Envisioning Telepresence Robots for Long Covid: A Critical Disability Lens

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Long Covid (LC) is a debilitating, multisystemic disease that has emerged as the largest mass-disabling event in recent history. Due to the episodic disability and stigma associated with the condition, people with LC (PwLC) often experience social isolation. Mobile telemanipulator robots (MTRs) have the potential to support remote social inclusion for PwLC. However, nuanced MTR design is necessary to accommodate PwLC's fluctuating symptoms and avoid exacerbating them due to the complexities of teleoperation. In this work, we conducted participatory research with eight PwLC to explore how MTRs can be designed to support their needs. Through online, semi-structured interviews, we found that all participants recognized the potential of MTRs to enhance social inclusion across various settings. Our findings highlight the importance of providing PwLC with adaptive, autonomous support during teleoperation to meet their pacing needs and minimize exertion. Many PwLC preferred MTRs with adjustable autonomy, as they would offer greater agency over the robot's actions in social spaces. Due to concerns about stigma, participants also wanted MTRs to provide flexible control over the visibility of their disability, allowing them to manage how others perceive them according to their preferences and context. Based on these findings, we present key design considerations, grounded in critical disability studies and critical access studies, for designing MTRs that support remote social inclusion for PwLC while safeguarding their well-being. This work serves as a basis for developing accessible MTR systems that promote inclusivity for PwLC and other chronic conditions.

CCS Concepts: • **Computer systems organization** → **Robotics**; • **Human-centered computing** → **Accessibility technologies**; *User centered design*; *Interaction design theory, concepts and paradigms*; *HCI theory, concepts and models*; • **Computing methodologies** → *Artificial intelligence*;

Additional Key Words and Phrases: Human Robot Interaction, Accessibility, Telepresence Robots, Chronic Illness, Critical Disability Studies

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1 Introduction

Amidst the unmitigated spread of COVID-19, **Long Covid (LC)** has emerged as the largest mass-disabling event in recent history, affecting over 65 million people worldwide [38, 40]. LC is a chronic illness characterized by a wide range of symptoms that persist more than 3 months after the acute phase of a COVID-19 infection. While estimates of its incidence vary, some studies report rates of 50–85% for unvaccinated individuals who were hospitalized, 10–35% for those who were not hospitalized, and 8–12% for vaccinated individuals [3, 18, 54, 89, 109, 148]. Within the United States, 7.5% adults—roughly 17 million people—live with LC, as of March 2024. Of these, 79% reported some form of activity limitation due to LC, and 25% stated that the illness significantly limits their activities [46].

Commonly reported symptoms include intense fatigue, cognitive impairments (such as brain fog), joint pain, and post-exertional malaise [24, 39, 84, 148]. Each person's experience with LC is unique, as individuals can have different symptoms with varying severity and durations, lasting anywhere from weeks to years. The severity of symptoms, lack of treatment options, and uncertainty of disease prognosis contribute to the challenges of managing LC [6].

Fatigue, defined as a "constant state of weariness that reduces a person's energy, motivation, and concentration," is one of the most debilitating symptoms of LC [32, 130]. Such intense fatigue often significantly impedes **People with LC (PwLC)**'s ability to engage in **Activities of Daily Living (ADL)**, such as eating and bathing, as well as instrumental ADLs, such as managing finances and shopping [38, 130, 159]. PwLC also often experience post-exertional malaise, an unpredictable and intense exacerbation of symptoms, which can last for days or weeks after minimal physical or cognitive exertion [50, 57].

LC is relapsing-remitting, which means that symptoms can come and go unpredictably, even without post-exertional malaise [104]. This impacts PwLC's ability to engage in daily routines such as work or recreation [43, 138]. For instance, PwLC are more likely to be unemployed and less likely to work full-time due to the nature of their condition [7, 113].

LC also makes it difficult for PwLC to maintain social relationships, with greater symptom severity linked to lower social connectedness [73, 156]. This difficulty is further exacerbated by social stigma. People living with chronic illnesses often "internalize, experience, and anticipate stigma," defined as the "social devaluation or discrediting" of individuals due to their illness [41]. Experienced stigma often refers to direct overt experiences of discrimination, where individuals are treated unfairly due to their condition, while anticipated stigma involves the expectation of bias or mistreatment by others. These forms of stigma can lead individuals to internalize negative beliefs about themselves and withdraw socially [68, 106]. For PwLC, such stigma, compounded by societal neglect and refusal to reduce the risk of reinfection, has contributed to widespread social isolation [11, 23].

In this context, platforms that facilitate remote participation are essential for people with chronic illnesses, such as LC. It allows them to take part in events that may be physically inaccessible and remain included in professional and social spheres. It also provides the flexibility to adjust their schedules according to their condition, making it easier to manage symptoms as they arise

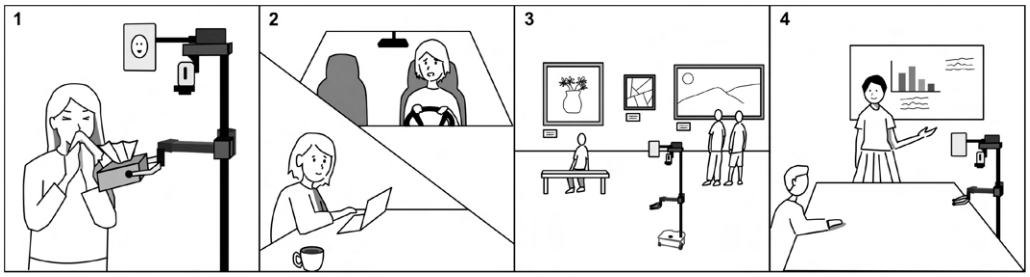


Fig. 1. In our study, people with LC reported that using mobile telemanipulator robots (MTRs) to attend remote activities could help (1) reduce reinfection risks and (2) eliminate the need to commute to different locations, thereby lowering their exertion levels. They also felt MTRs would provide greater bodily autonomy and agency than videoconferencing. Participants identified potential uses for MTRs in activities such as (3) visiting museums or (4) attending work meetings.

[88, 158]. A telepresence robot is one such platform that has the potential to facilitate the remote social inclusion of PwLC.

Telepresence robots provide operators with a social, physically embodied presence in remote environments [153]. In **Human–Robot Interaction (HRI)**, they have proven helpful in a range of settings, including tele-healthcare, remote schooling, and older adult care [2, 10, 67, 90]. One type of telepresence robot is **Mobile Telemanipulator Robots (MTRs)**, which can physically interact with the environment [2, 26, 121].

However, these systems are notoriously difficult to control due to limited situation awareness, substantial multitasking requirements, and overall lack of accessibility of control systems [29, 117]. Collectively, these outstanding issues make existing telepresence robot usage difficult, if not impossible, for many PwLC, as their symptoms can also complicate teleoperation [24].

MTR use may also contribute to social stigma, which is problematic for an already marginalized LC community. Rode [121], a disabled **Human–Computer Interaction (HCI)** scholar, highlights this issue by noting that when a robot acts as an embodiment of the user, limitations in a robot's design can create new forms of impairments for the user. These design shortcomings can reinforce the stigma and ableism often experienced by disabled individuals such as PwLC.

Thus, it is critical to explore how to better support PwLC during MTR use while also avoiding the perpetuation of social stigma. To achieve this, MTR design must be grounded in the insights of PwLC, accounting for the diversity and complexity of their needs.

PwLC use *pacing* strategies to manage energy levels and limit overexertion [51, 57, 130]. Pacing involves carefully balancing periods of rest and activity based on one's personal estimation of available energy [47, 129]. This can be challenging for many PwLC due to unpredictable fluctuations in energy levels, and they may not even recognize that they need or ought to stop in the middle of an activity such as teleoperation.

There is limited HRI research exploring the design and integration of pacing strategies for PwLC. To our knowledge, only one study has addressed this topic, proposing that assistive robots can be designed with specific features to support PwLC with pacing during daily household routines [119]. These proposed features were not examined in the context of MTRs, which serve as a medium for PwLC to project their remote presence and interact socially. The study also did not account for the complexities of teleoperation and how that may impact MTR use by PwLC.

