ABSTRACT

Title of Thesis: *"I'm not alone in this"*: Co-managing
                     stigmatized chronic health conditions

                     Shaan Chopra
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Thesis Directed by: Professor Eun Kyoung Choe
                     College of Information Studies

People living with chronic health conditions often have to take care of multiple
medical, logistical, and everyday tasks, including monitoring symptoms, following
treatments, going for appointments, as well as managing work, familial, and social
obligations. Unlike shorter illnesses, chronic health conditions are lifelong, often
requiring constant monitoring and management, and as such, it is challenging for
the individual to manage their daily life alongside their health, all by themselves.
Further, people often experience stigma around their self-image and abilities due
to their chronic conditions, further making acceptance of and life with the condi-
tion challenging. In this work, I look into how people living with chronic health
conditions informally share the responsibility of managing their health and affected
daily life activities with people in their close circle. I conducted in-depth interviews
with 16 people living with chronic health conditions who collaboratively manage
(or "co-manage") at least some aspects of their health with people in their close
circles. I report on their (a) current co-management practices, including their use of

technology to facilitate the same, and (b) experiences with stigma and its impacts on disclosure, support-seeking, and communication around their health, in different environments. I found that people appropriated different tools and technologies to monitor, coordinate, and collaborate with their co-managers. The nature of their relationship with co-managers and the physical or virtual space within which they co-managed were also key in shaping their current practices. I further identified avenues for designing technology to support people's diverse co-management needs, such as collaborative tracking, shared-space coordination, and navigating stigma during disclosure and support-seeking, contributing to HCI literature on designing for stigmatized health topics, chronic health management, and collaborative care.

"I'm not alone in this": Co-managing stigmatized chronic health conditions

by

Shaan Chopra

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Advisory Committee:
Dr. Eun Kyoung Choe, Chair and Advisor
Dr. Amanda Lazar
Dr. Beth St. Jean

Dedication

This study is dedicated to both people living with chronic health conditions, often facing stigma around their health, and the co-managers whose support helps them navigate the world.

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Finally, I would like to thank all the participants who spent time and shared their lived experiences with me, making this research possible.

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List of Abbreviations

EDS	Ehlers-Danlos syndrome
GAD	Generalized Anxiety Disorder
IBS	Irritable Bowel Syndrome
OCD	Obsessive–Compulsive Disorder
MDD	Moderate Depression Disorder
PCOD	Polycystic Ovarian Disease
PCOS	Polycystic Ovary Syndrome
POTS	Postural Orthostatic Tachycardia
PTSD	Post-Traumatic Stress Disorder
TMJ	Temporomandibular Joint

Chapter 1: Introduction

Collaborative management of health is a commonly observed practice done by many people, including those living with chronic health conditions. Many at times, there is no formal set-up (e.g., caregivers, patient-doctor relationships) that enables this, but a motivation to see oneself or the other person get better. I define *collaborative management of health* (or co-management hereafter) as the "*practice of informally sharing at least some responsibility of managing one's health with one or more people in one's close circles.*" Co-management is different from other forms of social support (e.g., through online support forums) as one works closely with someone they know well or is close to, who I call *co-managers*, to manage and possibly monitor their health and daily life activities affected by it. Further, depending on the nature of the chronic health conditions, people may experience internal or external stigma which influences their co-management practices as well as the arrangements they may have with their co-managers.

This thesis focuses on understanding how people living with chronic health conditions, who face or have faced stigma around their health, co-manage their health and daily life activities with people in their close circles. I aim to understand people's current co-management practices, including challenges they face in disclos-

ing (or not disclosing), seeking support, and communicating about their health, in different spaces and with different people. I further envision the role of technology in facilitating chronic health co-management within varying environments (e.g., workplace vs home, virtual vs co-located living).

1.1 Motivation

Involving other people in managing their health, especially by sharing health information [1, 2, 3] and caregiving responsibilities [4, 5, 6, 7], is a common practice seen among people living with chronic health conditions. While existing studies extensively look at how people living with chronic conditions leverage online forums to seek informational support [8, 9, 10, 11, 12, 13] as well as disclose about and deal with stigmatizing experiences [14, 15], there is a gap in terms of understanding how people with stigmatized chronic health conditions might be informally collaborating within their close circles of family members, friends, and colleagues—people who are not their doctors or formal caregivers—and within different environments (e.g., workplace vs home, virtual vs co-located setting) to share the responsibility of performing concrete chronic health management tasks (e.g., tracking and monitoring their health, managing medications and other logistics, helping with everyday activities, and providing physical and emotional support) that go beyond information-sharing and how their co-management decisions might be shaped by the stigma they experience associated with their conditions. It is important to study this gap because owing to the lifelong nature of chronic health conditions, they often require

constant monitoring and management, and people living with such conditions cannot always just stop doing daily life activities because of their chronic health. Thus, support from close ones in managing everyday tasks, including medical, work, familial, and social obligations, and receiving physical and emotional support, can go a long way for supporting people living with chronic health conditions.

Past research by Skeelz and colleagues [16] has identified the potential of technology to overcome barriers to social support that breast cancer patients seek/receive from their family and friends. In addition to identifying the types of tasks in which help would be useful to breast cancer patients, the authors prototyped their ideas using the Facebook Connect Platform, because Facebook as a social network has proven useful for promoting awareness among peer groups [17] and professional environments [18]. On the other hand, in our previous study on understanding people's lived experiences with Polycystic Ovary Syndrome (PCOS) [8], we observed that participants often tracked and co-managed their health with people close to them (e.g., parents, partners, friends) and found the stigma associated with the chronic condition to be key in defining their communication, collaboration, and support-seeking practices around their health, including who they chose to co-manage with and the kind of tasks they sought help with. I was interested in extending these works with the aim of broadening the understanding of co-management and one-on-one informal support to other stigmatized chronic health conditions people have.

1.2   Research Questions

To understand current co-management practices of people with chronic health conditions experiencing stigma, including challenges they face in disclosing, seeking support, and communicating about their chronic health conditions, and the potential role of technology in facilitating co-management, I address the following exploratory research questions in this thesis.

RQ1: How do people living with stigmatized chronic health conditions co-manage their health and daily life activities with people in their close circles?

  (a) How do their experiences with stigma impact their co-management practices, including disclosing, seeking support, and communicating about their health?

  (b) How do their co-management practices vary depending on the space they are in and relationship they share with co-manager(s)?

RQ2: How well do existing tools and technologies help to meet people's varying co-management needs within different environments (e.g., workplace vs home, virtual vs co-located living)?

1.3   Approach

To answer the above research questions, I conducted an in-depth interview study. The goal of the interviews was to learn about people's lived experiences with their chronic health conditions, especially their practices around co-managing their health with people in their close circles. The interviews further focused on

understanding why people felt stigmatized due to their chronic conditions and how this stigma impacted their co-management practices in different environments and with different people. Thus, to understand the influence of stigma on their co-management practices and disclosure decisions, I recruited participants who reported they face or have faced stigma associated with their chronic health conditions.

I thematically analyzed the interview data and reflected on my findings to provide design recommendations for technologies that can better support people's co-management practices.

1.4 Outline of Thesis

My thesis is structured as follows. Chapter 2 details the related work covered to understand past HCI research on dealing with stigma, collaborative care, and chronic health management. In Chapters 3 and 4, respectively, I present the methods used and findings from this study. In Chapter 5, I reflect on the findings and discuss future research opportunities and technology design implications for facilitating co-management of stigmatized chronic health conditions. Lastly, Chapter 6 is the conclusion from this research.

Chapter 2:   Related Work

This chapter delves into past HCI work around chronic health management, particularly research on designing for stigmatized health conditions and collaborative chronic health care. I ground my work at the intersection of chronic health, stigma, and informal collaborative care.

2.1   Designing for stigmatized health conditions

Stigma, being as personally-defined and subjective as it is [19], is often associated with different health topics and has become a growing area of interest within the CSCW and HCI communities. Prior works have covered a wide range of stigmatized health topics (e.g., menstruation [20, 21, 22, 23, 24, 25, 26, 27], menopause [28, 29, 30], HIV [31, 32, 33, 34, 35, 36]), including chronic health conditions such as PCOS [8], cancer [37, 38, 39, 40], and mental health conditions [14, 41, 42, 43]. A key portion of these works tends to focus on technology design for navigating stigma in order to seek social support and access proper health care. For example, Maestre and colleagues studied the use of online technology by people living with HIV and found social media to be key in coping with public HIV-related stigma [35]. They noted that participants disclosed their status and experi-

ences with others on social media in order to access social support but often took precautions (e.g., using fake IDs, resorting to anonymity) to navigate public stigma. The authors also identified tensions around disclosure and non-disclosure (e.g., social rejection, confidentiality breach, missed peer-to-peer support) and proposed a more "emphatic" and "respectful" approach for designing online technologies for people coping with stigma around their health. On the other hand, intimate care technologies, such as *Curious Cycles* [27], *Future Flora* [44], and *Labella* [45], took a slightly different path, helping people deal with "internalized" or "self" stigma associated with their health and bodies by encouraging them to closely *look, touch,* and *interact* with their bodies. Thus, past HCI work has explored technology design for dealing with both societal and internal stigma around health.

