"I use video calling in all areas of my life": Understanding the Video Calling Experiences of Chronically Ill People

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Abstract

Since the Covid-19 pandemic, video calling (VC) has become a staple means of daily communication. Beyond socializing, VC in the United States (U.S.) now supports remote work, healthcare and education. The sudden ubiquity of VC could have presented both advantages and challenges for chronically ill people. However, our understanding of chronically ill people's experiences with VC remains limited. To address this gap, we conducted the largest online survey study (N=55) on chronically ill people's VC experiences in the U.S.—investigating their routines, facilitators and barriers. Our quantitative and qualitative findings established that chronically ill people heavily depend on VC to cope with everyday life. At the same time, VC can also detrimentally exacerbate cognitive (e.g., brain fog), emotional (e.g., self-consciousness) and physical challenges (e.g., migraines) for chronically ill people. In response, we offer actionable design opportunities to improve the accessibility and experience of VC for chronically ill people.

CCS Concepts

• **Human-centered computing → Accessibility technologies**.

Keywords

Chronic illness; accessibility; survey; videoconferencing.

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1 Introduction

Each year, hundreds of millions of people worldwide are diagnosed with a chronic illness and over 25% of US adults live with multiple chronic conditions [16, 66, 107]. Chronic illnesses encompass a range of conditions that impact daily functioning and are not expected to be cured or immediately fatal [66]. Since the COVID-19-induced shift to remote work and services, video calling (VC) has become an essential tool for remote communication and collaboration in all areas of life [75]. Recent findings from the Pew Research Center [67] indicate that over 80% of adults in the United States (US) use VC regularly, and more than 20% make at least one video call per day. This rapid adoption of VC has presented both advantages and challenges for chronically ill people. Advantages of VC for chronically ill communities include remote work (telework), healthcare (telehealth), education (telelearning), a tailored home environment for symptom management, flexible scheduling, and immune system protection by reducing exposure to public spaces (e.g., commuting and offices) [65, 66, 72, 98]. Additionally, popular VC platforms (i.e., Microsoft Teams and Zoom) offer several accessibility features including: Bluetooth integration's for assistive technologies (ATs), interface adjustments, call recordings, artificial intelligence (AI) generated captions, transcriptions, and summaries [97, 98, 111].

Although VC offers flexibility in work schedules and settings, previous studies have noted a lower uptake (N=19%) of telework among communities with disabilities [59]. Prior research has also identified various accessibility challenges with VC, including AT-integration, screen sharing and collaborative editing [24, 98]. Small-scale autoethnographic studies have established amplified barriers for chronically ill people, such as fatigue, nausea, migraines and cognitive load experienced before, during and after VC [66, 98, 110]. The symptoms experienced by chronically ill people are often variable

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and hidden making them difficult to communicate to collaborators during VC [32, 63, 106]. Notably, Wu [105] alarmingly found for communities that stutter, prolonged hidden challenges with VC can compound into harmful emotions of fear, guilt, shame, social anxiety and self-stigma. Extensive research shows that chronically ill people face disproportionate barriers to employment [6, 32, 86, 102] and are more dependent on job-based health insurance leading to "job lock" [52, 95].

In this paper, we build upon these anecdotal findings [63, 66] to provide the first in-depth investigation into chronically ill people's experiences of VC, culminating in actionable design recommendations. Currently, little is formally known and widely established regarding VC experiences for chronically ill people – their routines, facilitators, barriers and envisaged improvements for this technology. Increasingly VC is becoming fundamental to professional, social, educational, and healthcare communications [105, 106], thus it is essential for this technology to accommodate and empower the diverse needs of chronically ill people. Indeed, more accessible VC enhances the ability of chronically ill people to: manage/protect their variable daily health needs [66], participate in the workforce [63, 70], access healthcare [34], and for remote education [66]. Beyond access to public services, improved VC-mediated communication enhances chronically ill people's social connection [61] and quality of life [69]. In addition to investigating experiences, we build on our findings by reporting envisaged VC improvements from chronically ill people and generate person-centered design directions. Respectively, our research questions were as follows:

RQ1: What are the routines and facilitators of VC for chronically ill people?
RQ2: What barriers do chronically ill people experience during VC and what improvements do they envisage?

To address these questions, we conducted an online survey, collecting data from 55 respondents who self-reported 128 chronic illnesses and health conditions. This study contributes to HCI and accessibility research by providing novel insights into the videoconferencing experiences of chronically ill people and reporting their envisaged improvements. A significant finding is that chronically ill respondents depend on VC far more than the general population, with many recognizing it as a vital tool for coping with everyday challenges. Despite its evident utility, respondents also reported hidden cognitive, emotional, and physical barriers during VC that were unpredictable in onset, intensity, and duration. The lack of non-verbal cues during VC exacerbates these barriers, reducing empathy, complicating social norm establishment and limiting opportunities for meeting breaks. In summary, we present three key contributions:

1. We conducted a survey with 55 chronically ill respondents, capturing their diverse experiences with VC – making this the first dedicated and largest study on VC usage concerning this community to date.
2. We employed quantitative and qualitative analysis of survey responses to shed novel insights on chronically ill people's experiences with existing VC technologies – this data can help refine research directions and identify opportunities for future exploration. We emphasise respondents dependence on VC to navigate everyday life and reveal the hidden physical and emotional barriers that can disrupt VC usage for unpredictable periods.
3. Building on these findings, we report envisaged VC improvements from chronically ill people and generate person-centered design directions for more equitable and empowering VC experiences.

2 Background

2.1 Chronic Illness and Video Calls

An estimated 129 million people in the US live with at least one major chronic illness [8] and a growing population of people are living with long Covid[1] [2, 85]. In this paper, we define a chronically ill person[2] as one with a condition that: impacts functioning, is not expected to go away or be fatal, may be supported through treatment and when left untreated, can be life-limiting [66]. The challenges endured from living with a chronic illness are both extensive and multi-faceted [72, 73]. Initially, many people living with chronic illnesses are denied the equivalent status granted from living with a disability; in many formal institutions chronic illness is *not* recognised as a disability [30, 73]. Many chronic illnesses are invisible and conditions cannot be readily determined from appearance – leading to misunderstandings, the added stressors of workplace disclosure and minimisation of personal difficulties [32, 73]. In terms of lifestyle, many chronic illnesses are multi-causal, complex and unpredictable – manifesting differently each day [66, 72]. Additionally, chronically ill people are more susceptible to multiple health conditions and everyday illness [43, 73]. As noted by Su et al. [96], living with chronic illnesses can be immensely challenging, involving regular high-stakes decision-making, navigating complex healthcare/insurance systems, adjusting daily routines, managing new diagnoses/disease progression, treatment changes, symptom control, and the emotional toll that follows. Consequently, fundamental livelihood aspirations (e.g., maintaining a 9-5 job and healthcare benefits) whilst withstanding the demands of chronic illness often requires extensive sustained accommodations and flexible support [73, 96]. Discriminatory underemployment of people with chronic illnesses and disabilities remains an unresolved societal concern [4, 33, 98] – especially given many chronically ill people's reliance on job-related health insurance, which perpetuates 'job lock' [52, 95].

Despite growing prevalence, Mack et al. [66] has noted that human computer interaction (HCI) research into chronic illness is comparatively underdeveloped. A small but growing body of research has identified chronically ill people as having access needs [66], explored their self-care [57, 58], relations to technologies [46, 60, 80, 92] and healthcare systems [13, 78, 88, 101]. Researchers have also explored chronically ill people's experiences in: families [12, 96], the workplace [32], public spaces [48] and on dating apps [82]. Recent scholarship has even made frameworks to avoid medicalised interpretations and better center on the variable nature of chronically ill people's experiences [66]. Autoethnographic research highlights

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[1] An emerging and debilitating chronic health condition with many symptoms i.e., fatigue, memory problems, breathing and sleep disorders etc. [2, 85].

[2] We also echo Mack et al. [66] and recognise that a chronically ill person may identify as chronically ill or diverge from mainstream conceptualisations from disability.

the challenges of managing unexpected, non-visible chronic illness symptoms during VC, such as motion sickness, fatigue, pain, nausea, and brain fog [63]. These symptoms can worsen during calls until the chronically ill person speaks up or a collaborator intervenes [63]. As a result, chronically ill individuals face the added social burden of communicating their fluctuating symptoms, needs and energy levels (i.e., "spoons") to collaborators before, during, and after VC [32, 66, 72]. Despite these findings, autoethnographic studies highlight the benefits of VC and remote collaboration for chronically ill individuals [66]. VC's flexibility allows chronically ill people to work more comfortably, manage unexpected symptoms, flare-ups and even turn off their camera feed during meetings [66]. However, outside of these auto-ethnographic studies, research on the diverse VC experiences of adults with chronic illnesses is still limited.

2.2 The Growing Importance But Inaccessibility of Video Calls

Research increasingly highlights that the rise of VC for remote work, telehealth, education, and personal use has brought both benefits and challenges for communities with disabilities [98]. The widespread adoption of VC allows for greater work, education, health and social flexibility [63, 66, 98], supporting people with disabilities to telework from more comfortable environments (e.g., home) [98, 110] and enabling asynchronous forms of collaborative engagement at their own pace [24, 25]. Many VC platforms have built-in features that improve accessibility, including: captions, recordings, transcriptions, integration for assistive technologies, and AI-generated summaries [97, 111]. The popularity of telework since the COVID-19 pandemic has made recent return-to-work policies both controversial and unpopular [35, 45, 50]. Currently, VC forms the backbone of many modern telehealth services, allowing communities with disabilities remote access [9, 55] of services, including solo [11] or group therapy [74] and doctors appointments [54, 62]. Subsequent studies [9, 14, 87] have found telehealth services to enrich communication and improve chronically ill patient outcomes. Finally, VC can help foster long-distance social connections – enabling more interactive video-based engagement with loved ones, family and friends [5, 31].

Research has also addressed the inaccessibility of VC for many communities [56, 98]. Initially, Tang [98] investigated the experiences of disabled teleworkers and identified a range of VC challenges including: fatigue from high daily call volumes, substantial cognitive effort, complexities controlling personalised VC arrangements/screen sharing [98]. Furthermore, Zolyomi et al. [110] noted that autistic adults can experience a multitude of unexpected non-visible stressors during VC such as: migraine-inducing sensory sensitivities, cognitive load from masking, trouble with concentration, and anxiety. In response, popular VC coping strategies included extensive preparation and turning the camera off [110]. For people who stutter, research has identified mixed satisfaction as VC can perpetuate: mental fatigue, stress from self-view, challenges with turn-taking, feelings of inadequacy and isolation [105, 106]. Furthermore, Neate et al. [74] identified challenges related to the lack of non-verbal communication cues amongst communities living with aphasia during the Covid-19 pandemic. Our research extends these findings by examining the broader impacts of VC on populations with a range of chronic illnesses.

3 Methodology

To address our research questions, we conducted a survey to gain deeper insights into how individuals with chronic illnesses prepare for, navigate, and overcome challenges with VC. Our survey design was informed by previous research and reflections on the VC experiences of chronically ill people [65, 66, 98], as well as nascent accessibility research highlighting the inaccessibility of VC [24, 25, 74, 105, 106, 110]. Consequently, our survey aimed to extend, confirm and expand upon these established previous findings. Ethical approval was granted by the Research Ethics Committee of Microsoft Research's Institutional Review Board. All survey design decisions adhered to Microsoft Research's best practices and guidelines.