As such, we engaged in participatory research with eight people with LC, to understand their perspectives on MTR design for remote inclusion. We conducted semi-structured interviews to understand how PwLC currently manage their symptoms through pacing. We then held an ideation

session in which participants envisioned ways MTRs could promote social inclusion and well-being. Specifically, we focused on integrating the concept of pacing into MTR design to support PwLC during teleoperation. We grounded these insights within a critical disability studies and critical access studies paradigm.

The contributions of this article are fourfold: First, we report insights drawn from PwLC's lived experiences on how MTRs can facilitate their social inclusion in different settings. Second, we highlight how they envision MTRs helping PwLC manage pacing during teleoperation, particularly through shared autonomy. Third, based on our findings, we present design considerations to the HRI community for developing socially acceptable MTR systems that support pacing by affording greater visibility and agency while minimizing exertion. Finally, our work highlights the pervasiveness of stigma and ableism surrounding people with chronic illnesses, which has implications for the integration of pacing strategies and the long-term use of MTRs.

2 Background

2.1 Telepresence in HRI

Telepresence robots allow operators to embody themselves in remote places and interact directly with people who are physically present with the robot. They have been used in diverse settings including hospitals, museums, nursing homes, offices, classrooms, and factories [2, 28, 81, 90, 114, 121, 143, 165, 166]. Unlike traditional videoconferencing platforms, telepresence robots offer remote operators greater autonomy, enabling them to freely move around in space and focus on different people or objects [131, 147, 152]. These robots can increase an operator's social connectedness and feelings of presence in remote settings [67, 160]. Moreover, numerous studies highlight their potential to improve accessibility for individuals who are unable to travel or participate in-person due to health, geographical, or logistical constraints [2, 28, 81, 90, 114, 121, 143, 165, 166].

However, operators can sometimes find them challenging to use due to issues like limited spatial awareness, insufficient interaction capabilities, and difficult control interfaces. These have often been reported by users of several telepresence robots, including commercially available models across different settings (such as work or school) [2, 26, 98, 117, 153]. Studies have found that such challenges can increase cognitive load and operator frustration and reduce task performance during teleoperation [29, 85, 117]. Furthermore, studies indicate that telepresence robot users are sometimes subjected to "othering" behaviors and socially excluded, negatively impacting sense of inclusion [15, 17, 81]. Thus, telepresence systems must be carefully designed to address these challenges to ensure that PwLC feel supported during teleoperation.

2.2 Telepresence Robots for People with Chronic Illnesses

Telepresence robots have often been used to support the remote inclusion of people with chronic illnesses. For example, several HRI studies explored their use in K-12 and higher education to support remote students unable to attend class in person due to their illness. These studies show that telepresence robots are effective in facilitating active learning, enhancing social connectivity, and improving the sense of remote presence for chronically ill students [2, 82, 131, 160]. Beyond education, telepresence robots for individuals with chronic illnesses have also been explored in nursing homes [165] and telework contexts [58, 121].

To our knowledge, no studies have explored telepresence robot use amongst PwLC; however, a related study with youth involving **Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)** provides some insights. AV1, a tabletop telepresence robot, was used for the remote inclusion of people with ME/CFS, a condition that shares many similarities with LC (e.g., fatigue and post-exertional malaise) [70, 76, 157]. AV1 supported the prolonged and more frequent presence

of ME/CFS youth in school, facilitating social connectedness [16, 34]. However, despite being a tabletop robot, the effort required to use it inadvertently worsened some students' symptoms [16].

This suggests that more complex systems, such as MTRs, could pose similar, if not greater, challenges for users with other complex conditions like LC. However, prior work has shown that a manipulator may be beneficial in supporting a broader range of interactions for operators in remote environments. [26, 83, 121]. Currently, many commercially available telepresence systems (e.g., Beam, Double, VGo) lack manipulators, limiting remote users to passive observation instead of active engagement in activities (e.g., in a classroom, hospital) [2, 13, 26]. A lack of a manipulator can also hinder users' ability to interact with the physical environment (e.g., opening doors) [83, 112]. This lack of a manipulator can cause users to feel as if they were disabled, as reported in multiple articles [81, 121, 145, 153]. Since many PwLC already face the challenges of living with a disability, it is important to ensure that the choice of robot and its capabilities do not exacerbate their difficulties.

Like many people with chronic illnesses, PwLC employ various symptom management strategies like pacing to maintain wellbeing. Yet, existing studies rarely consider how the unpredictability of a user's condition and their symptom management strategies could influence or improve telepresence robot design. Hence, in our work, we explore how MTRs might be designed to support pacing strategies, helping to safeguard PwLC's wellbeing during teleoperation.

It is important to note that while many PwLC have ME/CFS, the conditions are considered distinct [52, 111]. Insights from studies with people with ME/CFS, or even other illnesses, may not fully generalize to those with LC, which is associated with over 200 symptoms across various organ systems. Each PwLC experiences different subsets of these symptoms, often with varying severities, which can complicate teleoperation in different ways [24, 139]. Given this diversity, PwLC may also perceive and engage in MTR-mediated interactions differently compared to people with other chronic illnesses. Hence, it is necessary to explore MTR use specifically with PwLC.

2.3 "Spoon" Theory in Chronic Illness

Coined by Miserandino [96], *spoon theory* is a widely used metaphor among disabled people to explain the fluctuating and debilitating impacts of their condition, as well as the conscious choices they must make throughout the day as a result. The theory likens the limited energy available to people with chronic illnesses to a finite number of "spoons" at the start of each day, with each task or activity consuming a certain number of spoons. These tasks could be physical, cognitive, or emotional in nature. The number of spoons required can vary depending on the individual's bodymind, capacities, and needs on any given day, as well as the complexity or intensity of the task [132].

As the day progresses, once these spoons are depleted, it is difficult, if not impossible, to engage in more activities. Overexerting may leave the individual with fewer spoons the next day, and even trigger symptom flare-ups. Thus, unlike non-disabled people who typically have unlimited spoons and face fewer, less severe consequences from energy depletion, chronically ill people must constantly strategize and prioritize activities based on the limited number of spoons they have each day [96, 132]. For instance, someone with LC might have to choose between showering and having a short conversation with a friend, as engaging in one activity may leave them too energy-depleted to manage the other. This highlights the invisible, disabling impacts of chronic illnesses such as LC, as many are unaware of the constant, moment-to-moment negotiations an individual must make to manage their energy and overall well-being [132].

2.4 Pacing for LC Management

Pacing is a self-management strategy many people with chronic illnesses, including LC, use to balance periods of rest and activity to manage their symptoms and prevent overexertion [51, 57]. A key part of pacing involves using *spoon theory* to assess available physical, mental, and emotional energy for the day, which helps PwLC determine how to allocate their limited energy resources across various tasks. It also involves planning extra rest before and after strenuous activities to reduce the risk of post-exertional malaise. Studies have shown that pacing can improve health outcomes for people with ME/CFS and LC, particularly in areas such as physical functioning, fatigue, post-exertional malaise, and mental health [25, 47, 108].

Recent research in the HCI community describes the importance of wearable self-tracking technologies (e.g., Fitbit) and other devices in supporting pacing for people with LC and ME/CFS [37, 65, 66, 110]. One of the authors of this article also wrote about the potential of assistive robots in aiding pacing by helping with household tasks [119]. These studies all emphasize the importance of designing pacing technologies with the dynamic and long-term nature of LC in mind. However, there remains a general lack of research on how pacing can be integrated to enhance PwLC's experience while teleoperating MTRs.

2.5 Contextualizing Chronic Illness in Critical Disability Studies and Critical Access Studies

We use theories from critical disability studies and critical access studies to help frame MTR design for PwLC. Critical disability studies are the intersectional analysis of the political, cultural, and historical experience of disability [49, 61, 94]. Critical access studies examine the values underlying common approaches to accessibility, and the means of achieving it [95]. Collective Access is one such idea which describes a collective responsibility for creating accessible spaces [56].