In our previous work on PCOS, we also found stigma to be key in shaping people's lived experiences with their chronic condition, including their communication, collaboration, and support-seeking practices [8]. We further observed that participants sought informal one-on-one (or "co-management") support around their health from people close to them (e.g., parents, partners, close friends) and stigma, again, was a defining factor for who they chose as their co-managers and what kind of tasks they co-managed with them. Thus, building off that work, I explore how people's experiences with stigma specifically impact their collaboration and co-management practices around a wide range of stigmatized chronic health conditions.

2.2 Collaboration and Support in Chronic Health Management

HCI researchers have extensively studied collaboration practices of patients living with chronic conditions around their health. Sharing health information [1, 2, 3, 46] and care responsibilities [4, 5, 6, 7, 47] are common forms of collaboration. While prior work has examined people's online support and information-seeking practices around their chronic health [8, 48, 49, 50, 51, 52] or designed technology to support chronic health management in collaboration with formal caregivers [4, 5, 6, 7], a set of studies have also looked into collaboration with informal caregivers, including family members [1, 46, 47, 53, 54, 55]. For example, Pang and colleagues uncovered information-sharing practices of patients within their close circles in order to keep them informed about the patient's health and take on certain roles during the patient's treatment [1]. Similarly, Miller and colleagues discussed the involvement of informal caregivers of pediatric patients in care tasks and patient-provider interactions during in-patient stays [46, 47]. While an alternate line of work questions the ethics behind parental caregivers accessing medical data of adolescent patients [53, 54], Miller and colleagues stressed the importance of having parental or informal caregivers physically present in the pediatric patient's hospital room in order to receive detailed information about the patients' care and act upon it [47]. Contributing to such physical management tasks, being present or co-located with the patient, also falls under our definition of co-management.

Other research also focuses on the patient perspective on the kind of support they want from their family and friends. In a study with breast cancer patients,

Skeelz and colleagues examined the different types of tasks around which patients seek/receive social support from their family and friends, identifying the potential of technology to support the same [16]. The authors code different support tasks as medical-related tasks, managing/coordination tasks, everyday chores, and other ways to help. These tasks often required extensive collaboration, coordination, and communication between patients and their caregivers. Further, Consolvo and colleagues defined the term *Computer Supported Coordinated Care* (CSCC) as the area of coordination systems that can help caregivers in coordinating, allocating, and assigning care tasks [56]. The authors emphasize emotion, trust, and privacy as the underlying principles and important system design considerations to support CSCC and keep people health. Resonating with these underlying principles of CSCC, other researchers discussed the potential of collaboration and coordination between multiple informal or family caregivers for not just providing patients appropriate care but also balancing their other responsibilities, such as work and parenting [46, 47, 55, 57]. I extend the aforementioned understanding of social support and coordination to co-management of stigmatized chronic health conditions with the aim of designing technology that supports informal collaboration around more concrete chronic health management tasks (e.g., managing medications, helping with everyday activities, and providing physical and emotional support).

Further, effect of stigma on people's informal collaborative care practices around their chronic conditions, particularly with specific people in their close circles and within different environments (e.g., workplace vs home, virtual vs co-located living), is understudied in HCI. One such environment is the workplace. Prior stud-

ies have identified the advantages (e.g., feeling accepted in the work environment regardless of health conditions one has and receiving supportive workplace accommodations [36]) and disadvantages (e.g., receiving insensitive remarks and dismissive treatment [58]) of disclosing stigmatized health conditions as well as examined strategies that people use to do disclose or conceal their conditions [15]. While such disclosure might lead to receiving reasonable accommodations at the workplace, what is not known is how disclosure might be leading to the formation of chronic health co-management arrangements in the workplace. Another environment is the living space or home. While past works have looked into shared-space technologies (e.g., digital whiteboards [47]) for facilitating collaboration between people who have chronic health conditions and their informal caregiver(s), there is further potential in studying chronic health co-management within co-located living settings and how the shared space can facilitate co-management decisions. Thus, my work explores the different ways in which technology can be designed to support chronic health co-management in such varied environments (specifically, workplace vs home and within virtual vs co-located settings), including supporting collaboration, coordination, and communication around stigmatized chronic conditions.

2.3   Summary

Stigma around certain chronic health conditions often makes it difficult for people living with those conditions to communicate, seek support, and collaborate around managing their health. Past work demonstrates the importance of disclo-

sure, coordination, and collaborative care for chronic health management. Studies on information-sharing, collaborative care, and social support for chronic health management highlight the advantages and disadvantages of current tools and technologies that facilitate the same. However, one-on-one informal collaboration or co-management of stigmatized chronic conditions, especially the affect of stigma on co-management decisions within different environments, has not been studied before. This thesis delves deep into understanding this problem space from an HCI and technology design perspective.

Chapter 3: Methodology

This IRB-approved remote study took place from December 2020 to March 2021 in the U.S. My goal was to develop a deeper understanding of different aspects that shaped participants' experiences with co-managing their health condition(s) with people in their close circles and identify avenues for technology design to better support their practices and needs. I present my methodology below. I acknowledge that people living with chronic conditions have diverse experiences informed by multiple factors, including the nature of their health conditions and their cultural backgrounds. This is to emphasize that the group I am studying is not homogeneous in terms of the kinds of chronic health conditions they have or the cultural backgrounds they come from but they are all people who are living with chronic health conditions, have faced stigma around their health, and co-manage their health with people close to them. Moreover, I decided not to limit to only certain health condition(s) because it is difficult to define what a "stigmatized" chronic health condition is. People's experiences with stigma can be very personal [19] and it did not seem right to simply label certain chronic conditions as "stigmatized" based on my external view of them. Thus, I felt it important to let the people living with chronic conditions self-identify their condition(s) as stigmatized based on their

personal experiences instead of restricting recruitment to people whose conditions I felt might be stigmatized.

3.1 Participants

3.1.1 Recruitment and Screening Survey

Participants were recruited using a combination of snowball [59] and purposive sampling [60], using both electronic means (e.g., listserv, Facebook groups, Twitter, Reddit) and word-of-mouth. They were first asked to fill out a screening survey (see Appendix B). For participants to be eligible for the study, they had to (1) be 18 years old or above, (2) have one or more chronic health condition, (3) have experienced stigma associated with their chronic health condition, and (4) be sharing at least some responsibility of managing their health condition(s) with people in their close circles. My fourth inclusion criteria ensures that I recruit people who exhibit co-management based on my definition (see Section), thereby having co-managers (people who share at least some responsibility of managing the patient's chronic health and affected daily life activities by performing concrete chronic health management tasks such as tracking and monitoring their health, managing medications and other logistics, helping with everyday activities, and providing physical and/or emotional support), although participants might have not used the exact terms (i.e., co-manage, co-manager). In order to further contextualize our findings, I added a constraint that eligible participants must be currently living in the U.S. I decided not to limit participants to having certain health conditions as it was tough to sim-

ply label chronic conditions as "stigmatized" based on my external perspective. In addition to the screening questions, demographic details (e.g., age, gender, country of birth, race) of participants were collected. Further, participants were asked to list their chronic health conditions and year/age of diagnosis (for each one of them) and select the type of tasks they got help/received support from others on (question choices created based on a modified version of the coding scheme used by Skeels et al. [16] for different support tasks). The purpose of these questions was to tailor individual interviews and appropriately probe participants about their health conditions and co-management practices. Lastly, email addresses of participants were collected to contact them for scheduling interviews in case they met the eligibility criteria.

3.1.2   Demographics

A total of 39 participants filled out the screening survey out of which 17 met the eligibility criteria and agreed to participate in an hour-long online interview. One participant dropped out of the study after scheduling the interview. Table 3.1 shows the demographic details of the 16 participants and Table 3.2 details their chronic conditions, year/age of diagnosis, and type of tasks they got help/ received support from others on.