3.1 Survey Instrument

The survey was implemented and hosted on Microsoft Forms. We implemented several strategies to enhance accessibility these included following guidelines for accessible surveys [29, 104] and applying recommended user research methods for engaging chronically ill people [65]. To reduce completion time to approximately 30 minutes, most questions were multiple choice, minimizing cognitive load and fatigue from text entry. Throughout the survey, open response answer fields were strictly optional, which encouraged respondents to provide examples or further elaborate if desired. The survey began with an overview of the research purpose, outlined specific eligibility criteria, and obtained respondents' informed consent. At the beginning of each section, respondents were encouraged to take breaks as needed and informed about the number of upcoming questions. The initial survey draft was created by the first author and refined collaboratively with the co-authors. Plus, the survey was piloted with colleagues to ensure clarity and gather feedback on its scope.

Our survey comprised 47 questions—32 multiple-choice and 15 open responses. We organised the survey into four sections, each containing 5–22 related questions on the following topics: (1) personal demographics, (2) routine usage of VC, (3) how VC facilitates engagement, and (4) barriers to using current VC technology. Firstly, for personal demographics, we collected respondents self-reported chronic illness(es), employment status, work setting, age, gender identity, race, and ethnicity. Furthermore, we also asked whether their chronic illness was publicly visible during VC, their usage of ATs, and level of computer expertise. Secondly, we inquired about routine VC usage – to establish chronically ill people's purposes for engaging with VC technology. Specifically, we explored respondents typical use of VC including: frequency, years of use, applications, personal devices used, reasons for usage (i.e., work, connecting with family/friends, doctors appointments, or therapy/support groups) and overall ease of usage. Thirdly, we inquired about how VC facilitates engagement – to better understand how this technology supports chronically ill people's connection with others. In particular, we asked respondents about their access to social, health, and work engagements via VC, preferences for in-person engagements versus VC, and reasons why they may prefer VC. Fourthly and finally, we investigated barriers faced with VC – to determine the range and persistence of challenges experienced by chronically ill people. Initially, we explored respondents frequency and duration of VC interruptions due to unexpected health needs, how often their camera is on, the impact of VC on their self-presentation, the times of day when VC is more challenging, negative emotions from VC, and VC features they liked/disliked. We also asked respondents about any bodily/physical/communication challenges experienced during VC, reliance on a caregiver/close communication partner to support their voice during VC, and the timing of these challenges (i.e., before, during, or after VC). Following the recommendations of Mack et al. [66], we endeavoured to directly gather insights from this marginalized population on what solutions they believe could improve VC. Thus, we asked respondents to describe their *"dream feature"* for VC platforms and offer an explanation. The complete set of survey questions can be found in the supplementary materials.

3.2 Recruitment

The survey was distributed using anonymous links and shared through five mailing lists of US-based charities and organisations. These included: the Microsoft Disability Employee Resource Group (ERG)[3], the Seattle Center for Chronic illness[4], the American Parkinson Disease Association (APDA) Northwest Chapter[5] and the Stanford Medicine Alliance for Disability Inclusion and Equity (SMADIE)[6] and Stanford Medicine Department of Radiology (SMDR)[7]. The survey and flyer was also promoted through these organisations' private social media pages (e.g., private Facebook groups) and online resources (e.g., monthly blogs and newsletters). Recruitment materials emphasised that participation was strictly for adults living with chronic illnesses. Before distribution, we sought to ensure compliance with community norms by obtaining approval from organization leaders and moderators, including holding meetings with partners to secure their support. Distributing the survey through private online mailing lists and the resources of various organisations allowed us to engage with a wide range of people living with chronic illness whilst protecting the survey from bots/spam. Respondents were already active in online communities, making them likely comfortable with technology and experienced with VC. We did not offer payments or prizes to respondents. Instead, we highlighted our interest in their VC experiences and offered to share our findings with participating communities.

3.3 Respondent Overview

3.3.1 *Demographics.*

We received 55 valid survey responses to all questions. Each response underwent manual inspection to ensure accuracy and validity. No spam responses were detected. The survey was active for over one month from July 21st 2024 until September 1st 2024. The median completion time was 17 minutes and 56 seconds (avg.=77 minutes 14 seconds, min=4 minutes 13 seconds, max=1302 minutes 30 seconds). The 14 outlier responses (i.e., $\leq$10 minutes and $\geq$120 minutes) were manually reviewed and validated for inclusion by multiple authors. We believe these outlier timings reflect respondents either returning to complete the survey or artifacts of the Microsoft Forms timing mechanism. Table 1 presents a summary of survey respondents demographic information. All respondents identified as people living with chronic illness—33 (60%) of whom identified as women, 17 (30.9%) as men, 3 (5.5%) non-binary/gender-diverse and 2 preferred not to answer. The most common age group was 25–34 years (32.7%), followed closely by 35–44 years (25.5%). The majority of respondents were employed full-time (80%) and a smaller subset unemployed (16.4%). Predominantly, respondents worked remotely (60%) or in a hybrid setting (34.6%), with only a few working in-office (5.5%).

3.3.2 *Chronic Illnesses and Assistive Technology Usage.*

A full list of respondents and their conditions is reported in Table 3. From our 55 respondents, a total of 128 chronic illnesses and conditions were disclosed. Specifically, respondents lived with 67 unique chronic illnesses and conditions. We had a high level of representation from respondents living with multiple illnesses and conditions—averaging 2.51 conditions per respondent (σ=1.82). Our survey respondents were very heterogeneous, which is common amongst populations living with chronic illness [41, 84]. Almost half of respondents (49.1%) used assistive technologies. The average duration of living with a chronic illness was approximately 16.16 years (i.e., median of 15 years, σ=10.92, min=1 year, max=45 years).

Descriptively categorising into classes of descending quantity, 15 respondents reported living with autoimmune diseases (27.3% e.g., Lyme disease) and 15 respondents reported living with mental health disorders (27.3% e.g., Bipolar). Additionally, 14 respondents reported living with neurological conditions (25.5% e.g., Parkinson's disease) and a slightly smaller group of 13 respondents reported living with musculoskeletal conditions (23.6% e.g., Disk herniation). Furthermore, 11 respondents reported living with neurodiversity (20% e.g., ADHD). In contrast a smaller group of 5 respondents reported living with cancers (9.1% e.g., Hodgkins Lymphoma) and an equivalent 5 respondents reported being Blind and Low Vision (BLV) or Deaf and/or Hard of Hearing (DHH) (9.1%). Additionally, Table 2 summarises survey respondents most frequently reported illnesses and conditions (i.e., counts$\geq$3).

3.4 Data Analysis

Initially, we quantitatively analysed the 55 responses from survey respondents (i.e., Table 3). For responses to the 32 multiple choice questions we performed descriptive statistical analysis of responses and developed custom visualisations to present our findings. We began organizing survey respondents text-box entries using Taguette[8], exporting data to MS Excel for analysis. We then applied inductive Thematic Analysis – an iterative process of restructuring data into themes [17–19, 44]. The first author conducted multiple readings of the 401 responses from 648 text-box entries, which varied in length from a brief sentence to over 300 words. Following established guidelines [17–19, 44], the first author then solely carried out open coding, grouping insightful quotes into provisional semantic codes. The first author and second authors collaboratively refined these codes through independent iterative re-processing until stability and agreement was achieved. The first and second authors then

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[3] https://www.microsoft.com/en-us/diversity/inside-microsoft/default

[4] https://www.thecenterforchronicillness.org/

[5] https://www.apdaparkinson.org/community/northwest/

[6] https://med.stanford.edu/smadie.html

[7] https://med.stanford.edu/radiology.html

[8] https://www.taguette.org/

Table 1: Overview of respondents demographics: age, gender, race, employment and work location (N=55).

		N	%(1 d.p.)
Age	18–24	1	1.8%
	25–34	18	32.7%
	35–44	14	25.5%
	45–54	10	18.2%
	55–64	6	10.9%
	65–74	4	7.3%
	75 years or older	2	3.6%
Gender	Men	17	30.9%
	Women	33	60%
	Non-binary or gender diverse	3	5.5%
	Prefer not to answer	1	1.8%
	Other	1	1.8%
Race	American Indian or Alaskan Native	3	5.5%
	Asian	6	10.9%
	Black or African American	4	7.3%
	Hispanic or Latino	4	7.3%
	Native Hawaiian or Other Pacific Islander	1	1.8%
	White	44	80%
Employment	Employed full-time	44	80%
	Employment part-time	2	3.6%
	Unemployed	9	16.4%
Work location	In-office	3	5.5%
	Hybrid	19	34.6%
	Remote	33	60%

Table 2: Descending count of survey respondents (N=55) most frequently listed illnesses and conditions (i.e., frequency of N≥3).

Health Condition	N	%(1 d.p.)
Chronic migraines	10	18.2%
Diabetes	7	12.7%
ADHD	7	12.7%
Parkinson's disease	5	9.1%
Anxiety	5	9.1%
Depression	5	9.1%
Ehlers-Danlos Syndrome	4	7.3%
PTSD	4	7.3%
Chronic fatigue	4	7.3%
IBS	3	5.5%
BLV	3	5.5%
Asthma	3	5.5%

collaboratively clustered the codes, thematically mapping them into candidate sub-themes and themes. They met regularly to discuss, iterate, and refine the sub-themes and themes, including their definitions and naming, until consensus was reached. Next, these sub-themes and themes were reviewed by all paper authors against the original data to discuss, reword and refine. Once consensus across the team was reached, this process concluded. The analysis resulted in two themes and five sub-themes, derived from 327 statements and discussions relevant to the study.

3.5 Positionality Statement

The actions of collecting, analyzing and writing this research were informed by our own experiences and identities as researchers. The survey was written in English using Western disability terminology, conceptions of disability rights and culture. Most of our team's research has been conducted in UK and US contexts, and collectively, we have visible and invisible disabilities. Our motivation for this research stems from personal experiences and autoethnographic accounts of VC with a chronic illness [63, 66]. Our aspiration is to broaden the understanding of VC and provide meaningful insights for its improvement – focusing specifically on how people with