As PwLC face social barriers resulting from ableism, we explore their experiences and how those shape their interactions with MTRs from the perspective of the "critical, social and personal position of disability" [11]. One overlooked and invisible barrier people with chronic illnesses face is others' inadequate understanding of the concept of "crip time." Crip time refers to the nonlinear and non-normative experience of time by disabled and chronically ill individuals [72, 88, 128]. It challenges societal expectations about the "normal" amount of time or energy tasks should require, which can be exclusionary and restrictive. Instead, it advocates for a flexible, more inclusive approach to activity planning and scheduling to ensure accessibility for disabled individuals [19, 115]. Our work seeks to accommodate this notion of crip time during teleoperation by exploring design considerations that account for pacing into MTR design, as pacing involves variable periods of rest and activity.

Additionally, people with chronic illnesses, including PwLC, frequently experience stigma and worry about how they are perceived [23, 44, 69]. They often modify their appearance and behavior (e.g., covering or masking [14]) to reduce negative social consequences, even to their own detriment [1, 63, 102, 163]. People with invisible conditions also tend to struggle choosing between the utility of an assistive device and the self-consciousness of using one [35, 135]. Well-designed technology that acknowledges these tensions can help increase the user's visibility while mitigating stigma [44]. Our work takes into account the nuanced considerations of (in)visible disability in MTR design and how that relates with the concept of pacing during teleoperation.

3 Methodology

We engaged in participatory research to explore how PwLC envision MTRs that support their social inclusion while also safeguarding their well-being. This approach ensures that MTR designs

are grounded in PwLC's lived experiences of LC [123, 140]. To this end, we conducted a two-part, online qualitative study with eight PwLC. Given the fluctuating and complex nature of LC, we took specific steps to make the study accessible to this population. Below, we outline these steps, drawing on recommendations from prior work with chronically ill populations [80, 87, 88].

3.1 Accessible Participatory Research with People with LC

Participatory research in HRI encompasses a wide range of methods such as sketching, card sorting, or storyboarding [55, 78, 123]. However, these design activities can be inaccessible for PwLC, as their symptoms may limit their physical and cognitive engagement. Additionally, the strain of participating in such activities could worsen their symptoms, making it essential to adapt our methodology for greater accessibility and safety for our participants. As a result, we opted for semi-structured interviews, a common participatory research method that allows for flexible, in-depth conversations while minimizing physical and cognitive demands on participants [123, 140].

We designed our study to support remote participation, allowing participants to engage from locations that were most comfortable for them, such as from their bed or couch. This helps minimize the burden of physical travel and risks of reinfection [9, 88]. This also aligns with the motivations of our study, as we aim to design MTRs that would facilitate remote participation for PwLC who may find traveling difficult.

We carefully calibrated the duration of our study by breaking it into two parts, ensuring it was as short as possible to mitigate fatigue and cognitive load. In the first part, participants completed a few short tasks asynchronously at their own convenience, including familiarization with the robot and its controls through video tutorials. This preparation facilitated a more efficient transition to the second portion, where participants could immediately focus on controlling the robot after resolving any questions or concerns. The second part was a one-hour Zoom interview, and we offered breaks regularly, which all participants used.

Since participants had limited experience with telepresence robots, it was important for them to first experience controlling the robot so they could provide feedback on its design. However, to avoid physical or cognitive exhaustion, we limited the time spent controlling the MTR by reducing both the number and complexity of tasks participants had to complete. Subsequently, instead of engaging them in more taxing design activities, we focused on asking participants questions about their teleoperation experience and gathered their thoughts and ideas on improving the design of such robots. Our questions and scenarios (as well as the overall design and procedure) were developed by reviewing prior LC literature and in consultation with the author with LC [37, 64, 104, 119, 130, 138, 154].

As LC impacts each person differently, even these simplified activities could be challenging for some PwLC. Before participation, we provided a clear explanation of the study's requirements, allowing each potential participant to assess whether they were able and willing to take part based on their current condition. Overall, the steps we took to make the study accessible reflect our commitment to ensuring the active participation of PwLC within the robot design process.

3.2 Participants

We recruited 8 PwLC (3 males, 5 females; 35–64 years old) through convenience sampling via word of mouth, e-mail, and social media. For example, one of the authors has LC and connected us with another person they knew with LC. On social media, we searched for public hashtags relating to LC and privately messaged a few individuals who had publicly discussed their condition and were engaging in community discussions. We shared our research flyer/information sheet and asked if they were interested in participating. Subsequently, we had conversations over Zoom/phone with

prospective participants to explain what the research would entail, answer any of their questions, and obtain their consent for participation. During these conversations, all self-identified as a person with LC. We did not screen participants based on symptoms or other medical information as the diagnostic criteria for LC are constantly evolving [103]. Additionally, we follow best practices in research ethics and collect only the minimum amount of data necessary from participants to maintain confidentiality [134, 167].

Participants reported varying ethnic identities (63% (5) White or Caucasian, 25% (2) Hispanic or Latine, 13% (1) African American or Black, 13% (1) Asian American or Asian, 13% (1) Pacific Islander, 13% (1) Other). Four participants are employed, two are not working due to LC, one is retired, and one homeschools their children. Most participants were familiar with technology and used platforms like Zoom or FaceTime for remote meetings and social events. They generally had limited experience with robots. One participant indicated that they were extremely familiar with robots, three were not familiar at all, and the remaining four had mixed levels of familiarity. Additionally, while two had some prior experience, six had never remotely controlled robots before. All participants gave oral consent for participation, and signed consent forms for audio and/or video recording. They received a $25 gift card for participating. This study was approved by the UC San Diego IRB, under protocol number 804926.

3.3 Robot

Given that no commercially available telepresence robot currently combines telepresence capabilities with a mobile manipulator, we used the Stretch robot from Hello Robot, a widely used platform in the HRI community. It is a mobile manipulator with eight degrees of freedom [74]. It has a non-holonomic base for navigation, and an arm, wrist, and gripper for manipulation. It also has a head camera.

While we acknowledge that a manipulator may add cognitive load, we also recognize that its absence could cause operators with disabilities to feel further disabled [121]. It was important for our participants to be able to freely ideate and share their vision of how telepresence robots could support them, without being limited by the robot's capabilities. Thus, we used the Stretch robot as our design probe to facilitate the ideation of a broad range of MTR-mediated interactions (Figure 2). Additionally, since there is no one-size-fits-all solution for robot design, examining participants' perspectives on a unique platform like Stretch provides valuable insights into how telepresence robots can be improved to enhance accessibility.

We modified Stretch in several ways to enhance its suitability for telepresence applications. We developed a control interface for the Stretch designed on an earlier project (Figure 3 [90]). This included one mode to control the base and head camera, and another to control the arm. For a wider field of view within the interface, we attached two Logitech C920 webcams, one to the head camera and another at the gripper. We also attached an iPad Mini tablet near the head of the Stretch. This enabled participants to connect to the tablet via Zoom, providing two-way audio-visual communication capabilities to the operator and also showing the operator's face to people around the robot.

3.4 Procedure

In the first part of the study, participants watched two short video tutorials asynchronously. The first video helped familiarize them with Stretch's capabilities and telepresence use cases, and the other explained the interface controls. Participants were also given an optional short pre-study survey regarding their initial impressions of the robot and the interface. They were invited to share any questions they had regarding the videos, which were addressed in the next part of the study.