Participant ID	Gender	Age	Race	Country of Birth
P1	Female	24	White	United States
P2	Female	24	Asian	India
P3	Male	30	Asian	Pakistan
P4	Female	31	White	United States
P5	Female	23	White	United States
P6	Female	25	White	United States
P7	Female	24	White	United States
P8	Female	22	White	United States
P9	Female	43	White	United States
P10	Female	23	White	United States
P11	Nonbinary	28	White	United States
P12	Male	28	White	United States
P13	Female	33	From multiple races	United States
P14	Agender	23	Asian	United States
P15	Female	23	Asian	United States
P16	Female	23	From multiple races	United States

Table 3.1: Demographic details of interview participants

Participant ID	Chronic Health Conditions	Year/Age of Diagnosis	Co-management Tasks
P1	POTS	20 yr	Everyday practices & lifestyle measures, Coordinating tasks, Provide emotional support, Other ways to help
P2	PCOS	18 yr	Medical-related tasks, Everyday practices & lifestyle measures, Provide emotional support
P3	IBS Psoriasis	15 yr 26 yr	Everyday practices & lifestyle measures

P4	Escobar Syndrome, hearing loss, vision loss, adrenal insufficiency, chronic pain	11 months early childhood early childhood mid-20s mid-20s	Medical-related tasks, Everyday practices & lifestyle measures, Coordinating tasks, Provide emotional support, Other ways to help
P5	Crohn's disease, fibromyalgia, chronic migraines, inflammatory neuropathy, rheumatoid arthritis, PCOS, depression, anxiety, bipolar disorder	2017 2019 2017 2019 2020 - - - -	Medical-related tasks, Everyday practices & lifestyle measures, Provide emotional support, Other ways to help
P6	Chronic migraine, endometriosis	8 yr 23 yr	Medical-related tasks
P7	Endometriosis, IBS	2018 2015	Everyday practices & lifestyle measures, Provide emotional support
P8	Endometriosis, PCOS, POTS, GAD, depression	2015 2015 2019 2019 2019	Everyday practices & lifestyle measures, Provide emotional support
P9	Narcolepsy with cataplexy	2002	Coordinating tasks, Provide emotional support
P10	Endometriosis, costochondritis, GAD, MDD, PTSD, OCD	2018 2017 2017 2017 2017 2018	Medical-related tasks, Provide emotional support

P11	Fibromyalgia, migraine, bipolar 2	23 yr 16 yr 25 yr	Medical-related tasks, Everyday practices & lifestyle measures, Provide emotional support, Other ways to help
P12	EDS, asthma, depression, GAD	25 yr 7 yr 23 yr 23 yr	Medical-related tasks, Everyday practices & lifestyle measures, Coordinating tasks, Provide emotional support
P13	PTSD, anxiety, OCD, dysthymia	14 yr 14 yr 14 yr 14 yr	Everyday practices & lifestyle measures, Provide emotional support, Other ways to help
P14	PCOS, TMJ Disorder, sleep apnea	2010 2020 2020	Provide emotional support, Other ways to help
P15	Bipolar disorder, pelvic floor disfunction	14 yr 22 yr	Provide emotional support, Other ways to help
P16	Depression, anxiety, bipolar 2, eczema	2018 2018 2020 2015	Medical-related tasks, Everyday practices & lifestyle measures, Provide emotional support, Other ways to help

Table 3.2: Details of chronic health conditions and co-management tasks of participants

3.2   In-depth Interview

Post screening, I conducted in-depth individual interviews, each lasting between 35 to 60 minutes, with 16 participants. The goal of the interview was to learn about participants' lived experiences of co-managing their chronic conditions and their technology use in collaboratively managing and communicating about their health. I further wanted to understand whether their co-management set-up helped them better manage themselves as well as deal (or not deal) with the stigma that accompanied their health conditions.

I began by querying participants about their chronic health history, including how they discovered and got diagnosed with their conditions. Participants were then asked to detail their symptoms, management techniques (e.g., medical treatments, diet, things to avoid), and how those affect their daily lives, including challenges they faced. I further sought to understand why they felt stigmatized because of their chronic health conditions. I questioned them about their experiences with stigma and how they dealt with it (e.g., ignoring it, taking active steps to call out on others). Next, I queried participants about their current co-management and collaboration practices around their health. Participants were asked about who their co-managers were, what kind of a relationship they shared with them (including how they disclosed to them about their chronic conditions), and what kind of support they receive from them. Finally, I learned about participants' experiences of using technology to co-manage and communicate about their health with their co-managers. I focused on identifying opportunities for technology design to bet-

ter support their co-management needs (e.g., *"What kind of support do you feel is lacking in the technique or tool you use for co-managing your chronic condition(s)?", "Can you tell me about a time your co-management technique or tool did not work the way you wanted it to?"*). In case the participants got confused with technique/tool-related questions or reported to not use any specific physical or digital tools to co-manage their health, I asked them to reflect on how they communicated about their health with their co-managers and whether they used any physical objects or technology (including phone calls, text messaging, etc) for the same. This way, I tried to gauge if participants were appropriating existing tools or technologies to meet their collaboration, coordination, or even communication needs around their health.

All the interviews were remotely conducted via Zoom. Due to COVID-19, any sort of in-person study procedures were avoided. Informed consent was obtained via a digital consent form and permission to audio-record was also taken from each participant before the interview. All audio recordings were transcribed word-for-word for analysis. For one participant (P3) who preferred not have their interview audio-recorded, manual notes were taken. Participants were compensated with $30 for taking part in the interview.

3.3 Data Analysis

I subjected the interview data to thematic analysis [61], which involved using a combination of open and axial coding [62]. I first read and open-coded each

interview transcript line-by-line and then clustered codes based on emerging patterns in the data, such as *panic caused by ill-timed support-seeking messages* and *lack of quick responses to support-seeking messages.* I further grouped conceptually similar codes to form higher-level themes such as *challenges in virtual co-management.* I performed this process iteratively to formulate higher-level themes that structured my findings.

While I lead the data collections and performed the analysis, I remained in touch with another project member (i.e., my advisor) who provided feedback through the data collection and analysis stages.

3.4 Ethical Concerns and Study Limitations

The interview procedure was constructed based on the approval of our university's institutional review board (IRB). I made sure to maintain the privacy of participants while reporting quotes by anonymizing any personal data [63] and pseudonymous identities [64].

A major limitation of my study lies in the generalizability of the findings from the interviews. The recruited participants had a broad variety of chronic health conditions and come from different cultural backgrounds, making it impossible to generalize their experiences with their respective conditions to provide all-encompassing technology design recommendation for addressing co-management needs. Thus, the goal of this qualitative research is not to generalize but to uncover unique experiences of individuals and how they inform their specific co-management needs. Moreover,

an additional screening criteria ensured that all participants currently live in the U.S., an important consideration given that understanding accounts with the U.S. healthcare system is key to contextualizing their experiences. I also note that all my participants were aged between 22 to 43 years old. While this skew may be due to the use of digital means for recruitment, I also acknowledge that it was a conscious choice to not recruit older adults as designing to address their collaborative care needs becomes a whole different area of research.

Lastly, it is important to acknowledge the effect of the COVID-19 pandemic and quarantine on participants' work and personal space boundaries, health-related experiences, and co-management practices.

Chapter 4: Findings

Below, I present my findings from the interview study. The findings are split into five sections. The first four sections contextualize existing co-management practices of participants in terms of (1) the *space* of interaction, that is, the workplace and co-located living space (or "home") and (2) the *relationship* of participants with their co-managers. The last section details technological and physical means participants use to facilitate their existing co-management practices as well as their aspirations from the same. I present my findings below, referring to the quotes by participants using P#.

4.1 Disclosure (or non-disclosure) to facilitate co-management in the workplace

4.1.1 Motivation and means to disclose (or not)

Almost 50% of our participants shared their experiences with managing and disclosing (or not disclosing) their chronic conditions at their workplace, and how that affected their work and relationships with co-workers. In the workplace setting, disclosure was the step that most often preceded the formation a co-management

relationship. Participants report on multiple reasons that drove their decision to disclose or not disclose about their chronic conditions at their workplace. For example, disclosure could be driven by the need to seek reasonable accommodation. P1, who identifies as disabled, noted that *"some amount of accessibility can help [her],"* so her decision to self-disclosure was motivated by her need *"to be supported in"* specific ways (e.g., having people to help her walk to classes). Similarly, P9 negotiated accommodation when being hired for his current job such that he did not have to work overnight, *"needed to be able to go home at certain times a day,"* *"get rest,"* and *"just sort of be off the clock."* For P4, who lives with a more physically visible chronic condition, disclosure comes in the form of having *"honest conversations"* with her supervisor about her varying *"productivity or efficiency level(s)"* on particular days and is driven by the need to have certain strategies in place, such as *"mak(ing) sure that other people are trained to do my [her] tasks, so that someone can step in if they need to."* In other cases, the disclosure was driven by the co-worker's inquiries. For example, P7 shared about her endometriosis with a male co-worker when he noticed and asked about her health. For P9, these inquiries were a result of *"dramatic incidents"* that took place and were very *"noticeable."* For example, at a previous job, P9 had a Cataplexy episode right after a meeting wherein he ended up falling on the floor and co-workers who did not know what exactly was going on, felt the *"need to call the ambulance."* This led to him having an *"after-the-fact conversation"* with his co-workers, clarifying to them about his chronic condition, and convincing them that he was *"really okay."*

In certain scenarios, participants (P6, P7, P9, P11) did not want to disclose

about their chronic conditions because they wanted to stay employed and did not want others to think that they are not capable of doing their job. For example, because of a past negative experience, P11 noted becoming *"more strategic about what I [they] talked to people about"* in relation to their health at the workplace, giving vague information such as *"[they are] going to a doctor's appointment"* instead of explaining what they were actually experiencing. Other participants, too, correlated their decisions to not disclose to past negative experiences which made them uncomfortable. For example, P6 narrated an incident wherein she made a *"minor and fixable"* mistake in a task but was screamed at by a superior at work. Though she reported this incident to a higher supervisor, explaining how her endometriosis flair-up impacted her capability to work, her concerns were rather unempathetically met as the higher supervisor told P6 to just *"suck it up"* and that *"[she] should just be able to deal with it."* On the other hand, one participant felt that her chronic health condition was *"a very personal thing"* (P7) to bring up to her boss or co-workers. Some decisions to not disclose were also driven by the current virtual work environment created by the pandemic. For example, P9 did not feel the need to disclose about his chronic condition to a new co-worker because *"she wouldn't really notice that there's anything going on."* He also felt that it would be *"awkward to do it [disclosure] by email"* as he had *"only ever done it [disclosure] face-to-face"* and *"never put it in writing."*

Thus, disclosure and non-disclosure of chronic health conditions at the workplace was motivated by various factors, including co-worker inquiries, wanting reasonable accommodation, and not wanting to be judged on working ability.