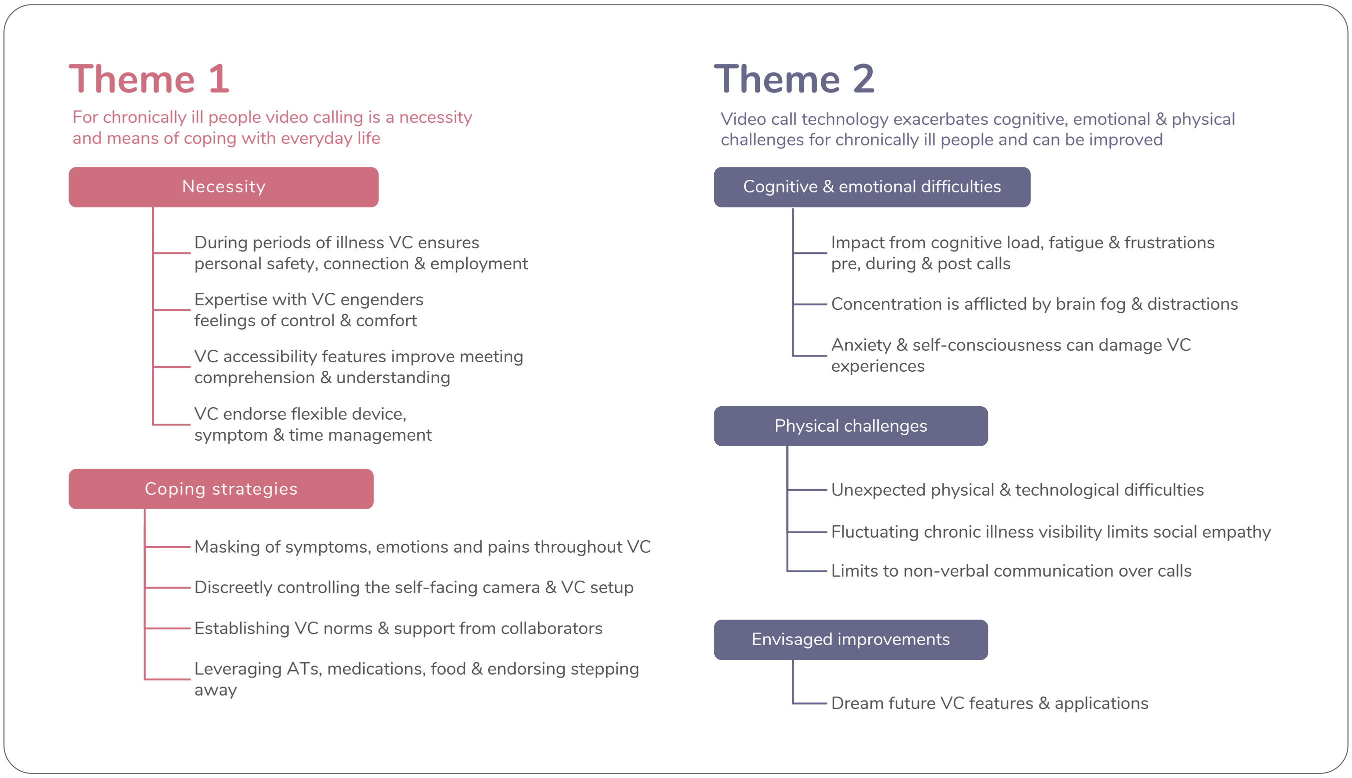

Figure 1: Outputs from thematic analysis compromising 2 themes and 5 sub-themes.

chronic illness use and feel about VC in their lives. Collectively, we have extensive experience in accessibility, disability studies and videoconferencing research across many different communities. Our team included a mix of ethnicities and genders, including White, Black, and Asian members, though we lacked representation from older adults. Our educational backgrounds span computer science, speech and language pathology, psychology, design and HCI. The team consists of both early-career and senior researchers, working in academia and industry. Some of our authors work within a large US multinational organization, where they are driven to promote accessible future videoconferencing innovation and shape corporate policy.

4 Findings

4.1 Theme 1: Video Calling is a Necessity and Means of Coping with Everyday Life

This theme describes the necessity of VC for chronically ill people as a means of coping with everyday life. Two crafted sub-themes consider: (1) the necessity of VC for chronically ill people and (2) coping strategies proactively employed during VC by chronically ill people.

4.1.1 For Chronically Ill People VC is a Necessity. **During periods of illness VC ensures personal safety, connection & employment.** Respondents reported a high-level of strong agreement with the statement, *"Video calling improves my access to social, health and work engagements"* with an average score of 4.53 (σ=0.79) on a five-point Likert scale, where 5 indicates 'Strong agreement'. Depicted in Figure 2, VC is an essential daily technology for many chronically ill people's livelihoods. P50 emphasized the integral and multifaceted role of VC in their life, spanning their work, healthcare, and connection with loved ones.

> *"I use video calling in all areas of my life, work, connecting with family, accessing healthcare, that would be extremely more difficult without video calling." [P50]*

Respondents used VC for a wide range of purposes but most frequently for Work (85.5%) and maintaining a livelihood whilst safeguarding their health. Indeed, P52 acknowledged their heightened vulnerability due to multiple conditions and found comfort in VC's protection against the debilitating complications of further sickness.

> *"Because of my chronic illnesses, I am immunocompromised. I prefer the option for virtual gatherings to keep myself safe!" [P52, Adenomyosis, EDS & Endometriosis]*
> *"Due to medications for my illness, I am immunocompromised and would not be able to work at all since Covid started if it weren't for video calling!" [P6, Ulcerative colitis]*

For P6, the post-pandemic availability of VC has provided relief, juxtaposed with undertones of anxiety at their precarious workforce position without it. Indeed, for a large proportion of respondents VC is their *sole* means of employment, *"I couldn't easily work in*

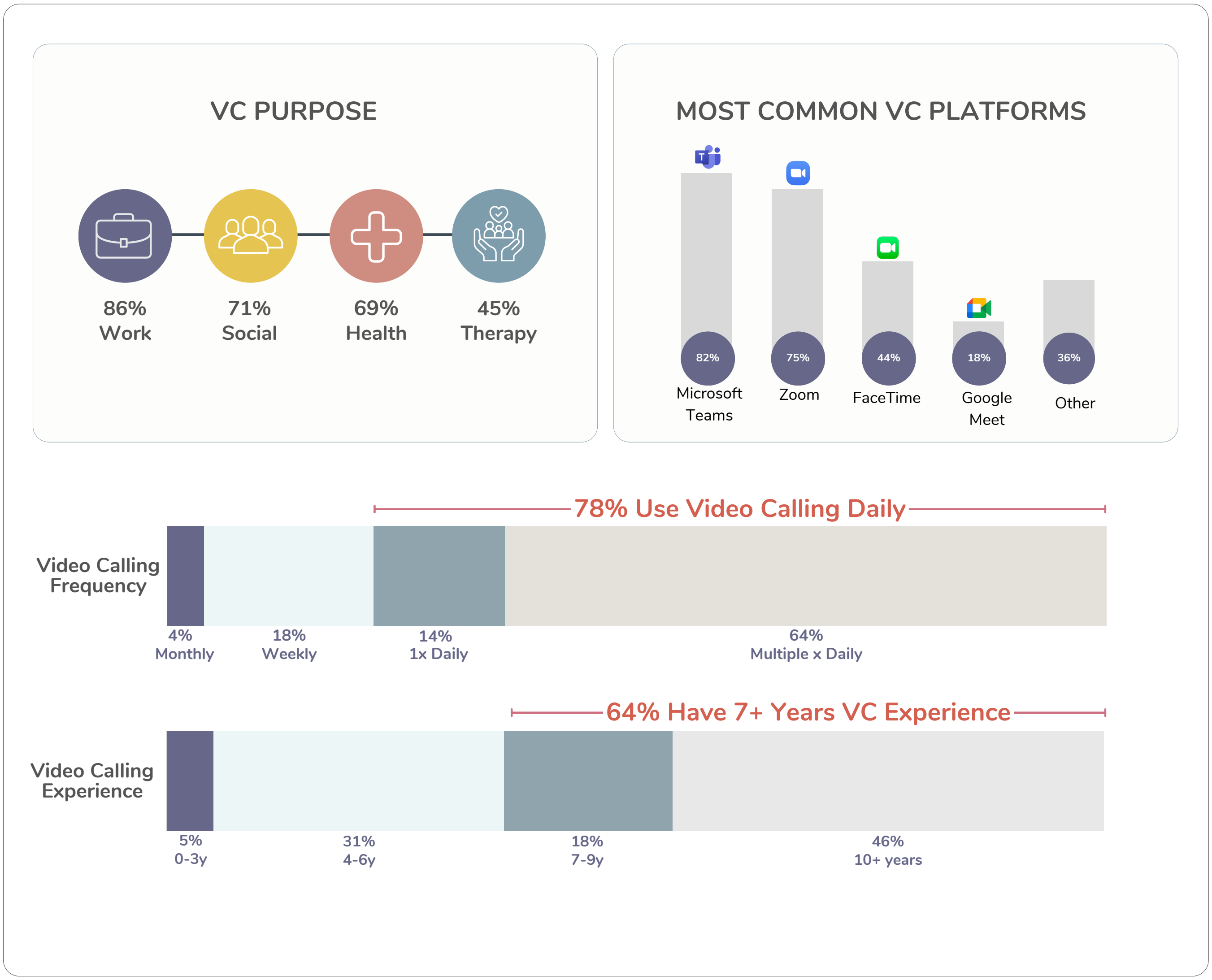

Figure 2: Infographic of chronically ill respondents' VC routines and practices.

office. Without the ability to use video calls, there's a good chance I would be unemployed." [P40] and *"I no longer work in person and do not know if I would be able to consistently anymore due to my health issues" [P53].* Beyond the workplace, respondents used VC for Social (70.9%, e.g., with friends/family), Health (69.1%, e,g., doctors appointments), and Therapy or support groups (45.4%). Both P16 and P24 recognized that VC enables them to maintain ongoing connections and nurture a sense of community, helping them avoid the prospect of complete isolation.

> *"Video calls have been a much easier way to stay connected with my care team and my family and friends." [P16]*
> *"Video calls are a strong enabler of staying in contact with customers and peers. I am able to maintain a sense of community even though most people I will ever meet [exclusively] on a video call." [P24]*

Both P16 and P24 use VC constantly to stay in contact and connect with peers and loved ones. However, P24's account is acutely aware that VC is their only means of reaching others, limiting their rituals of belonging and connection to the constraints of VC interactions and experiences.

Expertise with VC engenders feelings of comfort and control. Presented in Figure 2, nearly half of our respondents had over 10+ years of VC experience (45.5%) and *just* under a third had been VC for 4–6 years (30.9%). Matching experience, chronically ill respondents are prodigious users of VC, with almost two-thirds video calling multiple times per day (63.6%). Respondents like P15 recognized their proficiency with VC, which instilled a sense of ease and confidence in both themselves and the technology.

> *"Usually it's pretty idiot-proof!" [P15]*
> *"There are limits to conversation while videoconferencing but it is a mode I am very comfortable using" [P3]*

For respondents like P3, who live with fluctuating daily abilities due to their illnesses [66], expertise with VC fosters a stabilizing sense of personal agency and control. However, P3 also acknowledges the stark limitations of VC conversations compared to in-person interactions. Despite these constraints, VC continues to empower many chronically ill respondents including P18 to push beyond their personal comfort zones, even enabling them to present to larger audiences

> *"VC can be easy; it truly depends on the audience and how comfortable I am with them... I do 1:1 video calls, large audience calls, and customer video calls." [P18]*
> *"I have no issues using the VC software or with appearing on video calls." [P33]*
> *"Video calls are pretty easy to use; easily accessible" [P35]*

All three respondents, P18, P33, and P35, were comfortable with VC and had few reservations about taking VC – even with unpredictable and diverse audiences. Generally respondents reported a high-level expertise in response to the statement, *"Video calling is easy"* with an average score on a five-point Likert scale of 4.02 (σ=0.97), where 5 indicates 'High expertise'[9].

VC accessibility features improve meeting comprehension and understanding. Many built-in accessibility features allowed chronically ill people to better understand video calls and reflect afterward, enhancing workforce performance. Respondents were fairly agnostic about their choice of VC platforms, using an average 2.55 (σ=1.1) VC platforms each. Microsoft Teams (81.8%) was the most used platform, slightly more popular than Zoom (74.6%). VC features such as captioning, transcripts and AI-generated meeting summaries were seen by many like P26 as essential, *"It has been made easier by using things like transcription and Copilot to summarize the meeting and list actions items to ensure I didn't miss anything!" [P26, MS, Lupus Disease, PTSD & Cancer]*. For many respondents, VC captions and transcript-based AI tools enhanced comprehension, understanding and ensured equitable collaborator engagement.