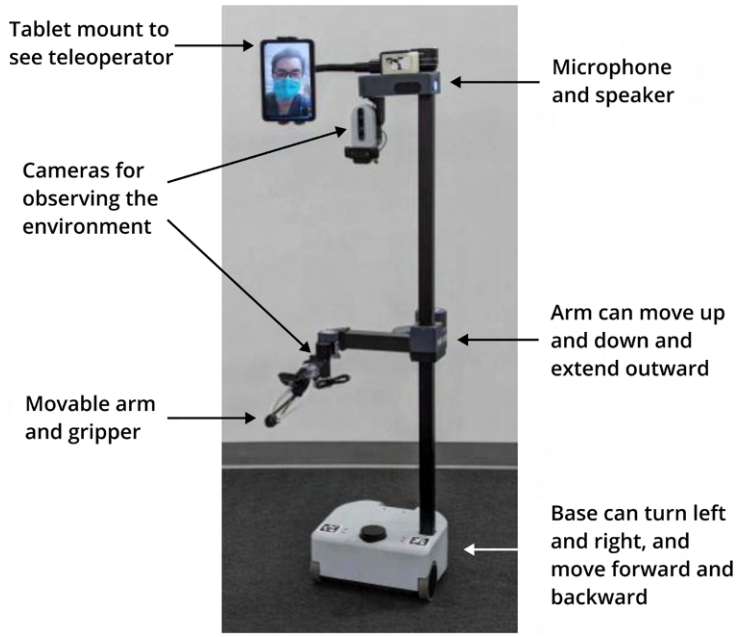


Fig. 2. PwLC teleoperated the Stretch robot.



Fig. 3. The Stretch teleoperation interface. *Left*: Navigation view is used to control the base and the camera of the robot. *Middle*: Manipulation view is used to control the arm, wrist, and gripper of the robot (in joint space). *Right*: A remote operator controls the Stretch through the interface.

Two researchers then conducted a synchronous meeting with participants over Zoom for approximately an hour, excluding breaks. The meeting was divided into three parts: live teleoperation, an interview on self-management strategies, and an ideation activity focused on participants' opinions on MTR design. Each part took approximately 20 minutes, though we were flexible with the times depending on the participants' needs and preferences.

First, a researcher discussed the participants' pre-study survey responses and answered any questions they had, facilitating a smooth transition between the asynchronous and synchronous portions of the study. Participants' pre-study questions were primarily focused on understanding the robot's design (e.g., the maximum weight it could carry, the orientation of the arm) and interface controls (e.g., camera alignment). Other comments reflected a mix of curiosity, excitement, and concern about controlling the MTR, with several participants specifically noting potential challenges for individuals with cognitive difficulties. After answering the participants' questions, we placed the robot in front of a mirror to provide visual feedback while reviewing the robot's controls once more (a practice recommended by Takayama and Harris [146]). This setup allowed remote participants to observe both the robot and its movements as they practiced using the controls (Figure 4).



Fig. 4. *Left*: Participants practiced using Stretch in front of a mirror so they could see themselves. *Right*: They then completed tasks including navigation, social interaction, and a handover.

Subsequently, we invited participants to attempt the live teleoperation task during which they navigated the robot to a researcher seated at a table, greeted them, and took a bottle from them. These tasks were selected as they were simple and enabled participants to experience all the functionalities of the telepresence robot—navigation, object manipulation, and audio-visual communication—while minimizing the risk of overexertion. This served as a foundation for the interview where we used the robot as a design probe. The other researcher provided participants with verbal instructions and support when needed.

After this, one researcher conducted a semi-structured interview. We sought to understand the participants' self-management, or pacing, strategies in their daily lives. Due to the diversity in daily activities and experience of illness, strategies differ from person to person. Thus, we asked participants about their pacing strategies and how they are used in different scenarios. This gave us and the participants the foundation to build on during our next phase, which was to explore new ways to make MTR design more accessible.

Then, in an ideation activity, participants explored ways the MTR could support their remote inclusion without exacerbating their symptoms. First, we asked them when they would want to use MTRs and how they would want to be supported when they control it. We then gave participants different scenarios that they might encounter when using MTRs. We included prompts to allow them to ideate on robot features or behaviors they might need and adapted the prompts based on their responses (see Appendix).

3.5 Data Analysis

We used **Reflexive Thematic Analysis (RTA)** to analyze the interview transcripts [20, 21]. RTA allows for a more nuanced understanding of the participants' experience with chronic illness, and their needs and preferences with respect to remote inclusion and MTR design.

Three researchers split the data such that two coders independently reviewed each transcript to account for differing interpretations. We iteratively refined the codes and generated overarching

themes. We inductively developed themes by grounding our analysis in the data. Our analysis was reflexive; we critically examined our biases and engaged with the data through the lens of critical disability studies and critical access studies to deepen our interpretations. As HRI researchers, we tried to avoid reinforcing technoableism—the belief that technology is a solution for eliminating disability [5]. We were also cautious to avoid inadvertently perpetuating stigma towards PwLC.

Following RTA, we used the generated themes to identify important considerations for MTR design. As per best RTA practices, we focused on depth of engagement with data rather than coder consensus and thus did not calculate inter-rater reliability [21, 93].

4 Findings

4.1 Experience of LC

Participants discussed their varied experiences of LC symptoms and the ramifications these have had on their mental health and social relationships. They also discussed their self-management strategies such as pacing to help mitigate their symptoms.

4.1.1 Health Effects. All participants experienced severe physical symptoms, including tachycardia and muscle pain. They emphasized the profound lack of energy due to LC. P1: "It's like your car with a dead battery. There's just no energy there whatsoever."

Participants also experienced cognitive difficulties. P2 described a crash: "I feel like I have dementia, and I am hung over with all the world hangovers and drugged out."

Such a debilitating, chronic condition impacted many participants' mental health. For example, P8 reflected on the uncertainty of their prognosis: "I'm better this year than last year. And so I'm like, well, maybe a year from now, you know. Maybe it'll take two more years [...] It just seems like a lot of time to lose."

4.1.2 Social Ramifications. As PwLC are forced to limit their social activity due to LC and concerns of reinfection, not all of those around them are fully understanding. P1 described, "So, a lot of people are very skeptical about LC still. Even close friends and family, they don't think it's as bad as you tell them. So our social world has shrunk pretty dramatically."

Some participants are hopeful that MTRs would enable them to socialize while maintaining their well-being. P7: "In the future maybe when I get a little bit better, or [...] I feel the world is safer, I would probably want something like [the robot] to help me [...] Because otherwise I could see myself going out [...] and then [...] it's a crash boom cycle over and over again."

4.1.3 Pacing. All participants mentioned the criticality of pacing to ration their energy between activities. P5: "Like anyone with any kind of chronic illness, pacing and spoons are the way of life. [...] [I've absorbed this] into how I do almost everything." P6 also emphasized the necessity of pacing to minimize overexertion: "And so I constantly am thinking like literally every minute of the day...how do I not overdo it?"

Since even minimal physical, cognitive, and emotional exertion can cause crashes, PwLC use different pacing strategies and tools to limit their activity (e.g., timers, wearable heart rate devices).

Cognitive and emotional pacing is difficult as there are no obvious indicators compared to their physical symptoms. P7: "I know when I push my body too hard, because immediately I'll feel inflammation [...] but with the brain, it's different." P6 found socializing to be particularly draining: "Unfortunately, emotional stuff, I tend to overdo it, because who doesn't like to see human beings. And so that's often when I crash is when I socialize."

Due to the inconsistency of symptoms, PwLC must constantly modify their strategies. P2: "It's really hard to gauge like a person's disability, especially when it's day to day or hour by hour. And for some of us in like 2020, it was moment by moment."



Fig. 5. *Left*: P7 compared their usage of FaceTime at social events as being passed around like a "hot potato." *Right*: In contrast, MTRs provide operators with bodily agency.

Although different devices can track body responses, they are not always accurate. P7: "your symptoms look like they're going down [on an app]. That doesn't always match what my body feels."

4.2 Reflections on Telepresence Robots

All participants saw the utility of these robots to support their inclusion in the world. They also discussed the importance of being mindful of the system design, because teleoperation could exacerbate symptoms and cause overexertion.

4.2.1 How They Can be Helpful for LC. All participants saw the utility of using MTRs to help support PwLC's remote inclusion (Figure 1). P7: "Connecting does become really difficult, especially if someone is immunocompromised, or [...] sick." P6: "[The robot] would [...] add a level of interaction that you don't normally get."