4.1.2 Impact of disclosure

Disclosing about their respective chronic conditions at the workplace had different impacts on different participant's jobs, work-life, and co-worker relationships. More positive impacts included receiving reasonable accommodation (as in the case of P1, P4, P9, P10) and finding co-workers who were understanding of the participant's experiences with their chronic conditions. In the case of P1, P7, P9, and P10, one or more of their co-workers actually became co-managers (see Table 4.1) who shared some responsibility of managing the participant's health conditions (e.g., by being on the lookout to physically assist them, advocate for them) at the workplace. P10 noted how she developed *"a very casual relationship"* with one of her previous bosses who was understanding about her chronic health issues, knew *"the drill,"* and accommodated her on occasions she needed. Thus, for these participants, disclosing about their chronic health conditions to their co-workers or bosses led to the formation of co-management relationships which helped them better manage their health at the workplace.

However, our participants reported on a greater number of negative experiences of disclosing about their chronic conditions at their workplace. For example, on learning about their multiple chronic conditions, P11 was forced to fill-out disability paperwork at a previous job, deeming them *"not fit to perform the duties of this [their] position"* when their need was just for some more accommodation. P6 actually ended up losing a job when an endometriosis flair-up impacted her work and her supervisors did not take her condition seriously.

Thus, I noted that disclosure became easier and was more likely to form workplace co-management relationships when the participant was in an environment where people are understanding. For example, in P1's case, she works in accessibility research and is *"around a lot of people with disabilities"* who *"understand how to accommodate me [her] and to know to ask to accommodate me [her] far more"* and *"their entire work revolves around supporting people with disabilities."* So for her, the self-disclosure was *"a very easy conversation to have"* and was met with people coming out to actively support her, including with physical tasks such as allowing her to hold someone's arm when walking to class. She also makes sure to *"do the same"* and accommodate her blind friends or friends who use wheelchairs (e.g., *"if there's a restaurant that's not wheelchair accessible, like, we won't go there"*) in the way they accommodate her. In this specific case, P1 actually ends up creating a safe environment for herself at her workplace by *"surrounding yourself [herself] with people who get it"*, and as a result forming co-management relationships with them. She reports how her workplace co-managers have helped her get out of emergency situations (e.g., *"I've gotten really sick on the bike path, like travelling to school before and I'll just sort of like send an SOS at people and be like, 'Hello, like, I've kind of collapsed on the bike path. Can someone please come help me?' My [co-worker] actually ended up running out to come get me since he knew where I was."*) and are *"on the lookout to help me [her]"* when needed.

Thus, in an amicable scenario, disclosure at the workplace led to people receiving reasonable accommodation as well as forming co-management relationships with co-workers who were understanding and accommodating of their needs within

the work environment.

Participant ID	Co-manager(s)	Currently living with at least one co-manager?
P1	Partner, labmates/work colleagues	Yes
P2	Mother, few close friends	No
P3	Mother, work colleagues	No
P4	Parents, sister, best friend	Yes
P5	Husband, grandparents, husband's family	Yes
P6	Close friend	Yes
P7	Mother, partner, work colleague	Yes
P8	Parents	Yes
P9	Wife, children, work colleagues, local friends	Yes
P10	Bible study group, work colleague	No
P11	Partner, sister, some family members	Yes
P12	Best friend	No
P13	Partner, mother, few close friends	Yes
P14	Best friend, childhood friend	No
P15	Mother, brother	No
P16	Roommate, few close friends	Yes

Table 4.1: Details of relationship participants shared with their co-managers, including whether they are currently co-located with at least one of them.

4.1.3 Effect of workplace co-management on stigma

Our participants indirectly noted the impact of disclosure on addressing stigma and misunderstandings they faced or would otherwise face at their respective workplaces. As reported in the previous subsection, in an amicable situation, a co-management arrangement is formed between the participant and one or more of their co-workers. While workplace co-managers of our participants had a wide range of roles, some of these were more directly tied to addressing or navigating the stigma

participants faced at the workplace, either from other people around (external) or from within (internal). One such role was advocating for the patient's needs, including actively accommodating them (e.g., as done by P4 and P10's bosses and P1's research supervisors), and in general, being considerate about the patient's conditions while making decisions. For example, P1 notes how her labmates try to actively accommodate her needs (e.g., not walking to far off restaurants for lunch as it would make her sick), which *"makes you [her] feel less stigmatized, less down, less depressed, makes you [her] feel like you [she] can be more of like a healthy human being."* Such consideration and accommodation, in turn, also helps her combat internal stigma and frustration with her chronic condition. Another way workplace co-managers tried to navigate the stigma around their co-worker's chronic condition was by trying to empathize with and normalize their experiences. For example, when P1 was struggling with brain fog, her supervisor tried to normalize the situation and according to P1, even empowered her by saying that *"even your [P1's] thoughts with brain fog are more valuable than not having your [P1's] thoughts."*

In contrast, sometimes the way that workplace co-managers tried to assist their co-workers drew attention from others, in some ways bolstering external stigma. For example, one of P9's co-workers who was *"very good about working with me [P9],"* grabbed him by his shoulder in front of his industry contacts at a trade show when he saw that P9 was *"about to have an issue"* and may possibly fall down. However, P9 felt that the suddenness of this action not only shocked and interrupted him but also drew some quizzical looks from people around.

However, in general, having workplace co-managers who accommodated their

needs that arose from their chronic conditions, helped participants deal with the internal stigma they felt about their abilities (including work productivity and efficiency) and in other cases, even navigate external stigma they faced from others at their respective workplaces.

4.2 Management and coordination in the personal living space

4.2.1 Co-located living with co-manager(s)

Ten out of 16 participants reported to be currently living with one or more of their co-managers, including one participant who lived in the same building as her main co-manager (see Table 4.1 for details of the current living situation of all participants and the relationship they share with their co-managers). All ten participants reported that living together with (or near) their co-managers brings in a unique dynamic into their co-management relationship, especially since they are not physically meeting with a lot of people owing to the pandemic. However, even with a co-located living situation, the type of support participants seek or receive from their co-managers (see Table 4.2) differs a lot and is heavily informed by their relationship with their co-manager(s) and the home dynamic (e.g., living in a family vs living with roommates).

Six participants reported that their co-managers assisted them in a lot of physical management tasks and also provided *"active service."* For example, P1 explained the active service her partner provided, especially on a bad day: *"If I'm super dizzy, I'll ask him to refill my water, I'll ask him to give me something to*

eat or pass my computer so that I can work." P6's friend helped by *"picking up my [her] prescriptions... bringing food or... whatever I [she] need(ed) when I'm [she's] not feeling well."* P5's husband helped her with similar things (e.g., bringing medications, making food, taking P5 for doctor appointments) but went a step ahead and also tried to provide P5 physical comfort and pain relief (e.g., by rubbing her back when she was in pain). P8's parents also helped their daughter in similar ways, by being on the lookout for when their physical assistance could be required.

> *"My dad is much more I think the physical helper / co-manager in the sense that, sometimes even just like picking me up from high school, if I had a lot of textbooks, like he would carry the bag for me or other really tiny things like that."* (P8)

P4's parents often helped her with daily physical tasks such as showering, getting dressed, and meal prep. P9, on the other hand, who lived with his wife (main co-manager) and children, noted that a major chunk of the co-management responsibilities that his wife took on were *"logistical support [things] with the kids"* that he could not do because of his chronic condition (e.g., driving kids to school or for activities) and not so much of directly managing his medical needs or chronic health. So for P9, the active service part of co-management came *"in terms of [supporting and managing] the family."* Moreover, three participants (P3, P4, P18), including two who used to live with their parents when they were younger, noted being accompanied for medical appointments by their parents who would speak with the doctor and even advocate for them when their concerns were not being heard.