> *"[I would like to use] meeting recordings, captions, transcripts, or Copilot features for the majority of my calls all of which I have found to be anxiety-reducing and major aids to my comprehension and memory of meeting details... I don't want the pace of discussion to be determined by my accessibility needs when there is assistive technology that empowers me to feel like I fit in" [P16, ADHD, GAD & Depression]*
> *"Basically, anywhere a phone call might occur, a video call (particularly with captions) increases my access... Now we have turn-taking and machine captions (which I don't have to pre-plan) with names. I feel that I am on a more equal footing" [P37, DHH]*

For P16, these VC features empower by reducing anxiety and cognitive load, improving performance and retention in meetings, and fostering a sense of belonging. In contrast, P37 finds that captioning streamlined meeting preparation, enabling more equitable engagement and preventing power imbalances with collaborators. Certainly, VC with no accessibility features can be profoundly incapacitating. Shown in Figure 3, popular VC features included toggling of microphones (96.4%), cameras (92.7%), chatbox (90.9%), virtual hand-raise (87.3%), volume (85.5%) and meeting recordings (85.5%). In contrast, the least popular features were video call notifications (7.3%) and breakout rooms (14.5%).

VC endorses flexible device, symptom & time management. Respondents used an average of 2.02 devices (σ=0.73) for VC. Laptops were the most popular device (85.5%) whilst over half used phones (67.3%) for VC. Presented in Figure 3, VC convenience (85.4%) is crucial for supporting chronically ill people to manage their symptoms without expending time and limited energies on preparation. As noted by P3, VC prevents overexertion whilst managing debilitating health symptoms, even enabling participation at events where in-person engagement would cause burnout.

> *"While I have a lot more capacity right now, a few years ago videoconferencing was the thing that enabled me to do my day-to-day life without significant symptoms taking over the rest of my day and it allowed me to say 'Yes' to more things!" [P3]*

Due to the fluctuating nature of daily symptoms, VC provided chronically ill people more time and flexibility (81.8%). For both P16 and P24, VC supports the option to avoid exacerbating illness through exhausting commutes. Several participants shared detailed stories about how commuting led to severe health complications.

> *"Time management and over stimulation (noise, stress, driving) are challenges for me and I've found it much easier and faster to schedule and seek medical/mental help through video appointments." [P16]*
> *"When symptoms are present, I know that in-person commute and meetings exacerbate my condition and can impact my health for days or weeks." [P24, Lupus disease]*

The flexibility of VC enhances respondents' routines and time management in diverse ways. For example, despite differing conditions, VC helps P16 and P24 maintain health stability amid busy yearly schedules. Elsewhere, for respondents P46, P47 and P52 schedules are already packed with many weekly telehealth appointments. Similarly, P31 faces challenges with commuting due to frequent medication changes that hinder regular driving.

4.1.2 Coping Strategies Employed During VC by Chronically Ill People. **Masking of symptoms, emotions and pains throughout VC.** Many respondents acknowledged that VC allowed them to *more* easily mask their illnesses, *"most of the time of I'm experiencing symptoms from this illness I can mask my issues to keep the call productive" [P10, CHF & HOCM]*. Both P16 and P33 reflected on compartmentalizing their emotions and masking intense pain during VC. In particular, P16 has become highly proficient at relying on their experience to guide them through calls.

> *"During the call I tend to be able to flip the switch and let my experience and practice take over so I do a better job of compartmentalizing my emotions and challenges during calls." [P16]*
> *"I work through constant pain, I don't usually let it interrupt a call. It would most likely look like taking medication or getting a drink." [P33, BLV, EDS, Brain tumours, Chronic migraines & Nerve damage]*

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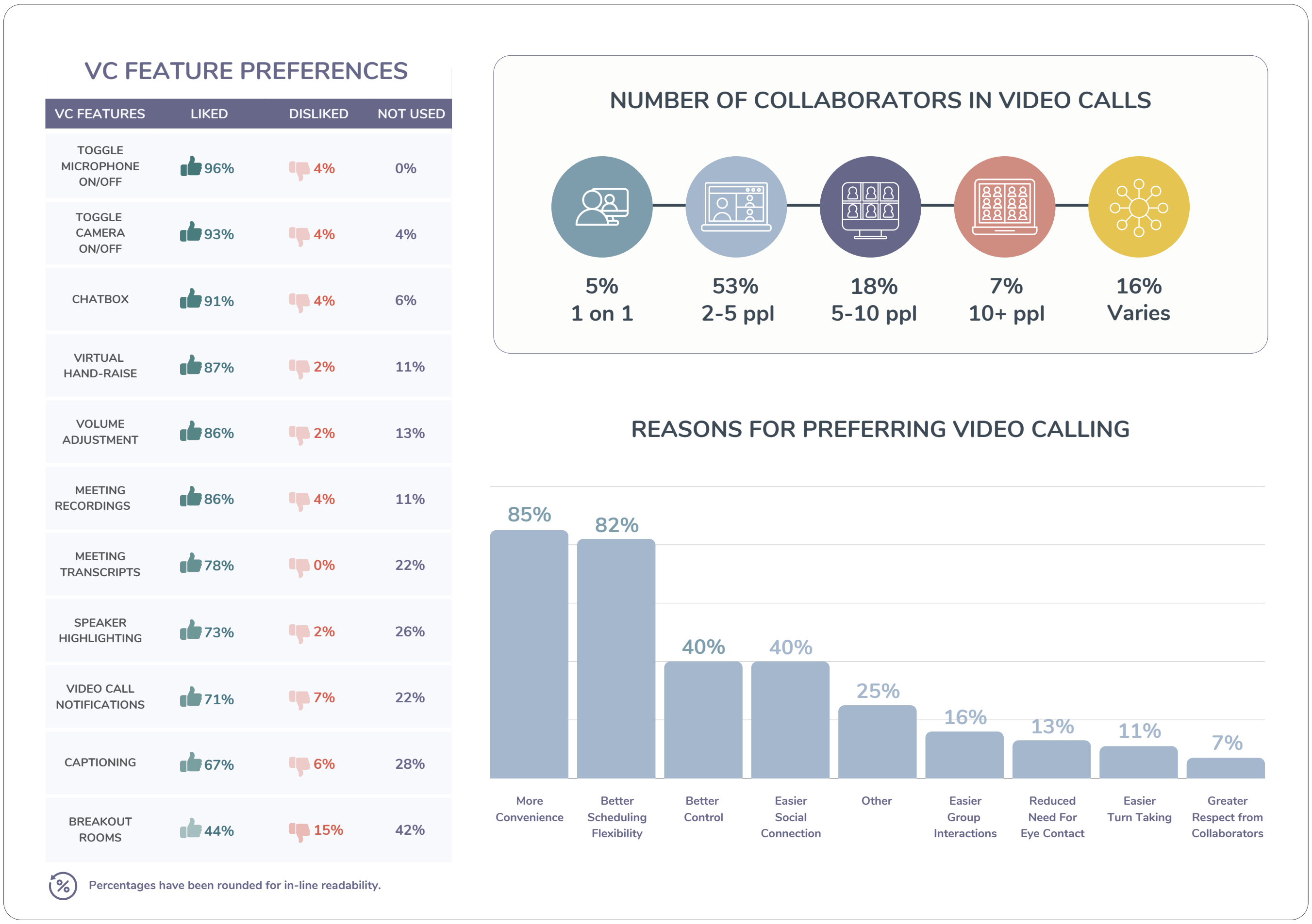
[9] Respondents reported an equivalently high-level of expertise with computers with an average score on a five-point Likert scale of 4.31 (σ=0.77).



VC FEATURE PREFERENCES

VC FEATURES	LIKED	DISLIKED	NOT USED
TOGGLE MICROPHONE ON/OFF	96%	4%	0%
TOGGLE CAMERA ON/OFF	93%	4%	4%
CHATBOX	91%	4%	6%
VIRTUAL HAND-RAISE	87%	2%	11%
VOLUME ADJUSTMENT	86%	2%	13%
MEETING RECORDINGS	86%	4%	11%
MEETING TRANSCRIPTS	78%	0%	22%
SPEAKER HIGHLIGHTING	73%	2%	26%
VIDEO CALL NOTIFICATIONS	71%	7%	22%
CAPTIONING	67%	6%	28%
BREAKOUT ROOMS	44%	15%	42%

Figure 3: Infographic of chronically ill respondents' VC facilitators.

Respondents like P6 take this further by actively prioritizing their collaborators needs over their own, stating, *"I tend to prioritize others' needs over my own health and will work unless I am literally unable to stand up or the leave the bathroom" [P6, Ulcerative colitis]*. Detrimentally these coping behaviors can compound to eventual feelings of in-authenticity, *"I don't feel like I can present my truest self on video calls. I tend to do quite a bit of covering/masking of my ADHD and anxiety symptoms when I'm on video calls." [P16]*. For P16, the underlying stress reflects the daily mental strain of masking symptoms related to ADHD and anxiety.

Discreetly controlling the self-facing camera & VC setup. Shown in Figure 4, respondents adjust the position of their cameras and VC setups to conceal health needs. Described by P40 as, *"manipulat[ing] the video optics enough to appear unconcerning"*. Whilst VC, many respondents 'Always–Sometimes' kept the camera off (67%) and 'Always–Sometimes' muted themselves (97%). Across participants, having the option to mute audio and conceal video were broadly recognised as particularly helpful during unexpected flare ups and migraines.

> *"Visible parts of my condition include skin rashes, red face flushing, and swollen joints. Most of the time I am able to conceal these on video calls. Either by lighting or using the filters in teams or no camera." [P24, Lupus disease]*
>
> *"I often turn camera off if I would be visibly in pain or cannot process visuals due to pain (even if I can still tolerate sound) and even if I can't tolerate sound I may put captions on and turn off all video." [P36, Autoimmune diseases, Chronic migraines & other]*

Both P24 and P36 make creative adjustments to their VC feeds for different personal reasons: P24 alterss the camera and lighting to conceal symptoms of chronic illness, while P36 turns off the camera to avoid migraine-triggering visuals. People with chronic illness often need to strategically improvise during VC to manage unexpected health needs. Muting audio and concealing video also greatly helps in larger meetings where sustained engagement is not required, *"I keep my video and audio off if I am at home but not presentable but won't be talking during the meeting" [P9]*. During prolonged VC, respondents like P3 adjusted the camera to position themselves more comfortably, *"reclining that could become visible, taking a call from the couch/floor, or while standing" [P3]*. Notably, most respondents felt that these discreet VC adjustments did not

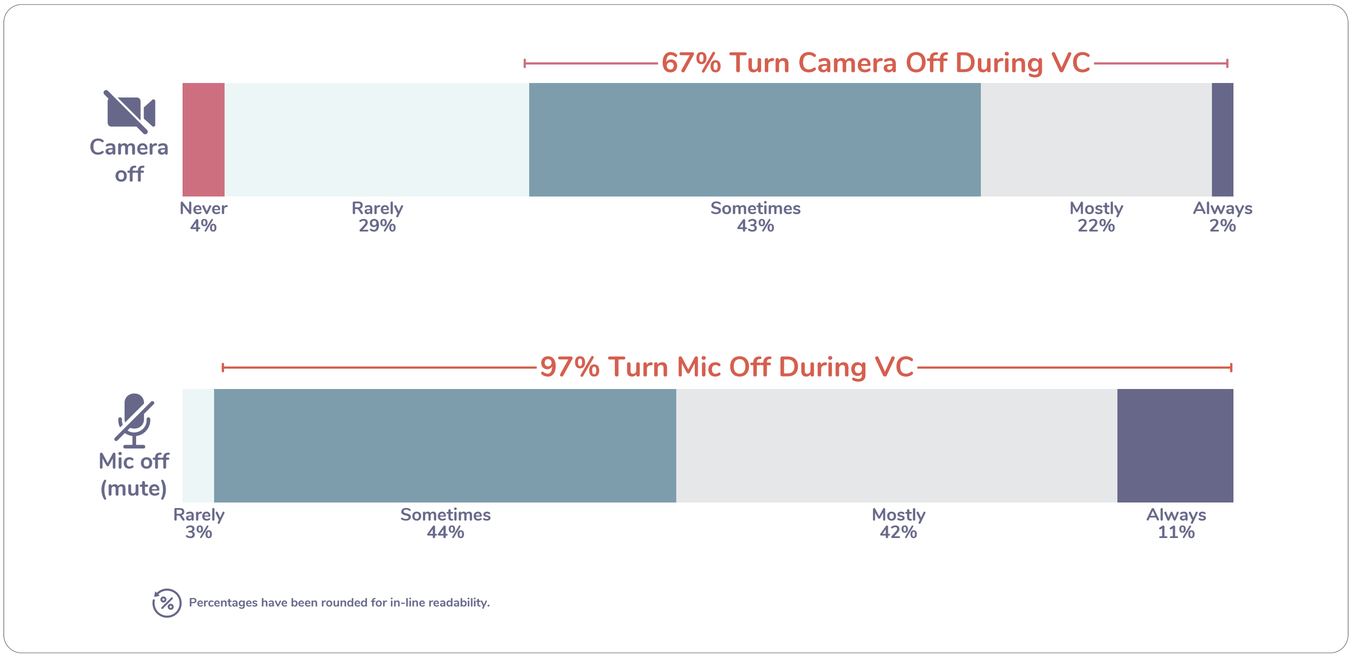


Figure 4: Data on chronically ill respondents' preferences for camera and microphone.

damage their self-presentation with an average score of *just* 2.0 (σ=1.11) for *"Video calls negatively affect my self-presentation"* across a five-point Likert scale where 1 indicates 'Strong disagreement'.