Additionally, all participants were excited about using MTRs to remotely participate in activities. P4: "I think it would be wonderful...to [go to] any of my meetings [...] to...feel like you are actually there [...] like watch a live show or watch my son play baseball...Go to museum like—It's not just the photos that I appreciate, but I really just love the sights and sounds of everything."

Multiple participants saw the benefit of MTRs in helping them "avoid reinfection" (P6) and with pacing by reducing their commute time. P3: "Sometimes I'm just there to observe something that's happening. So if I had a camera that I could drive around, that would save me almost a 2-hour round trip driving [to work]." P6: "To use the metaphor of like, keep my battery charged [...] for things that I can't do telepresence for."

All participants agreed that the MTRs could improve their sense of agency and presence compared to videoconferencing technologies. P7: "[On Facetime] I'm the one being passed around on a teeny, tiny screen, whereas [with the robot...] I could at least attend the event, and have some sort of bodily autonomy instead of being [passed] like [a] hot potato." (Figure 5)

P6 imagined attending work meetings and highlighted potential coworkers' frustration in constantly being asked for assistance. "Sitting in the room so you could actually participate without having somebody be a reminder on a laptop or a phone 'cause eventually, it's tiring for them. And it's annoying for you. So having that agency to kind of move around in that space would be really helpful."

Several participants also envisioned using MTRs in an assistive manner. They thought it would be particularly beneficial for PwLC who live alone and have no social support with daily activities, especially when they are exhausted. P5: "I know so many people who are in their apartments by themselves...they don't see anyone. They're...largely apartment bound or bedbound...For them,

getting up and getting medication or getting something to drink is a chore." P7 also thought it would be helpful if the robot could help fetch things like medication when "you have a really bad crash and you just can't get up." All participants also wanted to use the MTR "help you with grabbing your groceries" (P2).

4.2.2 How Telepresence Robots Could Exacerbate LC Symptoms. Despite the potential of MTRs, many participants cautioned the need for careful design as MTRs can be overwhelming. P5: "One of the problems that people [with LC] have…is problems with multiple lights […] and multiple sounds…people with cognitive problems would, would want to kill you [if you gave them this robot]."

P5 further explained how simply controlling an MTR could cause post-exertional malaise "To do that kind of manipulation that we just did even knowing how much both y'all help me […] I would have had PEM [post-exertional malaise] […] it would have caused me to [crash] tomorrow."

Other participants concurred. P8: "Not sure if […] I'd have the patience to learn it…because the way my brain works nowadays it's just tired […] So extra mental energy is like, no."

PwLC with cognitive impairments might struggle more while controlling the robot, which could cause even more frustration and lead to a: "'I'm really on my own' kind of response." (P5).

On the other hand, multiple participants also mentioned that with more experience, they would eventually get used to controlling MTRs. P2: "I feel like it would get easier to use, like anything, even without being sick… it takes time to learn something."

4.3 How MTRs Can Support Pacing

Participants discussed how MTRs could support PwLC with pacing, which might require these systems to monitor and adapt to their fluctuating symptoms. Suggestions included developing tools like timers and break reminders to help PwLC regulate periods of activity. Other approaches involved using automation to support resting and reduce PwLC's physical, cognitive, and emotional exertion, particularly during social interactions. However, participants expressed mixed opinions about the appropriate role of automation in these contexts.

4.3.1 Timers and Break Reminders. Some participants immediately imagined the robot supporting pacing by providing a timer or break reminders to prevent overexertion. P3 had another idea, "It would certainly be interesting if the robot could tell me I'm tired, go take a nap…If [the system] were somehow observing my behavior and…giving me…a notice that…'You seem to be over exerting yourself. It might be good to step away from this task.' Because that can be […] difficult to recognize in the moment."

4.3.2 Preset Automated Controls. All participants emphasized the need for the robot to have preset autonomous features to support pacing as it reduces their cognitive load. P7: "You're not having to control so many things. You can just hit a button and just be like, all right. I just need water from the kitchen. […] that would be really helpful for people who are chronically ill […] they're just cognitively exhausted." In addition to autonomous navigation and manipulation, P3 suggested that the robot could assist with, "automatic panning around to whoever is talking […] while I'm having low energy and not wanting to drive the view myself […] it's when I'm more tired that I might want the robot to be directing my attention more."

4.3.3 Automation to Support Social Interactions. Some participants saw the benefit of automation in supporting pacing during social interactions in specific instances.

Conversational Support. A few participants suggested that the robot could provide conversational support. P2: "In 2020 I couldn't talk at all […] right after my acute phase of Covid […] In that instance I would have definitely preferred for a robot to do my socializing, period." P4 likened the

robot's role to how they have a friend act as their "eyes and ears" for in-person activities, giving the robot "canned questions" to ask in their place like they would to a friend.

Others had mixed feelings about the robot providing conversational support. P2 was intrigued by the idea but uncertain about people's reactions to it, and wanted to communicate on their own. "I don't know that people would want to be conversing with a robot while you're resting [...] So I feel like that might be awkward for people." P6 strongly did not want this, "I wouldn't want [the robot] to automate my social interactions. I don't know what the other person would get, or I would get out of it."

P7 described that when they need to step away from controlling the MTR, they would just want to "observe in the same way that if you're [...] at a party, and you kind of wanna wallflower it [...] and just sort of get the vibe and the atmosphere of everything." Other participants wanted the robot to shut down altogether in social settings. P4: "it'd be nice if it just [...] went back in the corner [...] like the Roomba goes into its little home."

Offloading Social Pressure of Staying. Pacing involves taking breaks or discontinuing activities as needed to rest and avoid overexertion. However, P7 explained the difficulty of leaving social situations as many do not understand the severity of their condition. "Because I'm physically there, someone's going to guilt me." This causes them to emotionally overexert themselves because "you don't want to disappoint people [...] There's always so many things that you're limited in terms of what you can do socially already." They hoped to offload this pressure onto the robot when attending events remotely. P7 suggested the robot could "gracefully shut itself down" along with an on-screen message: "like 'User's Done.'"

However, they were concerned that needing to leave would further reinforce the stigma they already face due to their MTR usage. P7 jokingly suggested, "Could it pretend to break down? Kind of cover for you socially? 'Oh, no, my robot's broken [...] I couldn't make it to the end of the meeting.'" On the other hand, P1 preferred that "it would be me expressing it to the humans in the room. 'Hey, I can't, I gotta take off'" and then they would shut the robot down.

Offloading Social Engagement Cues. Participants wanted the robot to help communicate appropriate social engagement cues when they needed to rest. P3: "I wouldn't want it [the robot] to mislead people into thinking that I am paying attention when I'm not [...] It would be nice if it were providing visual cues of the extent of my engagement." Several participants suggested that the robot could automatically indicate their presence or lack thereof while having their camera off. Suggestions include visual indicators such as graying out an on-screen avatar or a status display similar to Slack's activity indicators (e.g., active, away, busy).

Participants also emphasized the importance of conveying the operator's level of involvement in the robot's seemingly autonomous actions. For example, if an operator is unable to turn the camera on, but is still able to control the robot, there needs to be a way to indicate that the operator is still present. P6 distinguished between two screen states: "One is inactive, as in the user's away," and the robot will not move at all. The other state would be "something to let them know that this could [autonomously] move and hit them."

4.4 Complexities of Integrating Pacing in MTRs

Participants expressed several concerns that may pose challenges to incorporating pacing support into MTRs. These included the unpredictability of LC symptoms and the need to balance the benefits of symptom monitoring with privacy considerations. While automation could help facilitate pacing during teleoperation, some participants noted that it could fail or behave unexpectedly. They emphasized the importance of avoiding frustration and maintaining a sense of control over the robot's actions in order to feel supported during teleoperation.

4.4.1 Dynamic Pacing Needs. PwLC's pacing strategies are constantly changing due to the unpredictable nature of LC symptoms. Consequently, MTRs would need to be able to dynamically adjust the pacing support they provide to PwLC during teleoperation. As P5 noted, integrating pacing into MTRs is "an impossible task [...]. The amount of time to do pacing changed throughout the day and for every day."