These participants also noted that the biggest benefit of having a co-located co-manager was that the emotional support and understanding they received from them was in the form of direct physical actions, which was not always possible on an everyday basis if the co-manager lived away from them. For example, P13 acknowledged that her partner *"liked to take care of me [her]"* and if it was not for her partner, P13 *"probably wouldn't eat three square meals a day."* Similarly, P16 noted how her roommate would prompt her to do things such as go for a walk with him if she had been in bed all day or tempt her to get out of bed by making her favourite food. P4 described her parents as her *"safety net"* because she felt safer just knowing that they were physically around to monitor her health and take care of things if something was to happen to her. Thus, understanding and doing actions to make the patient feel better, actively prompting them to *"check in"* with themselves, or even just being physically there or participating in things they did as a part of managing their health or self-care, were valuable to participants living with their co-managers. Moreover, the common context provided by the shared space allowed participants and their co-managers to use their surroundings, including physical objects, to facilitate coordination and collaboration essential for co-management (see Section 4.5.1).

On the contrary, some participants, such as P13 and P15, also noted negative experiences of living with some of their co-managers (e.g., their over-involvement in their medical processes, making fun of their chronic condition, not believing they had a certain chronic condition). In these cases, to be in a better space to manage their health, participants found it beneficial to move out from living with these

co-managers and maintaining their co-management relationship remotely.

4.2.2 Asking or not asking for help

Almost all participants, especially those who lived with one or more of their co-managers, said that they often received assistance from their closest co-managers without having to explicitly ask for it. For example, P13 shares how *"thoughtful"* and understanding her partner is:

> *"She [P13's partner] just helps me. That's so relieving in the sense that, you know, usually you always have to, like, ask for help. When someone knows what you're going through, like, they know you're stressed out, they know you're stretched thin, they know you're anxious and frustrated or whatever, but they don't do anything... they're not really like there for you even though they're there physically. With this relationship, it's very interesting that she'll [her partner] just do things without me asking... It's nice to have a very supportive partner, who can like just kind of predict your next movement without you asking them to do anything"*
> (P13)

Similarly, in the case of P8, her dad is *"great at like being in the background and seeing where holes are, or like seeing where needs aren't being met, and just swoop in and take care of those, even if I [P8] don't necessarily realize that I need help with something."* To show a contrast *"between a family who understands it and lives it every day, and then people who don't,"* she also narrated an incident with

her ex-boyfriend who refused to assist her in a way that her dad had been assisting her (and her mother) for years.

However, participants also reported feeling guilty asking for help. For example, P1 shared how on a bad day, say when she is feeling too dizzy, she would ask her partner to help with small active tasks (e.g., getting her water, passing her stuff); she felt bad about this as she did not want such tasks to be her partner's responsibility, especially since she is perfectly capable of doing these tasks on days when she is not feeling sick. On the other hand, P9 felt guilty for not being able to take on a lot of parental responsibilities (e.g., when his children were infants, he could not stay up at night because of his chronic condition) and his wife took on most of the hard work. Thus, he tried to not actively ask for a lot of assistance from his wife who already *"took on most of the hard work,"* including being a strong emotional support for him. P4 also subtly hinted at how she did not want to ask her parents for help especially at the last moment (e.g., driving her to office when her sister cancelled on her) because they have their full-time jobs and would get late. She further added that for her, *"making sure that everybody involved has clear expectations of who is doing what"* is important since she has had trouble in the past coordinating and co-managing her health conditions.

Thus, while having co-managers who lived with them and understood their chronic conditions made them feel more comfortable and supported, a certain guilt or unwillingness to ask for help arose when participants felt that they would further add to their co-manager's responsibilities and burden them by asking for further assistance.

4.2.3 Easing burden of active services on co-managers

As a means to ease the burden of certain tasks on co-managers (and avoid feeling guilty for burdening them), participants noted avoiding asking for help when not absolutely needed. In P1's example discussed earlier, she would only ask her partner to help with active service tasks, such as getting her things, only on a bad day, when she was feeling *"super dizzy."* Similarly P4, shared how she tried to do things mostly *"independently"* but sometimes depending on how she felt, she ended up having her parents help with tasks such as *"dressing [up], showering, meal prep, pretty much everything."*

On the other hand, participants such as P7 who started noticing trends in their productivity and pain levels, shared this information with their co-managers in a way to keep them informed and possibly ease the burden on them by being able to contribute to activities (e.g., household chores) when in a good state:

> *"If I'm noticing like a trend in the data that I'm collecting, I'll be like -*
> *hey, I'm realising I'm entering like my five day window of no pain. So*
> *like, anything we want to get done should be done between these dates,*
> *because I have a feeling like after that, nothing much is gonna get done."*
> (P7)

Thus, coordinating with co-managers, as well as keeping them informed about how they are feeling helped in some ways ease the burden of certain co-management responsibilities, especially active service tasks.

4.3 Virtual co-management support

4.3.1 Types of virtual support

All our participants reported seeking and/or receiving some sort of support from their co-managers virtually. While in some cases virtual co-managers were not as involved as co-located co-managers, in other cases virtual co-managers shared a unique set of responsibilities as compared to co-located co-managers. For example, P16's co-located co-manager helped her more with physical tasks such as providing active services and tracking her mental health, while her virtual co-managers were people who had experience with similar mental health conditions and in turn majorly provided her emotional support as well as empathized with her struggles. In case of participants such as P2 and P3 who are currently living alone in the U.S., away from their families based in South Asia, their current virtual co-managers were actually their main co-managers (e.g., their mothers) who had been involved in managing their health since the very beginning.

Virtual co-managers helped participants in living with their chronic health conditions in a wide range of ways. Emotional support was a big thing that multiple participants (e.g., P2, P12, P14, P16) reported their virtual co-managers provided. While the emotional support virtual co-managers provided was similar to as provided by some in-person co-managers, virtual co-managers could not perform the complementing physical management tasks (e.g., making food for the participant, helping the participant get dressed). The level of involvement and type of emo-

tional support provided online also varied. For example, in P12's case, his virtual co-manager was a close friend with whom he shared a *"family-type relationship"* and they would stay connected via text messages or as P12 noted:

> *"We spend a lot of our time on Zoom, just having Zoom open and doing whatever tasks we need to do... just so we don't feel quite so alone."*

Along with providing emotional support, P12's co-manager also regularly checked in on him via text and reminded him to do things (e.g., eat something, take pain medication, put on sunscreen). Similarly, P14's best friend provided them emotional support as well as practical advice; they often texted him to get things *"off my [their] chest"* but *"did not expect a quick response."*

Another way in which virtual co-managers supported participants was by keeping tabs on them. As noted by P12, his friend would regularly check on him. Similarly, P2 had her virtual co-manager, her mother, keep very active tabs on her health, particularly checking whether P2 was getting her periods or not. P2 emphasized how to discuss her health, her mother and she *"just communicated through phone [call]... that was our [their] main medium, not even text, just phone [call]"* as it allowed them to converse in much more detail and was easier as compared to text messaging, indicating that the medium of communication was important to facilitate their virtual co-management. P3, on the other hand, reported that his main co-manager, his mother, would very occasionally check in on him and his health (e.g., whether he was taking his medications), again primarily via phone calls. However, P3's mother did not dedicatedly call or message him to ask about

the details of his health; it was always a part of a larger conversation.

Other ways in which co-managers provided virtual support included playing games together, distracting each other, and doing self-care together online. Lastly, it is also important to acknowledge that given the COVID-19 pandemic, virtual co-management was a common practice I saw participants undertaking, even with people they otherwise met or were earlier co-located with.

4.3.2   "Realistic" expectations from and challenges of virtual support

While virtual connectedness, including seeking and/or receiving virtual support, became a common practice for participants, there were multiple challenges they faced. For example, P1 and P14 highlighted the problems ill-timed support-seeking messages could cause:

> "Sometimes if I just need emotional support, like I'm super sick... I just need someone to tell me something happy and talk to me. Sometimes I'll send like that to multiple people to see who's up... like, if it is at two in the morning, I'll be like, okay, who's up at two in the morning and... I'll message a couple of people. And finally, someone will help and so I won't respond to the other people, because like, I'm getting help... And so the other people will be left wondering like, 'Are you okay'... 'please let me know, when you get home' or... 'are you in need of anything else?"' (P1)

Also due to the asynchronous nature of texting, P14 described how they did not

expect *"quick"* responses to texts sent to their virtual co-manager. On the other hand, P2 and P3 shared how over time, physical distance from their co-managers and infrequent communication reduced the extent to which their co-managers could support them virtually (e.g., P2's mother *"doesn't keep a log of it [P2's periods] anymore"* but just occasionally asks about it when she remembers). Similar to the guilt participants felt in asking their co-located co-managers for more help, P13 and P14 also expressed hesitation in "reaching out" for help to their online friends especially when they were aware that the other people might be busy or dealing with their own things.

Thus, these challenges of and expectations from virtual support often limited the scope of co-management, at times even giving rise to misconceptions that needed to be clarified.