Establishing VC norms & support from collaborators. Collaborators and meeting norms are critical for ensuring VC runs smoothly, with familiar and experienced collaborators being optimal. Respondents reported that they most frequently met with 2–5 collaborators on video calls (52.7%), followed by 5–10 collaborators (18.2%) and additionally respondents reported varying numbers of collaborators (16.3%) across different calls. To repair conversations, respondents like P22 found that requesting clarifications and asking constructive questions greatly enhanced their VC meeting experiences. Some respondents including P15 even described their teams as empathetic – fostering supportive norms to make VC easier.

> *"It's commonplace [...] to multi-task occasionally and ask, 'Can you repeat the question?' when called upon from time to time." [P22]*
> *"I just keep my camera off if I want to. My team is very good about not pushing people to go camera-on. I generally will turn it on if everyone else is, or if I know someone else on the team needs video for better comprehension." [P15]*

Similarly, for P44 trusted meeting allies i.e., assistants, friends and family members, help reduce their VC barriers, *"often, my executive assistant joins the call. She provides me with assistance related to my access needs and the barriers that prevent me from being able to work to my full potential" [P44]*. When P44 meets unfamiliar collaborators, swiftly establishing preferred VC norms–such as recording meetings or enabling transcription–is critical. They explain, *"I don't have a physical visible disability that appears on video calls [...] However, I always ask people whether it's okay to turn on the recording and transcription because I cannot take physical notes or remember conversations." [P44, Long COVID, Cardiomyopathy, EDS, Fibromyalgia & Dyslexia].*

Leveraging assistive technologies, medications, food & endorsing stepping away. For many respondents, VC presented opportunities to discreetly use a wide range of ATs, medications and food to support their meeting experience. Examples included using prescription glasses for migraines (P30), arm braces, heating pads (P52), transcutaneous electrical nerve stimulations (TENS) machines[10] (P39) and medications.

> *"During light sensitive migraines I often have to wear prescription sunglasses to interact with screens." [P30, Chronic migraines, PTSD, Depression & Anxiety]*
> *"I am glad I don't always have to get dressed and professional looking. I can have sunglasses on (for migraines), a t-shirt with some sort of orthopedic braces etc. and not need to be on camera or in person to participate in life." [P39, CFS, Neuromuscular disease & Rheumatoid arthritis]*
> *"If I have sudden severe pain, I may need to step away for a few minutes to grab my heating pad, topical pain relief, medications, and/or TENS unit to manage my pain while working." [P52, Adenomyosis, EDS & Endometriosis]*

All three respondents—P30, P39, and P52—use a diverse range of assistive technologies (ATs) during VC engagements, but severe

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[10] A TENS machine is a compact, battery-powered device with leads attached to adhesive electrodes, which provide pain relief by delivering a mild electrical current [76].

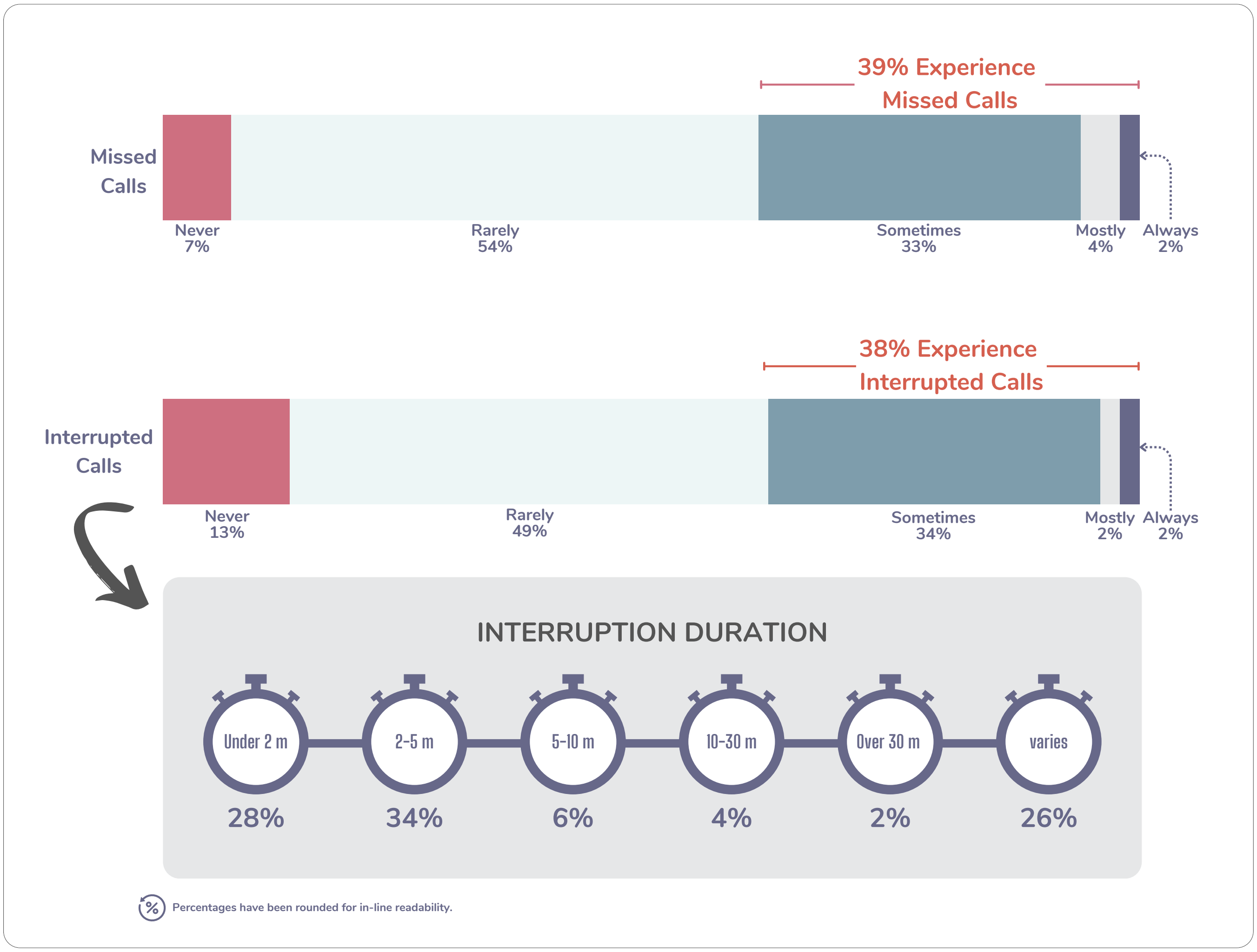

Figure 5: Infographic of chronically ill respondents' VC interruptions.

pains occasionally force them to disrupt calls. Summarised in Figure 5, a notable proportion of respondents 'Always-Sometimes' miss VC (39%) and 'Always-Sometimes' interrupt VC (38%) due to health related needs. Interruptions are typically brief, under 2 minutes (28%) or 2–5 minutes (34%) but can vary (26%). For some respondents, food helps manage fluctuating blood sugar levels, *"with my type 2 diabetes my condition can be visible if my blood sugar drops and I need to intake food/drink to stabilize my blood sugar." [P20, Diabetes & ADHD]*. If pain becomes too substantial, stepping away from VC is more accessible and excusable than in-person meetings, *"If I am entering a migraine it will interrupt the call entirely" [P2, Anemia, Endometriosis, Adenomyosis & others]* and *"Sometimes I'm too ill or weak to attend meetings, and have to make up the time asynch (listening to meeting recording, etc) later when I'm better." [P12, Neuromuscular disease, ME & CFS]*.

4.2 Theme 2: Video Call Technology Exacerbates Cognitive, Emotional and Physical Challenges but can be Improved

This theme describes difficulties chronically ill people encountered with VC across cognitive, emotional and physical dimensions, plus envisaged improvements from respondents. The three crafted subthemes are: (1) cognitive and emotional difficulties, (2) physical challenges and (3) envisaged improvements.

4.2.1 Cognitive and Emotional Difficulties. **Impact from cognitive load, fatigue & frustrations pre, during & post calls.** Depicted in Figure 6, respondents widely experienced non-visible fatigue (70.9%), cognitive load (43.6%) and unvoiced emotional frustrations related to VC. For respondents, physical and emotional challenges can be strongly interrelated. For both P10 and P37, fatigue and cognitive load are daily concerns.