Even participants may not know what strategies would help them, let alone tell a robot what it can do. P3: "I don't know how accurately I would predict what sort of situations would make me tired or how accurate I'd be able to put that into a form that the software would recognize."

4.4.2 Privacy-Preserving Pacing Support. Participants liked the idea of MTRs monitoring them to support their pacing, but were mindful of privacy and utility tradeoffs. For example, P4 was open to sharing their data with the MTR if it would support them: "Doctors can't be with you 24/7, and there's a lot of [...] scary moments [...] if you're alone. So like if a robot was monitoring [my] heart issues [...] I think that anybody would give [the robot] all their information."

P6 agreed but wanted to be informed about how the data is used. They also emphasized the need for confidentiality: "And so I would expect whoever's operating this to have robust security [...] I would expect it to almost be HIPAA compliant. So that I could feel completely [in] the zone of safety in using the device."

In contrast, P3 was reluctant to give out personal health information. However, they would be willing to use indirect measures of their well-being through the robot: "if it could somehow [...] notice I'm driving more erratically, or [...] I'm slower to respond[,] that [...] would mostly come from observing the robot rather than me directly [...] I would be more comfortable with [that] than something like directly measuring my engagement or energy level or pulse rate, or any sort of thing that's directly to do with me."

4.4.3 The Importance of Trust and Sense of Control over the Robot's Actions. Though PwLC acknowledged that automation could reduce the physical, cognitive, and emotional demands of teleoperation, thereby supporting pacing, many participants emphasized the need to be in control of the robot's actions and decision-making. They preferred systems that enabled shared control. As P1 explained, "Like, I can see some automation. But I [...] would still prefer I'm the one directing when and how that happens."

Participants also expressed the need for time to understand the robot's capabilities and calibrate their trust, which influenced their willingness to use its autonomous features. P3: "deciding what the robot should do would depend heavily on what I trusted [it] to do with [...] its level of autonomy. So if [...] driving across the building to where the next meeting is a task that it can simply and easily do, [then] I would be happy to offload to it." Building on this, P8 highlighted the importance of being able to supervise the robot when confidence in its capabilities was low: P8: "What if I said, 'Okay, I want you to do this task.' [...] Three hours later, I come back, and it [somehow got] stuck in a closet, and you're like, 'how'd you do that?'"

4.4.4 Frustration from Automation Failures. Some participants said they would be frustrated if the robot's autonomous actions did not behave in a way they expected. P7: "Instead of sitting there and waiting, or then being like really frustrated, and then probably having to figure out how to do it again [...] [it's important the robot's control system could] prevent those things from happening, or anticipate the frustration [...] because even being frustrated is just so tiring."

4.5 Managing Stigma

All participants were concerned about people perceiving them as "an iPad on a stick" (P3) and about the potential stigma associated with both their condition and their use of MTRs to attend

events remotely. They reflected on the social norms and cultural expectations that would need to shift for MTRs to be widely accepted and adopted.

4.5.1 Appropriate Representation of PwLC. P7 highlighted the importance of how robot appearance might "further [their] stigma. [...] I think that...the more human you would try to make it, the more it would be laughable almost. I think people would definitely parody it [...] I think people who are chronically ill are tired of not being taken seriously." P7 went on to say, "And so I think if [the robot] were almost seen as an appliance, a tool that['s] kind of a technology like utility, it would be more accepted."

Participants also expressed the importance of the robot not making them feel additionally self-conscious as they are already attending an event remotely, and don't want to inconvenience anyone. P7 stated, "that is a big part of [agreeing] to use [the robot...] to be your remote presence in a social activity [...] you don't want to be like, 'Oh God, Robot John['s] come in again. He's gonna knock over the tray of donuts. That's gonna be real fun. I don't understand why he can't put on a hazmat suit, just come in person.'" P6 had a similar concern: "until people are more comfortable with them, I think you become the weirdo in a telepresence suit. [...] Or worse, you'd be the focus of the party just because they've never seen it." P7 went on to say that the robot should have a slim design to avoid drawing attention to itself: "I always feel like the slimmer the better because...You don't want it to be this big thing that's like knocking over hors d'oeuvres or scaring dogs."

P7 also emphasized the importance of visibility of PwLC: "I feel like people who are chronically ill need to be seen...That's one of the most important components, is that it's our face, that they understand that there is a person behind it. [...Otherwise] people weren't seeing us. So I think it's a very powerful piece that someone's face is there." P7 added that this visibility would give them a better sense of agency and empowerment: "And we do have control over those things, because there's so little we do have control of—with our own bodies and to a larger point with the way that we're perceived."

4.5.2 Social Norms for Telepresence Robots. Multiple participants believed that there is a need for appropriate social etiquette for MTR usage. In this context, P6 questioned "how do you do it so not to offend the people in the room?" For example, they imagined going to a concert via MTR and "having a whole bunch of robots like inching up to block everybody else's view would be hilarious." They further questioned the appropriateness of attending a funeral via the MTR: "That might be weird. But at the same time, if that means I could attend one [...] that could be really powerful cause then you get to still interact and commiserate."

P7 extended the idea of social etiquette to a need for cultural norms: "not everybody's gonna be enthusiastic about a robotic presence...I just foresee there being just like weird anti-robot sort of pushback on that...And then even more sort of negative push back on people who are chronically ill."

4.5.3 Infrastructure and Deployment. Participants were concerned about the MTR's safety in their physical absence and wanted robot wranglers. P8 was worried that somebody might "accidentally break it" or "steal it." In such instances, P1 suggested having "somebody in the area of it, that [...] could address those issues."

Other participants wondered about robot deployment logistics and if robot ownership would be privately or publicly available. P3 mentioned the need for physical accessibility accommodations like ramps and automatic doors for the robot due to mobility limitations.

5 Discussion

Participants expressed key concepts critical to the design, development, and deployment of MTRs for people with chronic illnesses and disabilities, such as LC.

First, all participants recognized the potential of MTRs to facilitate remote inclusion in various professional and social activities, though many agreed that teleoperation is currently too exhausting, and could potentially exacerbate their symptoms. To address this, participants suggested several features that could help them manage pacing, such as timers or automation. However, there were differing opinions on how automation should be used to reduce exertion. Some participants were open to the idea of automation assisting with conversations, social signaling, and navigating difficult social expectations. Others had concerns about privacy, sense of agency, and social acceptability of the robot's behaviors in social settings. Many also noted that it can be difficult to design MTRs that effectively support them with pacing due to the unpredictability of symptoms. As such, there is a need for further research to create adaptive systems that can meet the diverse and changing pacing needs of individuals with chronic illnesses such as LC.

We also noted that running across all ideas is an overarching theme from [14]: "designing out stigma." This refers to the importance of considering the social consequences of an **Assistive Technology (AT)** across the design lifecycle: its appearance, its capability, and how it affects the ways in which disabled users navigate stigma and ableism when using it. Our participants shared this concern for these consequences: the stigma they experienced in their lives affected how they anticipated the stigma they might experience using an MTR. This, in turn, affected their MTR design preferences. Thus, it is crucial for HRI researchers to build socially acceptable MTR systems that can minimize operator exertion, by providing pacing support, while also mitigating stigma.

Ultimately, while our participants have their own unique circumstances, there were common patterns across their pacing strategies and lived experiences. We generalized these findings into key design considerations for accessible MTR design for PwLC in (Table 1) and expand on each concept below.

5.1 Design Considerations for MTRs

Provide Control for Disability Visibility. PwLC should have control over how the robot represents them and the (in)visibility of their disability. They emphasized the need to be seen as the one controlling the MTR as a means of showcasing identity and agency.

The (in)visibility of chronic illnesses is linked to broader societal expectations of productivity. Society expects people with chronic illnesses to push through their illness even at the cost of their own health [59]. Despite nearly half of PwLC requiring reduced work hours compared to pre-illness, many still face resistance in getting workplace accommodations [75, 91]. The use of MTRs is one way for individuals to manage their participation in activities more flexibly, allowing them to pace themselves based on their fluctuating conditions. In doing so, MTRs can also make chronic illnesses like LC more visible, showing the overlooked, isolating, and incapacitating impacts of LC, thereby legitimizing the experiences of PwLC.