4.4 Co-manager's awareness about and engagement with patient's health

4.4.1 Level of awareness and engagement

Different co-managers had varying levels of awareness about the participants' conditions which often influenced their level of engagement with managing their health as well as the tasks they co-managed with participants (see Table 3.2 and Table 4.2).The level of awareness and engagement ranged from providing super hands-on co-management support (e.g., actively tracking and keeping regular tabs on the patient's health, regularly reminding them to do things including taking

medications, and providing active service during sickness) to occasionally checking-in with them to helping when *"reached out"* to or just emotionally being there for them to just being considerate and understanding of their conditions.

Tracking and monitoring the patient's health was one very hands-on way of co-management. Three participants (P1, P2, P16) reported how their main co-managers actually observed, tracked, and assessed certain variables of their health. For example, P1's partner tracked her *"exercise, food, water, what was your [P1's] average dizziness for the day, your [P1's] maximum, maximum and average nausea, amount of water I [P1] drink, what medications I [P1] took, blood pressure, and heart rate"* by asking her at the end of the day. He maintained a spreadsheet of her health data and had a *"Jupyter Notebook with a bunch of scripts"* for visualizing and analyzing her health data. However, P1 noted that they had not yet used this data to moderate any of her management practices. P2's mother had a more manual calendar-based tracking system in which she would just mark or *"put a circle"* on the date P2 had her periods. Her tracking mechanism was such that no one besides her mother understood *"what data was being tracked on it [the calendar]."* P2 noted how they shared this tracked information with her gynecologist and also used it to decide when to consume medications, including home remedies (e.g., *"when drinking ginger water for home remedy, you are not supposed to drink during your period... you're supposed to stop like four days before"* (P2)). Similarly, P16's roommate observed and used a paper-based notepad to track her *"mood shifts and periods where I'm [she's] unusually energized or talkative"* as they are all the signs of mania. However, at times, P16 felt *"a little awkward"* when she could see her roommate taking notes,

giving her the feeling that she's *"being observed or watched."*

Types of tasks	Example	#Participants who co-managed these tasks
Medical-related tasks	Come to a doctor appointment, assist with self-care, ensure they are comfortable after surgery, help with keeping track of medications & following treatments	8
Everyday practices & lifestyle measures	Help with household chores, cook for them, make sure they eat, exercise, sleep, and do everyday chores.	11
Coordinating tasks & logistical support	Booking appointments, make sure they get to the doctor, help with transportation, ensure they get to work, organize calendar	4
Provide emotional support	Being there with them in good and bad times, talking and providing conversational support, motivating, mourning	14
Other ways to help	send cards/flowers/cakes, come visit, help sort out work issues, spend time with them	7

Table 4.2: The different types of tasks that participants' co-managers helped them with or shared at least responsibility of managing.

Other participants, such as P4, P8, and P13, reported how their co-managers *"just kind of monitor(ed) how I'm [she is] doing overall"* (P4) or *"check(ed)-in"* (P13) on them from time to time, making suggestions or asking questions about how they felt. P12's co-manager went a step ahead and sent him frequent reminders

to do *"general self care tasks, like sleeping and eating and medication."* These methods, too, are on the higher end of the spectrum in terms of engagement from the co-manager in managing the patient's health and resulting life-style.

On the other end of the spectrum, P13 noted how some of her close friends supported her but only when she *"reached out"* and asked them for emotional support. This is where the definition of who the participant considered to be their co-manager got unclear. In some cases, participants (e.g., P2, P3, P16) also reported that people who they considered to be their co-managers (e.g., friends, co-workers) did not even know the full details of their health condition or even that they had any chronic health conditions. For example, P3 shared how he engaged in *"longer chit-chats"*— which he would not count as emotional support—with his colleagues when he got IBS episodes due to the stress at work because these colleagues were unaware that he had this chronic condition.

Thus, the level at which co-managers engaged and were aware about the health condition varied significantly across participants, their differential needs, and their relationships and understanding with their respective co-managers.

4.4.2 Who has the control?

Another important factor that influenced the co-manager's level of awareness and engagement with the patient's health was that who was taking on the burden and in control of tracking and keeping tab on the patient's health. One side of this was that the co-manager took the direct initiative of tracking or monitoring the

patient's health. For example in the case of P1 and P2, their respective co-managers wanted to see them *"get better,"* and thus took on the responsibility of asking the questions and tracking their health. P1 shared that she was actually *"fine with the way things are,"* that is her partner taking charge of tracking her health, because her own *"experience of tracking has been kind of sad"* and she has no motivation to *"investigate and look for trends"* in her health data. Similarly, in P4's case, her parents took the initiative of monitoring her overall health and well-being, and asking how she felt on days they noticed something odd (e.g., *"you've been more tired lately,"* *"you've been wanting to use the ventilator more,"* *"you seem to be asking for help with more activities than usual"*). In P16's case, while her roommate did track her moods and take notes on her mental health, he had been asked by P16 (and her therapist) to do so because she often found herself under-reporting periods when she was feeling exceptionally positive or happy (signs of mania). So while P16's co-manager was continually involved in tracking P16's health, he was not the one who initiated it.

On the other side, some co-managers were not actively involved in health monitoring or in control of what was being monitored; they were more like receivers of information while the people with the chronic health conditions exercised full control over their health data and management practices. For example, P5 talked to her grandparents and her mother-in-law about the journal she maintained to track different aspects of her health, just so that they were *"aware"* about what is going on and how she was dealing with her multiple chronic conditions. While P5's co-managers were not actively involved in her health tracking and monitoring, they

were made aware of P5's health and management practices. Similarly P8 noted that her parents were *"aware"* that she kept track of her health and food but she did not do any *"direct"* or *"super detailed"* health data sharing with them.

In some cases, participants were very particular not to share their direct health records or self-tracked health data with their co-managers. One participant (P11) reported a negative incident in which their ex-partner, who was formally put on P11's paperwork *"abused this power"* by calling up P11's psychiatrist *"to try to get [them] prescribed Adavan, which is not something I [P11] was prescribed."* After this incident, P11 made sure they *"do not have anyone else on my [their] health records that can like speak to my [their] doctors for me [them]"* and tended not to *"formally share data with people."* Similarly, P13 noted that no matter how understanding her partner was as a co-manager, she did not share the notes she made and data she tracked around her mental health *"with anybody."*

But while sometimes co-managers were simply receivers of information, multiple participants, including P11 and P13, collaboratively made sense of their health data with their co-managers along with sharing the reflections and insights they drew from it. For example, P16 noted how her roommate and her shared and collaboratively tried to make sense of the information they both tracked around P16's mental health; they *"look(ed) at it [P16 and her co-manager's tracked data and notes] visually together,"* *"talk(ed) through it,"* and tried to assess whether *"the medication was working in the way I [P16] wanted it to."* P15 also noted that while she did not directly share her detailed *"patient portal information,"* she showed some of her test results to her mother, who was a nurse, so that her mother could help *"read*

some of my [P15's] charts for me [P15] and help me [P15] analyse them."

Thus, who has the control in the co-management relationship and who takes on the burden of tracking and monitoring the patient's health, were important considerations tied to the co-manager's level of awareness and engagement with the participant's health.

4.5   Technological and physical means to facilitate co-management

4.5.1   Physical cues and tools

Six participants reported using physical or paper-based tools to facilitate co-management, mostly with their co-located co-managers. They used these for a variety of purposes, including coordination, health tracking, and collaborative sense-making.

One purpose physical tools were used for was to facilitate coordination between co-located co-managers. For example, P9 coordinated various family activities and commitments—an essential part of their co-management arrangement—using a paper calendar in their kitchen:

> *"who has what, or who is doing what, who's taking which kid where, and knowing about, sort of, when one of us makes an appointment for the kids, you know, 'oh, this is the time of day when I could do it!"'* (P9)

However, when it *"got to the point where the kids have more activities than we can really fit on a standard sized calendar"*, they migrated to a shared *"family*

electronic calendar", though their communication became mostly face-to-face due to being home quarantined during the pandemic. Besides calendars, journals and other physical objects such as sticky notes were also used by participants (e.g., P13) to manage themselves but by the virtue of being *"left open"*, they were often read by their co-managers. While these did not necessarily serve the purpose of facilitating coordination, they were a physical medium used by the co-manager to perform small gestures and show the participant that they cared for them.

> *"I did notice that recently I had one of my journals open and she [P13's partner/co-manager] wrote, like, on the bottom of the page 'I love you.' She leaves me little notes like that at random places... So once in a while, like, she'll surprise me and write somewhere I didn't think she was looking"* (P13)

Health tracking and collaborative sense-making was another purpose for which physical and paper-based tools were used. For example, in P2's case, her mother used to track her periods on a *"publicly hung"* calendar in the kitchen of her house. However, once P2 felt that after she moved away from home, her mother did not use the calendar as much as she used to. P16's roommate wrote down *"detailed and contextual"* observations about P16's mental health in his paper-based notepad. They found this method of tracking very beneficial as P16's co-manager's notes were *"really good for providing extra context"* about *"why her data looks the way it does."* Similarly, P5 also tried to maintain a journal to track her various chronic health conditions. She noted that while she is *"super into apps and technology,"* she

could not find one that could track her *"multiple chronic illnesses and everything else that's going on,"* closely resonating with findings from my past work wherein people with PCOS were unable to find mobile apps to tracked their PCOS alongside other health variables, including their comorbidities. P5 further shared what she wrote and tracked in her journal with her co-managers, telling them in as much detail as possible about what she was going through and how she was dealing with everything.