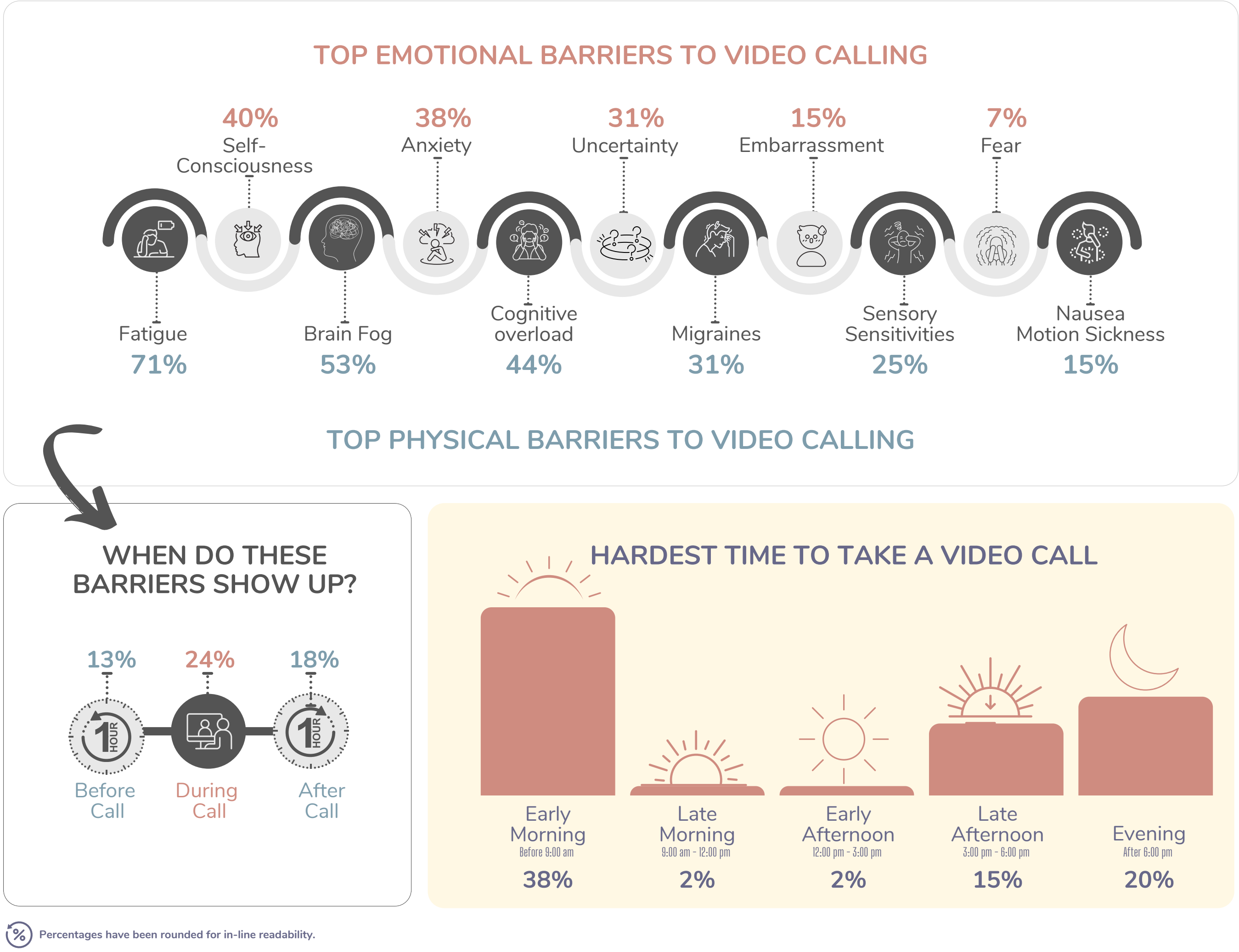

Figure 6: Infographic of chronically ill respondents' VC barriers and challenges.

> *"Sometimes knowing it's going to be a long meeting where I'm leading for more than 1.5 hours I worry about getting fatigued and then stumbling my words." [P10]*
> *"Fatigue/cognitive load comes from the burden of listening to and understanding people [...] No captions induces great mental fatigue to me because understanding what people say is very tiring." [P37]*

Respondents faced issues with mental load and fatigue, which for P10 perpetuated worries about performance and P37 created frustrations with understanding collaborators. In particular, survey respondents revealed the hardest times for VC was early morning (38.2%) and evenings (20%). Morning meetings can be especially challenging, *"my circadian rhythm is disrupted both by my illness/medication. I am typically unable to be awake for early morning appointments." [P46]* and exhaustion compounds throughout the workday, *"as someone on calls for most of the day, it usually builds over time and I'm drained at the end of the day!" [P29].*

Concentration is afflicted by brain fog & distractions. Presented in Figure 6, many respondents struggled with distractions during VC, difficulties arising from brain fog and collaborators' surroundings.

> *"it is sometimes hard to stay focused" [P1]*
> *"I feel fatigue/brain fog during or after calls." [P21]*
> *"Online etiquette is often a problem as others allow ambient noise interruptions from others (dogs, family, phones ringing, etc.)" [P45]*

While P1 and P21 highlighted how internal brain fog disrupted their ability to focus, P45 emphasized a different challenge: the distracting impact of external ambient noise during calls. For respondents, distractions manifest from both physical and environmental sources. Overall, respondents most commonly reported challenges with brain fog (52.7%), migraines (30.9%) and sensory sensitivities (25.4%). For some participants, like P16, the self-facing camera proves highly distracting, *"I am talking however I also find* *viewing myself on camera distracting and I worry about my appearance/lighting/background instead of the content of the video call/speaker." [P16]*. Additionally, P44 highlighted issues with VC interfaces, noting that physical spasms interfere with there ability to click buttons or share screens, diverting their focus from the conversation.

> *"I do have some difficulties with finding things in Microsoft Teams [...] Also, because my hand sometimes spasms, and I can get distracted and brain fogged, having the share screen buttons so close to the leave button has occasionally meant I've accidentally clicked the wrong button." [P44]*
>
> *"Due to having only one lung, I get breathless easy, causing self-consciousness. This lack of oxygen flow also when speaking frequently causes brain fog and limited retention. Copilot summary of meetings seems to help ensure I have not missed any details but I am always worried that I do miss or fail to retain some information." [P23]*

P23's experiences illustrates the complex physical, emotional, and social dynamics that profoundly impact many chronically ill people's ability to concentrate during VC. Many respondents reported struggling with severe brain fog and distractions, which worsened memory loss and hindered retention of key information.

Anxiety & self-consciousness can damage VC experiences. Shown in Figure 6, a considerable proportion of respondents experience the negative emotions of self consciousness (40%), anxiety (38.2%), and uncertainty (30.9%) in relation to VC. P12 experiences intense anxiety around their in-meeting performance, which escalates into stress and insecurity about their job, *"I worry people will think I'm not engaged or not a good performer because I'm either off camera or looking tired/droopy when I am on camera. I worry about the perception it creates and whether that will impact my job security" [P12]*. For P20, anxieties typically manifested immediately after meetings from *"lack of meeting closure" [P20]* and abrupt endings, stating, *"Video calls can sometimes create more anxiety than in-person engagements because of the often abrupt nature of which video meetings end" [P20]*. For P16, cycles of anxiety and self-consciousness often triggered intermittent episodes of negative self-talk:

> *"The self-consciousness and high mental load often contribute to or are accompanied by negative self-talk after the video calls. My anxiety spikes right before video calls start and I am often more sensitive to disruptions and stimuli." [P16]*

Other respondents, including P23, expressed anxiety over their physical limitations and the unpredictable bodily reactions they experienced during meetings. In contrast, P44 felt self-conscious about asserting their needs and feared being judged for disclosing their disability.

> *"Anxiety and stress of preparation before a call and then actually delivering materials or speaking during the call as I never know for sure how my body will react to the exertion/stress." [P23]*
>
> *"I have trained myself to try not to feel self-conscious or embarrassed about stating my needs, such as recording and transcription, having my camera on when I am lying down [...] I do feel uncertainty about exposing my circumstances by having my camera on when I don't have an opportunity to explain why I am lying down. I don't want people to think I am lazy. I realise this is internalised ableism!" [P44]*

P44 exemplifies the complex emotions, anxieties, and self-consciousness many chronically ill respondents experience during VC. Although P44 makes a conscious effort to advocate for themselves, they struggle with internal insecurities rooted in societal stigma towards people with disabilities. They even fear that their outward coping strategies during VC might be misinterpreted as laziness.

4.2.2 Physical Challenges. **Unexpected physical & technological difficulties.** Respondents faced vulnerability to unexpected physical difficulties and technological difficulties with VC. However, the physical challenges varied: P47 and P50 highlighted issues with urgent toileting, while P19's the concern was with captioning.

> *"Urgent toileting needs" [P47]*
>
> *"It can be challenging when captions are not available or functioning properly" [P19]*
>
> *"Sometimes I just need a break to take medication or use the bathrooms, other times I'm too sick to rejoin" [P50]*

Many respondents grapple with the unpredictability of both their bodies and the VC technology they rely on, each contributing to challenges in different ways. For P52, the rapid onset of illness was particularly difficult, whereas P29 faces physical limitations that debilitate their entire body. Generally respondents reported that physical, technological and emotional challenges are most likely to manifest during (23.7%) or in the 1hr period after a call (18.2%).

> *"My chronic illness causes daily pain, which can get suddenly more severe without warning. I cannot predict when I will be incapacitated due to my illness" [P52, Adenomyosis, EDS & Endometriosis]*
>
> *"Pains felt throughout the body, my migraines are partially triggered by photophobia, so looking at screens for most of the day can lead to eye fatigue, general fatigue, migraine, headaches, or some nausea" [P29]*

For P13 and other participants using ATs, serious frustrations arose from unpredictable experiences with Bluetooth and ATs across different VC platforms – compounding challenges for many respondents.

> *"FaceTime is super easy [...] My phone connects directly to my hearing aids, and the UI is intuitive. Google Meet is quite challenging, because the mobile app is not appropriate for use of video for work-calls, but my computer can't stream audio into my hearing aid" [P13]*

For P13, the inability to connect or stream audio would entirely compromise their VC experience, making meaningful participation impossible.

Fluctuating chronic illness visibility limits social empathy. The fluctuating visibility of chronic illness can limit social empathy from VC collaborators.

> *"No one can tell if I have a migraine or not because it is not visible pain!" [P8]*
>
> *"Unless I'm having an active asthma attack (for which I need to use my inhaler), actively having a migraine*

> *(which makes me very grumpy and squinty), or actively having an allergic reaction (anaphylaxic or regular), people can't generally tell." [P15]*

Despite almost half of our respondents (49.1%) using ATs, only a small fraction (18.2%) reported that their chronic health condition was visible to VC collaborators. Noted by P23 and P6 this lack of visibility can inadvertently make VC more challenging, promulgating anxiety.

> *"I look fine externally but have trouble speaking for extended conversations and anxiety develops when put on the spot for tough situations/conversations." [P23]*
> *"It is not publicly visible, but if I am having a flare-up, I have to quickly get shut off the video and sound and run to the bathroom up to several times an hour." [P6]*

Respondents like P6 frequently had to navigate the fluctuating physical challenges of their illness in isolation. Even during telehealth appointments respondents sometimes had to leverage their cameras to showcase their needs, *"I have done telemedicine visits where my doctor can see this if I am directed to change the camera angle and move so she can see more of me actually moving"* (P45).

Limits to non-verbal communication over calls. Respondents were divided on the statement, *"I prefer in-person social, health and work engagements over VC"*, with an average score of 3.04 (σ=1.09) on a five-point Likert scale where 3 indicates 'Neither agree nor disagree'. However, many respondents expressed frustration with the limitations of communication over VC. There was a fairly even distribution, but non-verbal (32.7%) and verbal (29.1%) difficulties proved more common, including issues with reading and comprehending collaborators cues (25.5%). Specifically, some respondents noted challenges with verbal turn-taking (P4) and non-verbal comprehension (P29, P31).

> *"speech difficulties are particularly difficult to accommodate because of the slow and difficult responses" [P4, ALS]*
> *"In-person allows me to pick up on non-verbal cues more easily than on a video call" [P29]*
> *"As long as my neck and head view are working, I am good. Barriers have to include the non-verbal side, since some folks do not use their cameras" [P31, Shoulder muscular spasticity]*

For P4, non-verbal barriers are worsened when collaborators' cameras are switched off. Similarly, for P46, communicating the urgency of their needs can be particularly challenging on a 2D VC screen, even during telehealth appointments.

> *"Doctors often find it easier to dismiss my concerns as I am not physically present with them. Because I look "fine" my distress is seen as hyperbole" [P46, PMR, Chronic migraines, CFS, Chronic pain]*
> *"I am an extrovert and gain energy from being around people. That just isn't the same on a video call" [P44, Cardiomyopathy, Dyslexia, EDS, Fibromyalgia & Long Covid]*

For P44, the energy and connection of in-person interactions are noticeably absent during a full day of VC meetings. Respondents with chronic illnesses are particularly vulnerable to Zoom fatigue and VC burnout.