However, participants voiced concerns about how their condition was made visible through MTRs. These concerns can be categorized into two main areas: the visibility of the effects of their illness, and the robot's appearance or behaviors. Both of these factors can lead to negative perceptions of PwLC and can be a source of emotional stress.

First, the visibility offered by MTRs means that the effects of the condition are also visible. Some participants wanted the option to turn their cameras off when they need to rest, allowing them to observe remote activities from non-typical locations, like their bed when they are tired. This concern mirrors that of students who attended class remotely via a robot and were worried about having their illness (such as vomiting) visible to others on the camera [2, 114]. In response to such concerns, researchers have recommended providing operators the option to display a static image on the screen [2, 114], or an avatar [87], which was similarly desired by our participants.

Table 1. Design Considerations for Accessible MTRs to Support PwLC

Design Consideration	Description	Example
Provide Control for Disability Visibility	Provide operators control over how the robot represents them and the (in)visibility of their disability.	Operator is attending a social event via the MTR but suddenly experiences nausea and must leave. The operator selects a button for the MTR to display a message "User Done" to interactants and shuts down.
Social Etiquette	Support users in establishing "social etiquette" affordances on the robot so users can navigate interactions smoothly and appropriately.	Operator is navigating the MTR through a crowded place. To avoid being viewed as invading personal space, the operator turns on left or right signals to indicate their intended movement.
Consider Crip Time	Acknowledge that PwLC may experience time nonlinearly, requiring flexible and adaptive interactions to accommodate their fluctuating symptoms and pacing needs.	Operator is manually navigating their MTR to the next museum exhibit. However, the system determines that the user may need more support by observing erratic robot behavior. The system then provides an option for the user to switch to the autonomous navigation mode.
Prevent Cognitive Load	Provide varying levels of abstractions to simplify robot control and reduce cognitive overload.	Operator is remotely logged into meeting at work through the MTR and is manually panning the camera to focus on different speakers. Over time, the operator is overstimulated and activates the robot's feature to automatically pan to the person speaking.
Respect Personal Autonomy when Designing Robot Autonomy	MTRs need to have adjustable autonomy to reduce cognitive load while also supporting PwLC's agency and decision-making.	The MTR is autonomously navigating itself to the appropriate aisle in a grocery store to reduce operator effort. However, once it reaches, the operator takes over control to decide between different brands for a particular item.
Robots Need to be Robust	Design to anticipate and reduce frustration with automation.	Operator is remotely logged into a classroom as a teacher through the MTR and asks it to autonomously navigate to their office. While navigating, the robot becomes stuck and spins in circles. To reduce operator frustration with the unexpected action, the MTR stops, explains its behavior, and lets the operator decide the next steps.
Consider Infrastructure	Plan for logistics of widespread usage and robot deployment.	Buildings should have doors that are able to open automatically so that the operator does not have to manually press accessibility buttons via the MTR.

Some participants also wanted the option to leave a remote activity when they were tired without the need to explain themselves. Often, PwLC are pressured into staying in situations longer than they should, as many people do not understand the severity of their condition. MTRs can act as a mediator for such difficult conversations by automatically shutting down after a preset time, as determined by the operator. They can also act as a scapegoat and allow the operator to exit without drawing attention to their reason for leaving.

PwLC were also concerned about the MTRs drawing unwanted attention or inconveniencing other people due to its appearance or behaviors. These included knocking over items, and looking "weird" or "awkward." These sentiments are frequently reported in AT literature [17, 44, 62, 69]. Shinohara et al. [136] discussed the concept of "informant fatigue," where the focus of conversation is more on the technology people with disabilities use rather than about themselves as a person. This negatively influences perceptions of social inclusion and leads to technology abandonment [44, 62, 69].

One participant also strongly emphasized that, while it was important for them to be recognized as the person behind the robot, they did not want the robot to appear too human-like, as they were concerned that it might lead to mockery and amplify stigma. These concerns are supported by prior research, which shows that people often have mixed, and sometimes negative, feelings about anthropomorphic robots [33, 53, 122, 124]. Interacting via a robot already introduces new challenges for the operator (e.g., limitations in mobility or communication) that may inadvertently reinforce certain stereotypes about disability [121]. Given that these robots serve as remote proxies for disabled individuals, it is crucial to consider how design choices can influence the types of identities and characteristics projected onto the operator. Such projections, in turn, may lead to negative social consequences, such as being deprioritized in everyday situations like elevator usage [8].

Ultimately, in designing MTRs to support pacing, the design must also consider PwLC's varying preferences for disability (in)visibility. This relates to [14] which suggested designing technology to support both disability covering and disclosure as a way to mitigate stigma, which in turn supports continued technology use [62, 63].

Social Etiquette. It is important to support users in establishing "social etiquette" affordances on the robot so users can navigate interactions smoothly and appropriately. In doing so, it would allow for greater social acceptance of MTR usage.

Robot autonomy can assist operators during social interactions by tracking speakers or conversation partners [30, 31, 97, 120], directing an operator's attention to relevant areas [27], or filtering speech to ensure politeness [36]. While there may be potential benefits to including them in MTRs to reduce exertion and support pacing during social interactions, our participants had conflicting perspectives on their desire for automated behaviors. Many expressed concerns about how the robot's behaviors might impact how they are perceived by others. For instance, our participants were concerned about unpredictable reactions towards the MTR, such as robot abuse [22, 127].

Studies have found that people tend to treat the remote operator as a robot or an object, instead of a person [42, 81, 121]. They may also be perceived as less trustworthy compared to those who are physically present [141]. Additionally, operators of MTRs may experience "othering" [17] and even blame when MTRs violate social norms while behaving autonomously [144, 155]. Hence, it is important to carefully consider the social impacts of pacing-related automated behaviors in MTRs during social interactions to avoid perpetuating negative perceptions toward operators. One potential solution for fostering more positive interpersonal interactions is to employ empathy-eliciting interventions, as recommended by Asadi et al. [4].

HRI research has also explored the appropriateness of various human–robot interpersonal behaviors and proxemics [125, 133]. However, many studies yielded conflicting results due to

different ways of operationalizing "appropriateness" [99]. Due to this uncertainty, more work is needed to establish social etiquette norms for both periods of rest and active engagement during MTR-mediated interaction with PwLC. Additionally, drawing on the concepts of mutual aid and interdependence from critical disability studies, it is crucial to build a strong network of formal and informal allies across various social settings. These allies can help PwLC establish routines and ultimately encourage greater social acceptance of remote MTR users [45, 71, 101, 161].

Consider "Crip Time." As PwLC experience time non-linearly, MTR design must support flexible and adaptive interactions to accommodate the operator's fluctuating symptoms and pacing needs.

To consider "crip time," MTRs must be able to monitor a user's behaviors, understand what they mean in a given context, and dynamically provide the appropriate level of support based on the operator's real-time need for rest, or ability to more actively engage in teleoperation. This adaptation of MTR behaviors is based on the concept of pacing, and is essential for accommodating the fluctuating nature of LC during teleoperation and preventing the operator from overexerting themself. Given that the impacts of LC vary significantly from person to person, it also makes the system more accessible to more PwLC.

This approach connects closely with *ability-based design*, which emphasizes designing technology that can accommodate a wide range of abilities and needs [164]. This type of design leverages the user's current abilities rather than disabilities, shifting the responsibility of adapting to the technology instead of the user. Though limited, current research on the ability-based design of telepresence robots primarily focuses on supporting user customization of the teleoperation interface [116]. More work needs to be done to explore other ways the robot can adapt to users with unpredictable conditions. Longitudinal behavioral adaptation methods proposed by [79] may offer useful strategies and recommendations in this regard.