Thus, because of the widely flexible ways in which paper-based items could be used, they became an important means to facilitate some aspects (e.g., coordination, health tracking, collaborative sense-making) of co-management.

4.5.2 Technology-supported facilitation

All participants reported using technology to facilitate co-management. Different purposes of use included coordination, collaborative health tracking, collaborative sense-making, and communication (including general check-ins and SOS messages as well).

One main purpose was to facilitate coordination essential for co-management. For example, P9 and his family used a *"shared iCloud calendar"*, as it *"helps a lot in coordinating."* P9 noted the value of being able to sync his work and personal/family calendar as it supported *"double bookkeeping of key family activities that might intrude in the working workday,"* in turn helping better coordinate and manage family commitments with his wife (main co-manager). Similarly, P13 and

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her partner (main co-manager) maintained a shared Google calendar which they used to send invites and set reminders to do self-care activities (e.g., stretch before bed, put eye-mask) together. However, P13 noted that since her partner was not very tech savvy, she would *"verbally say she wants to do something"* but it would be P13 who would create a reminder or event on the Google calendar and share it with her partner, who would then accept it. Additionally, P13 shared that while they set up reminders in order to *"prioritize our [their] self-care"* and *"things we [they] want to do together,"* they never actually ended up doing the planned activities, even when the *"calendar is like constantly going off for a reminder."* Thus while a calendar could help the participants and their co-managers organize and coordinate their activities, it was up to them to actually implement and follow what they planned for.

Collaborative health tracking and sense-making was another aspect of co-management that was facilitated by digital systems. One participant, P1, and her co-manager used an *"Excel spreadsheet - Jupyter Notebook combo"* to track, visualize, and analyze P1's health data. P1 noted that at one point in time, she was *"trying to keep a bullet journal to help track these things [P1's health paramters]"* but while *"pretty and artistic,"* the data was *"static"* and they could not *"easily compare things"* or *"put it into a different visualization."* Thus her partner/co-manager, who is a software engineer, resorted to writing his own computer programme to track and visualize P1's health data.

Further, basic communication, a key requirement for facilitating aspects of co-management, too, was facilitated using various tools. Once again, it is important

to acknowledge that a lot of these practices were altered or shaped by the pandemic. Participants used video calls via Zoom or FaceTime to connect with their co-managers who lived away from them. For example, P12 and his co-manager spent *"a lot of our time on zoom, just having zoom open and doing whatever tasks we [they] need(ed) to do."* P8 noted how she texted, called, or FaceTimed her parents when she lived alone at college and *"if I [P8] was FaceTiming them, I [she] was probably feeling overwhelmed"* and just wanted to see *"a familiar face"* or her pets or her house in the background as *"it was nice to have something else to focus on while talking about it [her health]."* P8 further added that video calls helped her see faces and learn from people's reactions, something she could not get over the phone. Other participants such as P2 and P3 spoke with their co-managers (for both P2 and P3, their mothers) via call as their co-managers were not tech-savvy or comfortable with texting. P2's mother further communicated about P2's health only through phone calls, *"not even text, just phone [call]"*. Other modes, such as text messages, were used by participants to have asynchronous conversations, stay in touch with their co-managers, receive reminders to perform certain tasks from co-managers, and collectively reach out to co-managers in case of emergencies. P14's co-manager stayed in touch and was always there for them to answer questions and *"helping me [P14] feel better"*, primarily via text. However, P14 did not always expect quick responses from him and also narrated incidents when they needed emotional support at odd hours in the morning but could not reach him. P12's co-manager used text messages to send him reminders to do daily activities such as *"eat something, go to bed, take your pills."* P1 used Slack to contact her labmates, often sending

out *"an SOS on the general Slack channel"* if she was in an emergency situation, such as having collapsed on the bike path. P1 emphasized the importance of group messaging as it was easier to identify *"who is best able to get me [P1] help now"* than having to message different people individually to check for their availability.

Thus, different types of technology facilitated different aspects of co-management for participants; however, there is potential for improving and customizing some of these to better support participants' co-management practices.

Chapter 5:   Discussion

In this chapter, I reflect on the findings and discuss opportunities for future research and design recommendations that can positively influence and support co-management of stigmatized chronic health conditions.

5.1   Co-management and Stigma

5.1.1   Facilitating disclosure and workplace co-management

In sections 4.1, I discussed the disclosure and non-disclosure practices of participants at the workplace, as well as their impact on navigating stigma. While with family and close friends, disclosure was more organic as co-managers "lived through" diagnosis and various experiences the patient had with their health, workplace disclosure was usually different as it was done for a specific purpose, such as for getting reasonable accommodations. While past work has studied strategies people living with invisible chronic conditions use to disclose about their health conditions at the workplace in order to get accommodations and basic understanding from co-workers [15], my study found one of the more positive outcomes of disclosure to be the formation of co-management relationships with co-workers.

To facilitate workplace co-management, tackling stigma, especially during disclosure, was one of the key considerations. However, misconceptions that arose during disclosure often added to the stigma, discouraging people from future disclosures (as seen with P11 being forced to file for disability paperwork at a past job). Past works also note how disclosure at times led to hurtful and judgemental comments [36] and even panic, such as in P9's case wherein uninformed co-workers wanted to call an ambulance when he had a Cataplexy episode at work. These issues arose due to other people's unawareness about their co-worker's chronic conditions. Porter and colleagues, in a study on online dating and disability, discuss the implications of designing platforms that allow people with stigmatized identities (i.e., an identity that is socially devalued with negative stereotypes and beliefs by the virtue of being stigmatized [65, 66]) to negotiate disclosure [67]. Applying the same to workplace setting and inviting open discussions to improve the understanding of people's lived experiences with their stigmatized chronic conditions could be an essential design consideration to reduce stigma around health at the workplace. Another consideration could be to encourage people to disclose their chronic conditions during their orientation periods, in self-introductions, so as to make their colleagues aware from the beginning and reduce misunderstandings later on. However, this could lead to them becoming the "poster child" and being identified as someone living with those specific conditions (e.g., P9 - *"The Narcoleptic Lawyer"*). One the other hand, as noted by other researchers, this could also place restrictions on their work duties and lead to resignation or job loss [36]. An alternate strategy could be to selectively disclose different dimensions of their chronic condition(s), depending on how it may

impact their work, within specific work teams or only with close collaborators. This could help everyone be on the same page as well as potentially navigate the stigma around people with chronic conditions not being "capable" of doing their jobs. Another challenge is unawareness about certain chronic conditions among people at the workplace. From P7's example, we saw how her male co-worker was unaware about what endometriosis was and it took her quite some effort and explaining to make him understand about her condition. Training materials at workplaces—similar to sexual harassment modules and privacy policies documents created for employee training and onboarding—to educate employees about chronic conditions their colleagues have could be used for designing workplace co-management strategies and tools. Moreover, these modules and materials could be co-designed with people living with stigmatized chronic health conditions so as to create contextually-sensitive materials by carefully considering people's unique experiences with their conditions and resulting stigma.

Beyond basic understanding from co-workers, I imagine that a deeper engagement with close co-workers could be formed, with workplace co-managers helping the person manage their chronic conditions at work, concealing (or disclosing) it with others and even advocating for the person when needed. Future research can dive deeper into the dynamics of workplace chronic health co-management, exploring strategies and designing of tools to facilitate effective disclosure to navigate stigma and form workplace co-management relationships.

5.1.2 Advocates, Allies, and Solidarity

Throughout the findings, specifically in 4.1.3 and 4.2.1, I found that co-managers often advocated for patients in different scenarios as well as constituted their safe environment within which they could freely deal with their chronic conditions. Participants (P1, P12) noted having friends and colleagues who advocated for them in getting access to necessities such as a seat on the bus or accommodated them in multiple ways, such as going to restaurants that were a closer walking distance. In a study on dealing with menstruation on the go, researchers found that menstruating women relied on solidarity from other women to "protect" them from stigma they might experience because of a period stain [22]. This echoed with my findings as I saw that co-managers that constituted a participant's *safe environment* were often people who themselves were living with similar chronic conditions or disabilities (e.g., P1's blind friends and friends using wheelchairs) and understood the difficulties, including stigma, participants experienced. There was often a mutual understanding, if not a give and take relationship between the patient and their co-manager(s) (as P1 noted, she did the same to accommodate her blind friends as they did to accommodate her). Future work can investigate this dynamic of mutual understanding and co-management and design to support solidarity among people experiencing stigma in relation to their health.