4.2.3 *Envisaged Improvements.*

Below we outline 8 actionable VC improvements suggested by our respondents:

Captioning and transcription quality. Respondents requested *"Better auto captioning" [P2]* and more customisation, *"Live captions could last longer on screen" [P19]*. Plus personalised transcription, *"Auto-transcription [...] including people talking over each other, nicknames, switching into other languages, matching up with what's happening in the chat etc." [P15]*. Additionally, *"a larger area to read and review the closed captions would also be helpful" [P16]*.

Camera adaptations. Many respondents desired more natural body language and eye-contact, *"place video of speaker near the camera so eye contact is maintained" [P5]* and have, *"a built-in camera to the screen at eye level so it actually looks like we're making eye contact" [P53]*. Others desired better camera focus in the midst of lighting changes, *"I currently just need my camera to adapt to my room lighting better" [P33]* and *"complimentary lighting built into the computer camera" [P47]*.

Constructive meeting notes & recap. Respondents desired more seamless note taking, *"recap and summary of all conversations and option to auto-save summaries in a file or OneNote" [P23]*. Especially post-meeting action items, *"Auto generated meeting notes and action items after the meeting ends" [P27]*. Plus, when recapping meeting recordings, *"some way to map what's happening in chat to what's being discussed and/or visualized in the meeting" [P12]*.

Design for breaks. Respondents requested VC to include features that allow breaks from screen-time, *"Maybe a feature that would give you a break from screen time after a prolonged time on a video call" [P35]* and *"forced 15-minute breaks after 2 hours on back-to-back calls" [P11]*. Including, making it easier for intermittent breaks like, *"a button to indicate you had to step away for a minute" [P28]*.

Easier turn taking. Several respondents wanted improvements in turn taking, *"I wish the video conferencing software could do a better job of indicating who is speaking" [P13]* and interjections, *"something to help me avoid interrupting others [...] or something to help cue me as to when is good to jump in" [P36]*. In short, *"something that would stop people talking over each other and enable me to see the social cues of when somebody is going to talk" [P44]*. Suggestions included, *"Color changes to assist with transition in speakers" [P40]* and meeting agendas for added structure, *"agenda section with timer so you could stay on topic and make the most of the time" [P10]*.

Sentiment analysis. Some respondents desired sentiment analysis to allow, *"better facilitation and connection between in-person respondents and online respondents" [P34]* and easier *"emotion interpretation" [P51]*, thereby supporting the constructive decoding of collaborators' cues.

Setting of social norms. Respondents asked for easier means to disclose non-visible personal needs, *"the ability to set and share meeting norms in a way that is pervasively viewable to all meeting attendees" [P3]*. Even a simple, *"disclaimer as to 'why' I turn my video on and off at times" [P18]*. Indeed, *"a way to indicate to video call respondents that I am camera off due to my chronic illness, a way to communicate it's a high pain or low spoons day. 'Hey, I'm camera off today for health reasons! Thanks for your understanding!!'" [P52]*.

User interface personalisation. Finally, respondents desired customisable user interface (UI) settings to mitigate migraine triggers, *"Unfortunately, none of the preset options work for me as the light modes trigger migraines and my extremely poor eye site makes dark modes basically unusable" [P17].* Or, user interface/experience (UI/UX) design to reduce distraction, *"Blocking out everything that is not a voice during presentations. Forced focus for all meeting respondents" [P24]* like de-clutter options to make focus easier, *"specifically the ability to de-clutter/remove buttons, etc. [...] enlarge specific UI elements that I need 'in focus"' [P22].* Additionally, adaptive UI/UX to make VC more controllable and accessible in light of fat-thumbs, *"Make the buttons not move around. Maybe a 'lock mute' button so I don't accidentally un-mute at bad moments" [P12].*

5 Discussion

5.1 Towards More Accessible Video Calling

Despite demographic prominence, prior research [66] notes a lack of HCI studies on chronically ill people and emphasized the potential for *more* human-centered technologies to make significant impact amongst this community. In response, this study systematically examines chronically ill people's VC routines, facilitators, barriers, and envisaged improvements.

A key finding from this research is the significant reliance of chronically ill people on VC to manage the multi-faceted challenges of their conditions. Survey respondents often reported being unable to commute or engage in prolonged public exposure due to immunodeficiencies, leading many to depend on VC for remote work. Consequently, we argue that backlash against remote work practices from influential executives (e.g., Elon Musk) [37] and return-to-office mandates [45] could create insurmountable challenges for chronically ill people. For many respondents, full-time return to the office is not viable. To promote inclusivity and prevent discrimination, we strongly advocate for VC and remote collaboration tools in the workplace.

Another notable finding, is that chronically ill people liberally use VC for many purposes beyond the workplace. Respondents used VC to maintain social connections, access healthcare appointments/prescriptions, therapy and support groups. Complementing this finding, previous HCI research has investigated VC for: playful interactions [28], connecting distributed families [31], practicing religious faith [22], language therapy [74] and doctor/patient meetings [39]. We encourage future HCI research to expand on these areas to ensure VC technology addresses the holistic and varied needs of chronically ill people beyond workplace settings.

This research confirms and extends previous findings, which established that flexible VC is a significant benefit for chronically ill individuals. VC enables consequence-based decision making for chronically ill people [63, 66], allowing for contextual adaptations such as staying home unexpectedly and quickly shifting meetings online. Equally, VC supports chronically ill people to leverage off-camera resources, such as assistive technologies (ATs), medication and food, to manage unexpected flare-ups effectively [63, 66]. However, we extend this research by reporting new ways respondents creatively adapt their VC setup and self-facing camera to manage and conceal symptoms including using: filters/lighting to mask redness (P24), migraine sunglasses (P30), heating pads (P52), arm braces (P39) and disabling migraine-inducing visuals to focus on audio (P17).

A further finding from this research is that many respondents reported needing to mask emotions and painful symptoms during VC, a coping mechanism described as *'white knuckling'* for the sake of productivity. Similarly, both Zolyomi et al. [110], and Das et al. [25] found neurodivergent adults to mask during VC, which imposed a significant cognitive load. We build on this research by providing insights from chronically ill communities, emphasizing individual variations and systematically examining the hidden cognitive, emotional, and physical barriers faced during VC, which can vary unpredictably in onset, intensity, and duration. Across respondents, fatigue, brain fog, and cognitive load were commonly reported, contributing to negative emotions of self-consciousness, anxiety, and uncertainty. These barriers were especially prevalent during morning VC meetings. In response, some respondents found turning the camera off a helpful strategy–also favoured amongst BLV people [98] and people living with autism [110]. The recent development of avatars for Zoom [112] and MS Teams [71] could make turning the camera off even more accessible for many chronically ill people.

Beyond DHH communities [53], this work emphasises that inbuilt VC captioning greatly supports many chronically ill people. Future VC technology should consider setting captions as the *default* VC option as it is an essential communication access tool. Many chronically ill respondents reflected on being denied captioning during calls, which led to disempowerment during meetings [68, 98]. However, current VC caption technology still does not work optimally for diverse speakers (e.g., accents and atypical speech) [74, 105, 106] – suggesting the need for more representative datasets to improve inclusivity [100]. Additionally, captions lack customization options [68] and often impose a high cognitive load on users [53]. Future research should focus on developing more accessible VC captions and evaluating captioning technologies with chronically ill people.

Significantly, we found that fostering inclusive social norms that encourage stepping away from VC when needed, along with providing post-meeting transcripts – can greatly empower many chronically ill individuals. For several respondents, symptoms during VC are sometimes too painful, making it necessary to leave and catch up later. In light of these findings, we recommend the continued development of tools (e.g., Copilot meeting notes) that support exits and post-meeting experiences for chronically ill people. Also, previously researched post-meeting VC tools including Coco [90] and Meeting Coach [89] could be reconfigured to offer personalised feedback for chronically ill users – diminishing their post-meeting anxiety. Admittedly many of these tools depend on meeting transcript recordings, which raise privacy and security concerns [1, 103].

Survey respondents widely reported that prior relations with collaborators significantly shape the overall meeting experience–both positively and negatively. This unique finding highlights the need for VC research to place greater emphasis on co-constructed communication [51]. Currently, allied collaborators can proactively reduce VC barriers and support chronically ill people (e.g., by answering clarifications and questions) [10]. Future VC research should explore and enhance co-constructed and interdependent communication methods for chronically ill people. This could include developing accessible cues to signal non-visible needs, encouraging supportive actions from collaborators, fostering shared understanding and common ground [94].

5.2 Design Considerations for the Future of Video Calling

Extending from envisaged improvements provided by respondents in Section 4.2.3, we offer 3 broader considerations for future VC research.

5.2.1 *Non-verbally Setting Energy and Emotional Expectations.*

Many respondents noted that the invisibility of chronic illness over VC can limit social empathy from collaborators. For example, P8's comment about migraines being invisible pain highlights the importance of allowing people with chronic illness to express their internal states in ways that are useful and meaningful to them. Prior work has similarly highlighted hidden costs of VC for people who stutter, emphasizing the need for appropriate self-disclosure that respectfully acknowledges the challenges faced by marginalized communities [56, 105]. Much VC research has focused on efficiency [56], neglecting the importance of fostering rich human connection. Re-imagining non-verbal communication modes could help recover communication techniques lost when confined to 2-D VC. Improved non-verbal VC communication has been identified as crucial amongst several communities, including: BLV [93], DHH [47], people living with aphasia [74], people who stutter [106] and neurodivergent professionals [25]. Therefore, we recommend that future VC research more strongly considers non-verbal communication, including designing features to set expectations across collaborators and provide opportunities for empathetic support. Notable non-verbal VC adaptions in prior work have included word clouds to support DHH collaborators [47] and extensive prop usage amongst communities with aphasia [74]. Future VC toolkits could consider non-verbal real-time visual signifiers to set social expectations such as indicating a meeting participant's cognitive load, an active impairment (e.g., migraine), current mood (e.g., frustration), or energy levels (e.g., a visualisation of *"spoons"* [72]). For people with experiences similar to P8, these non-verbal cues could signal to their conversation partners that their participation in a discussion might be reduced due to the onset of a migraine. These cues might signal to conversation partners that they should try to limit audio or visual distractions, such as barking dogs or ringing phones (mentioned by P45), which could worsen discomfort. Equally, these cues could vary in opacity depending on the context, with higher opacity for personal calls and lower for calls with work colleagues. Importantly, this feature could rely on self-disclosure to avoid ethical and performance pitfalls associated with real-time AI VC affect recognition [7]. Non-verbal improvements to VC could enhance communication beyond our current modalities of sharing and strengthen relationships between meeting participants.

5.2.2 *Aligned AI Before and During VC.*

Currently, AI-generated captions and post-meeting summaries support chronically ill people's comprehension by mitigating challenges such as cognitive load, brain fog, and post-meeting anxiety. For VC users like P26 who prefer using AI technologies in most of their virtual meetings, understanding how people with chronic illness utilize these tools can help develop AI solutions tailored to their needs. Research on AI-driven post-meeting tools, such as Coco [90] and MeetingCoach [89], has focused on supporting turn-taking, sentiment, and inclusivity. However, AI assistance for pre-meeting and in-meeting engagement remains under-explored. Aligned AI could gather resources before meetings to aid preparation, provide peripheral information during VC to mitigate cognitive load, and generate summaries of missed conversations when chronically ill people briefly step away from a call. For instance, P50 mentioned needing to step away for bathroom breaks or medication. Aligned AI could track the meeting, summarize missed content, and provide reminders, improving experience without losing engagement. Additionally, aligned AI-agent technologies could co-pilot, assist or outsource low-level activities during VC (e.g., constructive note taking) [20, 36, 42, 108, 109]. Many chronically ill people already rely on allies (e.g., family, friends, colleagues, or paid assistants) for these similar forms of support.