However, the constant monitoring required to do this raises concerns about privacy and the usage of PwLC's personal health information. Some participants were comfortable with MTRs monitoring them if confidentiality was guaranteed. Another only wanted indirect measures e.g., based on the MTR's performance) to track their well-being. This aligns with growing work on privacy-preserving robots, though more research is needed in this space [77, 86, 126].

Reduce Cognitive Load. To simplify robot control and reduce cognitive overload of PwLC, MTRs can be designed with varying levels of abstraction. PwLC become exhausted by both physical and cognitive exertion. While MTR usage reduces PwLC's physical exertion, it can still be cognitively taxing. Participants suggested preset robot behaviors to help operators reduce cognitive exertion, such as autonomous navigation or automatic camera panning to direct the operator's attention, which is supported by prior work [105, 117].

Another way of reducing cognitive load is to improve the usability of teleoperation interfaces, as that is often a major bottleneck to operator performance [117]. Prior work has explored improving sensor data visualizations for better operator situational awareness [60, 118, 142] as well as multimodal feedback and input [100, 107, 151]. However, further research needs to be done to understand how these different interface features should be designed with PwLC's various neurocognitive symptoms in mind (e.g., brain fog) [24].

Respect Personal Autonomy when Designing Robot Autonomy. MTRs should provide adjustable autonomy to reduce cognitive load while supporting PwLC's agency and decision-making. This concept of "sliding autonomy" allows operators to determine the robot's level of autonomy based on factors including their level of trust in the robot's capabilities, task complexity, and interface usability [12].

There should be careful consideration of automation design as it may reflect algorithmic paternalism [48, 92]. This is the concept that the automated system is all-knowing and knows what is best for the user. In this context, a fully automated MTR would remove all sense of agency and control

from PwLC, in contrast to our participants' desire. Some of this desire comes from a lack of trust in the robot, which can be improved with time as they better understand the robot's capabilities. Implementing shared control in MTRs thus gives PwLC agency over complex decision-making and the trust calibration process in different tasks and situations.

Robots Need to Be Robust. When designing automated behaviors for MTRs, we must anticipate and reduce frustration PwLC may face when the robot fails, since even frustration can be exhausting. Failures are common and unavoidable in HRI, especially due to the unreliability of robot autonomy [137, 162]. When the robot does not behave in the way operators intend, it can leave them frustrated and angry [137]. Our participants also mentioned that they would find it tiring to redo the task should the robot fail. Additionally, manually redoing the task might be even more challenging as the user may have forgotten what the robot was trying to do. As even frustration can be exhausting for PwLC, it is essential to design MTR systems with proper error handling and failure recovery systems without requiring substantial operator effort. This would help reduce the likelihood of MTR abandonment due to frustration-induced exhaustion.

Consider Infrastructure. When building accessible technologies such as MTRs, it is important to plan for the logistics involved in widespread usage and deployment by disabled people [5]. We are mindful that we are in some ways building an AT that has the potential to be overly technopositivist and technoableist. However, as existing infrastructure often reflects ableist assumptions and fails to accommodate disabled people's access needs [5], alternative approaches to supporting access and inclusion remain essential.

We hope that technologies such as MTRs can serve as a promising solution to facilitate remote social inclusion for PwLC and those with other chronic illnesses. Yet, we also recognize that MTRs will require physical access accommodations and robot wranglers to support their use by these communities. Furthermore, MTR integration into society will take substantial time. Given these challenges and the importance of inclusivity, a more proactive approach to accessibility is essential. Rather than expect PwLC to individually navigate through the physical, fiscal, and social barriers that can limit access, we as researchers and robot designers should advocate for the creation of accessible spaces. Thomassen [149] raises helpful policy and ethical considerations in this regard, such as the risks of perpetuating inequalities by differentially regulating access to public spaces through technologies. These insights can be beneficial to the field moving forward.

5.2 Limitations and Future Work

Our work has a few limitations. Despite the broad range of LC severity and manifestations, our participants only represent a subset of PwLC experiences due to self-selection bias. We recruited individuals from social media who were both able and willing to engage in a research study conducted within a specific country and timezone. This may have excluded the participation of those with more severe, fluctuating symptoms or those from other socio-economic and cultural backgrounds. In future work, we aim to address this by diversifying our recruitment strategies and providing more flexible remote participation options to include PwLC with a wider range of experiences and identities.

We plan to use these design considerations to further develop MTR systems that better support the remote inclusion of PwLC, and plan to run feasibility studies at several key locations (e.g., museums or schools) to explore their usage with our PwLC partners. Given the unique presentation and individual impacts of each condition, it would also be interesting to explore how findings from this study might translate to other chronic conditions. Further research involving diverse chronically ill populations is necessary to discern the nuanced requirements for MTR design.

5.3 Conclusion

In this article, we engaged in participatory research with PwLC to understand how MTRs should be designed to facilitate social inclusion, support pacing, and mitigate stigma associated with MTR usage. Drawing from these insights, we offer design considerations rooted in critical disability studies and critical access studies. We also emphasize the complex sociocultural factors that shape MTR-mediated interactions for chronically ill populations. Our contributions lay the foundation for developing accessible MTR systems that both support social inclusion and accommodate the pacing needs of a community that has been largely isolated.

Ultimately, as HRI researchers, we have a responsibility to advocate for more inclusive technology designs that resist technoableism by centering the lived experiences of people with chronic illnesses. Hofmann et al. [61] identified opportunities to combine perspectives from disability studies and accessibility research, which are excellent paths forward for researchers. Adopting these perspectives will deepen our understanding of how robot design can both contribute to and counteract the stigmatization of these communities.

Additionally, models like Lancet Commissions provide a great approach for how transdisciplinary researchers can work together to institute significant changes at the policy level [150]. This includes co-designing technologies with people with the condition and involving them in all aspects of development.

We encourage the HRI community to build on this work to critically examine the importance of pacing as a vital access need when designing telepresence robots for people with chronic illnesses. In doing so, we can move towards creating more inclusive and accessible technologies for these historically overlooked and marginalized communities.

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Appendix

A Questions from Semi-Structured Interview

A.1 Understanding Participants' Self-Management Strategies and When They Use Them

(1) Are you familiar with activity pacing, or energy management? If so, do you use it?
   (a) If yes, what strategies do you currently use and how do you use them to support activity pacing/energy management?

(b) If not, what strategies do you use to help you deal with the activities of everyday life?
(2) In your daily life, do your energy levels fluctuate throughout the day?
(a) If so, do you change your activities or strategies to accommodate these fluctuations?
(b) Are there times when you prioritize certain activities regardless of energy levels?
(3) What are some activities involving other people where you need to use your strategies? What are some activities where you don't need to use them?
(a) This could be for work, school, or leisure.

A.2 Co-Ideation Activity

(1) When would you imagine wanting or needing to use a telepresence robot to remotely attend activities?
(2) What are some expectations you have about how a telepresence robot should support you when you use it to remotely attend activities?
(3) Is there any feature it should or should not have?
(4) When you were controlling the robot, is there anything the robot could have done or information it could have provided to help you at different times of the day or when you are tired?
(a) This could be about the robot, the environment, yourself, or about the current task you are doing.
(5) Imagine you have started the day with good energy, but you know you have a stressful work meeting ahead of you. You know that you will be drained afterwards. Use this prompt to answer the following question , "I want/need to do ___ but I think I will become very tired"
(a) **Q1:** How can the robot support you before, during, and after the meeting?
(b) Possible prompts if stuck: monitor your energy, give you an alert about time/energy levels, etc.
(6) Imagine any activity that might require you to take a lot of breaks: Use this prompt to answer the following questions: "My energy levels are changing drastically while in the middle of ___"
(a) **Q1:** If you need to take a break from/stop controlling the robot for a while to rest, what should the robot do? Pretend that the robot is able to do things on its own for you.
(b) **Q2:** If you want the robot to do things for you, how would you decide what the robot should do, and for how long?
(c) Possible prompts if stuck: give an alert (to friends), monitor your energy, continue doing whatever task you were doing, etc.
(7) Finally, do you have any other ideas about the robot and how you would interact with it?

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