots. These included: *consider crip time* (i.e., adapt autonomous assistance based on real-time need for rest/activity), *respect personal autonomy when designing robot autonomy* (i.e., maintain users' sense of agency), and *design robots to be robust* (i.e., design to anticipate and reduce frustration with automation). Overall, this work highlights the importance of supporting pacing in remote telepresence through nuanced robot design.

3 Disability-Centered Autonomous Assistance

To respect PwCI's agency while supporting pacing, we examined *paternalism* in assistive robots and strategies to mitigate it [34].

Paternalism refers to an interference with an individual's autonomy, under the assumption that it is for their own good [35]. Historically, disabled people have often been subjected to unwanted "assistance" based on assumptions about their autonomy and need for care. As many robots built and deployed in home and healthcare settings interact with disabled people, it is imperative to critically examine our HRI research and praxis to avoid perpetuating paternalistic dynamics. This concern is especially salient given that prior work has shown how robots can act paternalistically towards users by nudging them towards specific behaviors or decisions [36, 37].

In our work, we draw from multidisciplinary literature, including critical HCI and crip technoscience, to examine how paternalism may manifest and impact disabled users during assistive robot design, development and deployment. We then reflected on current HRI practice and proposed strategies for researchers to develop a more disability-centered praxis, guided by Berne et al.'s [38] disability justice (DJ) principles. We chose DJ as it is a framework that centers disabled people's lived experiences. In doing so, it illuminates both the interconnected systems of marginalization disabled people face and ways they can achieve collective liberation [38, 39].

Critically engaging with DJ principles can help HRI researchers adopt nuanced robot design practices that account for intersectionality within disabled communities, emphasize *inter*dependence rather than independence, and avoid perpetuating societal ableism.

In our work, we suggest engaging with disability-led scholarship/media to reflect on research agendas and challenge dominant disability narratives. We also propose ways we might organize on educational/institutional levels to foster broader, systemic change.

Ultimately, our work reinforces the need to carefully evaluate the design of pacing-aware telepresence robots and the socioethical implications of providing autonomous assistance to PwCI.

4 Ongoing and Future Work

For many PwCI, telepresence systems create a paradox: being included often means needing to conform to ableist norms of constant visibility, engagement, and productivity [14, 15, 40, 41]. These expectations can be difficult for PwCI to navigate, since resting is not optional but vital for pacing [27, 28, 42]. Despite rest being critical to PwCI, to our knowledge, it has not been directly explored in HRI.

Thus, we will study how to design telepresence robots that actively support the need to rest. Here, we ask: *What does rest mean for chronically ill users of telepresence robots during remote social interactions, like telework?* Specifically, we will examine: (1) What does it mean for PwCI to rest or slow down during periods of physical pain, brain fog, or emotional fatigue? (2) How should teleoperation systems be designed to support users when they transition from periods of activity to rest, and vice versa? (3) How do PwCI want to be represented in the remote environment during periods of rest?

Drawing from prior HCI work on slow technology [43, 44], we will conduct design fiction workshops with PwCI to co-design and test prototypes of robot behaviors, control interfaces, and AI tools.

This research contributes to the design of pacing-aware telepresence robots that promote accessible remote participation for PwCI by accommodating the fluctuating nature of their symptoms. In doing so, our work helps promote the social acceptability of rest during telepresence, and challenges the notion that constant engagement and productivity are prerequisites for inclusion.

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