5.2.3 *Automatic Adaptive Personalisation of VC Experiences.*

Adaptive assistive technology (AAT) presents a vision of automatically adapting UI/UX features based on chronically ill people's technology usage [38, 64, 66, 80]. Currently, the UI/UX of VC does not detect or adapt to support the management of symptoms for chronically ill people. Instead, future VC technologies could look to adaptively personalise UI/UX to support users experiences of tremors, migraines, distraction, and fatigue. Respondents initial suggestions included resizing UI elements (P22) and locking features to prevent *"fat thumb"* errors like accidentally pressing the un-mute button (P12). In addition, to improve speaker turn-taking the VC platform could adaptively use prominent UI colours or other signifiers – reducing cognitive load/fatigue (P40). Whilst to mitigate migraines, the VC platform could transition to accessible multimodal interactions for screen-free VC through: immersive audio [49], screen-readers [23], on-body interaction techniques [77], speech input [83], or gesture/motion capture [79]. Furthermore, the VC platform could automatically support *more* personalised camera adaptions to enhance eye contact [99] and conceal flare ups [3]. Finally, to mitigate against missing important calls during periods of extended illness, digital twin technologies [42, 108] could optionally co-pilot or participate in video calls on chronically ill people's behalf. Admittedly, any adaptive interfaces will have to be thoughtfully designed to prevent unpredictability introducing further challenges for sensitive users. However, research from Findlater et al. [26, 27] on gradual onset of adaptation can help mitigate these tensions.

5.3 Reflection on Methods with Chronically Ill People

Given the limited research on chronically ill people [66], this work provides further evidence for more direct engagement with chronically ill communities to work towards human-centered VC technologies. Broadly, we strongly believe it is important to collaborate with chronically ill people – exploring their unique challenges and technological solutions, which extend beyond strictly cognitive, sensory, and physical disabilities [66]. Chronically ill people are prodigious users of VC and offered valuable insights for improving its accessibility. Emerging HCI work has engaged with this community through field studies [13], auto-ethnography [63, 66] and interviews [80, 96]. We recommend future work to collaboratively build and develop technologies through direct engagement i.e., participatory methods [14]. Given the needs of this community, remote co-design engagements may be necessary [15, 40, 91]. Chronically ill people's heightened interoceptive awareness from living with the burden of unexpected bodily symptoms [66, 80] makes them a valuable resource for insights and collaborative design. Indeed, chronically ill people can be highly conscious of their daily bodily experience and the impacts of technology [80]. Our respondents identified a range of facilitators/barriers experienced during VC, which other communities may not have the presence of mind and interoceptive awareness to effectively articulate.

6 Limitations

This research has several limitations. Firstly, it accounts for a limited context as all respondents had experience with VC, were US-based and owned a smartphone indicating widespread technology literacy. People with disabilities are very diverse—therefore not all chronically ill people would offer similar responses [21, 81]. Consequently, generalising the findings to broader populations may be challenging. Additionally, the technical aspects of our proposed VC changes have yet to be employed and evaluated in real-world settings. Despite this, our work identifies evident facilitators, barriers and presents under-explored design opportunities to improve VC for chronically ill people. There is significant potential to extend this work via iterative development of inclusive VC experiences.

7 Conclusion

Our work offers an extensive exploration of chronically ill people's VC routines, facilitators and barriers. Using survey data (N=55), our research provides both quantitative and qualitative findings and actionable recommendations from respondents to improve the experience of VC. We found a deep dependency on VC across all areas of life among our respondents, as well as cognitive, emotional and physical difficulties with VC. Despite these challenges, VC engenders positive feelings of comfort and control for chronically ill people—providing a stabilising sense of agency and autonomy. Therefore improving this technology would enrich many chronically ill people's livelihoods. We contextualise these findings within wider research and discuss 3 broader considerations for VC: (1) nonverbally setting expectations of emotions/energy; (2) AI-aligned supports before and during meetings; and (3) automatic adaptive personalisations of VC experiences. Finally, we recommend further adoption of participatory methods with chronically ill people given their attuned knowledge of VC, interoceptive cognitive/bodily awareness and ability to succinctly articulate complex personal experiences.

8 Appendix

8.1 Survey respondents

8.1.1 Acronyms for respondents disabilities, chronic illnesses and diagnoses.

- ADHD: Attention deficit hyperactivity disorder
- ALS: Amyotrophic lateral sclerosis
- ASD: Autism spectrum disorder
- CFS: Chronic fatigue syndrome
- CHF: Congestive heart failure
- COVID: Coronavirus disease
- COPD: Chronic obstructive pulmonary disease
- DHH: Deaf and hard of hearing
- EDS: Ehlers-Danlos syndrome
- FSGS: Focal segmental glomerulosclerosis
- GAD: Generalised anxiety disorder
- HOCM: Hypertrophic obstructive cardiomyopathy
- IBS: Irritable bowel syndrome
- IIH: Idiopathic intracranial hypertension
- MCAS: Mast cell activation syndrome
- ME: Myalgic encephalomyelitis
- MS: Multiple sclerosis
- POTS: Postural orthostatic tachycardia syndrome
- PTSD: Post-traumatic stress disorder
- PMR: Polymyalgia rheumatica
- TBI: Traumatic brain injury
- VNS: Vagus nerve stimulation

Table 3: The 55 survey respondents including: gender, age range, diagnosed chronic illness, years lived with condition, assistive technology usage, visibility of chronic illness over VC and frequency of VC. Survey respondents that participated in subsequent co-design workshops are denoted in grey. X's denote prefer not to answer.

Name (Gender)	Age Range	Chronic Illness	Years?	AT?	Visible?	Frequency?
P1 (Woman)	45–54	Lyme disease	18	Yes	No	Multiple per day
P2 (Non-binary)	35–44	Adenomyosis, Anemia, Endometriosis & Others	25	Yes	No	Weekly
P3 (Woman)	25–34	Hypermobility, IBS, MCAS & POTS	5	Yes	No	Multiple per day
P4 (Man)	65–74	ALS	4	Yes	No	Weekly
P5 (Man)	35–44	Chronic kidney disease & FSGS	18	No	No	Once per day
P6 (Woman)	45–54	Ulcerative colitis	16	No	No	Multiple per day
P7 (Woman)	18–24	X	X	Yes	Yes	Multiple per day
P8 (Woman)	35–44	Chronic migraines	25	No	No	Weekly
P9 (Woman)	55–64	Diabetes & Thyroid disease	10	No	No	Multiple per day
P10 (Man)	35–44	CHF & HOCM	3.5	No	Yes	Weekly
P11 (Woman)	45–54	X	10	Yes	No	Multiple per day
P12 (Woman)	45–54	CFS, ME & Neuromuscular disease	2	Yes	No	Multiple per day
P13 (Woman)	25–34	Meniere's disease	13	Yes	No	Multiple per day
P14 (Man)	55–64	Cancer & MS	14	No	No	Multiple per day
P15 (Woman)	35–44	ADHD, ASD, Asthma, Chronic migraines, Long COVID & MCAS	20	Yes	No	Multiple per day
P16 (Woman)	25–34	ADHD, GAD & Major depression	26	No	Yes	Multiple per day
P17 (Woman)	25–34	Chronic migraines	20+	No	No	Multiple per day
P18 (Man)	45–54	ADHD, Dysgraphia & Dyslexia	30+	Yes	Yes	Multiple per day
P19 (Woman)	45–54	ADHD, Bipolar disorder, DHH & PTSD	17+	Yes	No	Multiple per day
P20 (Man)	45–54	ADHD & Diabetes	6	No	No	Multiple per day
P21 (Man)	25–34	Adrenal insufficiency, Diabetes, Hypopituarism & Hypothyroidism	6	No	No	Multiple per day
P22 (Man)	45–54	ADHD	45	No	No	Multiple per day
P23 (Woman)	55–64	Anxiety, Asthma, COPD, Kidney disease & Lung Cancer	30+	No	No	Once per day
P24 (Man)	45–54	Lupus disease	8	No	No	Multiple per day
P25 (Woman)	25–34	Diabetes & BLV	20+	Yes	No	Multiple per day
P26 (Man)	45–54	Cancer, Lupus disease, MS & PTSD	22	Yes	No	Multiple per day
P27 (Man)	45–54	Cataracts, Diabetes, Heart disease & Hypertension	15	No	No	Multiple per day
P28 (Woman)	35–44	Celiac disease & Diabetes	30	No	Yes	Monthly
P29 (Woman)	25–34	Anxiety, Chronic migraines & Depression	10+	No	No	Multiple per day
P30 (Woman)	35–44	Anxiety, Chronic migraines, Depression & PTSD	25	Yes	Yes	Multiple per day
P31 (Man)	55–64	Shoulder muscular spasticity	15	Yes	No	Multiple per day
P32 (Woman)	25–34	X	2	Yes	No	Multiple per day
P33 (Woman)	25–34	BLV, Brain tumours (meningioma), Chronic migraines, EDS, Hypermobility & Nerve damage	16	Yes	Yes	Multiple per day
P34 (Woman)	25–34	Diabetes	1	No	No	Multiple per day
P35 (Woman)	25–34	Chronic migraines & IIH	8	No	No	Multiple per day
P36 (Non-binary)	25–34	Autoimmune disease, Chronic migraines & Other conditions	15	Yes	No	Multiple per day
P37 (X)	25–34	DHH	27	Yes	No	Once per day
P38 (Man)	35–44	Epilepsy, Intellectual disability, TBI & VNS	32	No	No	Weekly
P39 (Woman)	35–44	CFS, Neuromuscular disease & Rheumatoid arthritis	10+	Yes	No	Multiple per day

Name (Gender)	**Age Range**	**Chronic Illness**	**Years?**	**AT?**	**Visible?**	**Frequency?**
P40 (Woman)	35–44	Lyme disease & TBI	30	Yes	No	Weekly
P41 (Man)	65–74	Parkinsons disease	8	No	No	Monthly
P42 (Woman)	>75	Parkinsons disease	1	No	Yes	Weekly
P43 (Woman)	65–74	Parkinsons disease	10	No	No	Weekly
P44 (Woman)	35–44	Cardiomyopathy, Dyslexia, EDS, Fibromyalgia & Long COVID	44	Yes	Yes	Multiple per day
P45 (Woman)	>75	Parkinsons disease	4	No	No	Weekly
P46 (Genderqueer)	25–34	Chronic migraines, Chronic pain, CFS & PMR	10	Yes	No	Weekly
P47 (Woman)	65–74	Parkinsons disease	4	No	No	Once per day
P48 (Woman)	35–44	EDS, Essential tremor, Hashimotos thyroiditis & IBS	36	Yes	No	Once per day
P49 (Woman)	25–34	Cerebral palsy	25+	Yes	Yes	Once per day
P50 (Woman)	25–34	Asthma, ADHD, ASD, Chronic migraines, Chronic pain, Chronic gastritis, Depression, GAD, Gastroparesis, IBS, Non-allergic rhinitis & Severe allergies	25+	No	No	Once per day
P51 (Man)	25–34	Severe myopia	5	No	No	Multiple times per day
P52 (Woman)	25–34	Adenomyosis, EDS & Endometriosis	13	Yes	No	Multiple times per day
P53 (Man)	35–44	Bone spurs, Neck & Back disk herniations	13	No	No	Multiple times per day
P54 (Man)	55–64	Thyroid cancer	2	No	No	Multiple times per day
P55 (Non-binary)	35–44	PTSD & Treatment-resistant depression	35+	Yes	No	Multiple times per day

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