Since our research participants also had co-managers who were not living with stigmatized chronic health conditions but advocated for the patient's needs, similar to allies for communities such as LGBTQ+ [68], I see the opportunity for recog-

nizing chronic health co-managers as allies who advocate as well as help patients deal with the stigma of their chronic condition(s) and feel empowered. Moreover, research participants noted the role of their co-managers in helping them combat internal stigma and frustration with their chronic conditions. Acknowledging roles of allies, such as respecting safe spaces of patients, acceptance and normalization, education and self-sufficiency, and active engagement in social issues [68], could be an important consideration in CSCW and HCI research around co-management of stigmatized chronic health conditions. Thus, another area for future exploration is to understand and design for supporting allyship along with co-management of stigmatized chronic health condition with the goal of combating stigma around health.

Another specific scenario where co-managers advocated for patients was interactions with doctors, especially when participants (e.g., P2, P3, P4) were younger and were accompanied by their parents for medical appointments. Past research with pediatric patients and their informal caregivers (mostly parents) discuss the caregivers' involvement in patient-provider interactions during in-patient stays [46, 47], highlighting the importance of having caregivers being physically present in the hospital room to receive detailed information about the patients' care or interact with doctors [47]. Applying the same consideration to facilitate co-management during virtual or asynchronous patient-provider interactions such as those facilitated by telehealth or patient portals, co-managers also need be a part of the system and have access to the patient's health information. Moreover, in order to advocate or bear "witness" to the patient's experiences in out-patient settings, co-managers may also need access to add their own notes and observations on the portal. However,

some participants, such as P11, had bad experiences with putting co-managers on their health records, so granting more control to patients to choose what health data they wish to share with co-managers on the patient-provider portal could be a key design consideration, as also noted by past works on pediatric and adolescent care [53]. An alternative could also be to create two sections on the patients portal; one for health records and the other for reporting experiences and advocating for the patient's needs. Patients can then individually customize access to the two sections depending on the capacity of involvement they desire from their co-managers on their health records as well as on the advocacy front, separately or in tandem. Future research can explore the design of patient-provider portals that support adding multiple co-managers, giving them variable access to health information, and allowing co-managers to add their own observations and advocate for the patient's needs.

5.2 Technology-Supported Co-management

5.2.1 Shared-space coordination & collaboration systems

I found that in co-located settings, co-managers performed a variety of co-management tasks, including providing *"active service"* and helping with everyday things such as showering, meal prep, and driving to work. A lot of these tasks took place in the background, that is, though they were not directly tied to addressing medical needs of patients, they were necessary to support smooth functioning of the patient's daily life which was affected by their chronic health condition(s). Moreover,

these co-management tasks often required collaboration and coordination between the patient and their one or more co-managers, strongly resonating with past work that discusses collaboration and coordination between multiple informal or family caregivers to support patients while balancing their other responsibilities, such as work and parenting [46, 47, 57]. Further, Computer Supported Coordinated Care (CSCC) emphasizes emotion, trust, and privacy as important considerations for designing coordination systems to support caregivers in allocating and assigning care tasks and keeping the patient healthy [56]. I extend a similar understanding to coordination and collaboration done to facilitate co-management, wherein co-managers not only coordinate with other co-managers but directly with the patient as well to distribute care tasks and daily life responsibilities.

In section 4.5, I discussed a wide array of physical and digital tools used by participants to co-manage their conditions, including coordinating various tasks with their co-managers. Physical tools such as shared calendar, sticky notes, and journals, were used by multiple participants but fell short in terms of not being dynamic, interactive, and scalable. Thus, replacing or augmenting physical tools with digital ones could add to the interactivity of the interface as well as allow dynamic exploration of the data added. Another important consideration for shared co-management tools could be to allow multiple co-managers to distribute responsibilities, giving them the provision to directly take notes and add events. This could be on the same lines as to how P1 appropriated her lab Slack group to seek co-management support from her multiple lab mates at the same time by sending them a group message instead of individual messages and seeing who was in the

best position to respond to her immediate help requests. A digital whiteboard, such as the one suggested by [47], placed in a shared space between the co-manager(s) and patient, could provide valuable common context, allowing co-managers to better understand the patient's status and possible co-management needs. This could in turn facilitate better two-sided collaboration in a co-located setting and potentially reduce the burden on co-managers, allowing them to better plan, coordinate, and balance their co-management care responsibilities with other responsibilities. It could further act as a CSCC system [56], allowing coordination across multiple co-managers (e.g., multiple family members living in the same house) and between the patient and co-managers, to provide appropriate care to the patient while also balancing other responsibilities and activities impacted by the patient's chronic health (e.g., P9 and his wife coordinating to manage their children's various activities). Further, allowing remote co-managers to view and contribute to the digital whiteboard could make it suitable for virtual co-management as well.

However, given the added dimension of stigma, people might feel hesitant to have co-management tools such as a digital whiteboard in a shared space, especially spaces which non-co-managers also have access to. In such a scenario, the privacy consideration of the CSCC system is compromised [56]. Inspired from P2's mother's practice of tracking P2's period on a shared calendar in the kitchen of their house in such a way that no one apart from her knew what was being tracked, an important design consideration for shared-space co-management tools could be to allow users to customize how they encode the information they are entering in the shared-space co-management system. They could use distinctive marks or label the information

entered in different colors so that no one apart from them are aware of what information is being entered. Another consideration could be to allow selective visibility and password or biometric-protected access to information on the system. Users could additionally choose to lock the screen when other people are around.

Another issue reported by participants related to using digital tools for coordinating with their co-managers was the lack of "tech savvy-ness" by one or both sides. For example, P13's co-manager was unable to create events on Google Calendar and would just accept the ones she received invitations for. This, too, can be addressed by a collaboration tool such as the digital whiteboard wherein participants can just write or "scribble" onto it and don't have to type to enter information in specific areas. Future work can focus on designing and evaluating concrete digital interfaces which can facilitate in-home coordination and collaboration between patients and co-managers, finding the right balance between entering information in a flexible manner and have an organized interface. I further believe that aligning with key design considerations of CSCC—emotion, trust, and privacy—is a promising direction for creating shared-space co-management tools.

5.2.2 Reminders and check-ins

Communication between patients and co-managers took place for a variety of important purposes, for example, for reminding purposes, crying out for help, and seeking information, when needed. Out of these, sending reminders and checking-in with patients from time to time emerged as a common way of co-management

performed in both co-located and virtual settings. Co-manager's engagement and check-in frequency also varied across participants, as seen in section 4.4. In the situations in which patients were co-located with their co-managers (e.g., for P4, P8, P13), talking was the simplest way to check-in and keep tabs on the patient's health. Shared-space co-management systems discussed in section 5.2.1, could also support reminders with the potential of further being linked to people's individual mobile devices; that is, a co-manager could set a reminder using the shared-space co-management system and the system could then accordingly send a timed reminder to the patient. This set-up could support co-managers in balancing patient care with their other activities responsibilities by setting reminders beforehand so that they don't have to wait for the appropriate time to remind the patient.

There is further potential to support check-ins and reminders in virtual co-management. Miller and colleagues found that caregivers used video-conferencing for remotely participating in the patient's care during in-patient stays [47]. This resonates with my findings on virtual co-management wherein I observed that co-managers frequently communicated with patients using voice or video calls (e.g., Zoom) to stay informed about the patient's condition and care needs. While at times these calls were not specifically aimed at addressing healthcare-related issues, check-ins and reminders happened as a part of them (e.g., P3's mother checking-in on his health as a part of larger phone conversations). Past research also reports commitment and time issues caused by video calls, making them secondary in preference to voice calls [1]. Another medium commonly used for check-ins and reminders is text messaging. As seen in P12's case, his co-manager reminded him to do daily activi-

ties, including take medications. Further, P12 leveraged visual cues such as different colored boxes to separate his various medications. A potential consideration could be to augment phone-based reminders directly with physical medication boxes. Past researchers have proposed Internet of Things (IoT) based smart medicine reminder devices to remind people to take medications on time [69]. These are self-sufficient devices and do not require co-managers to operate them. However, given the added dimension of stigma that my participants experienced because of their chronic conditions, I believe that having a human presence in the operation of the system can make patients feel more comfortable using it. Co-managers can be directly involved in reminding patients, ensuring they follow procedures and don't slack off as chronic conditions require lifelong management. Thus, a mechanism that allows the co-manager to send a reminder (or signal) directly to the patient's physical medication box could help further streamline the medication reminder pipeline, removing the text message intermediary which a patient may tend to ignore or forget about. The medication box could light up or display a text message reminding the patient to take specific doses of their medications. Future research can expand this idea of IoT-based systems to remind patients about other things beyond medications. Moreover, researchers can look into the affordances of different communication mediums and explore their use in supporting different co-management tasks of stigmatized chronic conditions, especially for virtual co-management.

5.2.3 Collaborative tracking and health monitoring

In section 4.4 I saw one of the most hands-on ways of co-management to be tracking and actively monitoring the patient's health. Co-managers observed, tracked, and assessed different variables of the patient's health as well as explained their observations to patients so that they could act upon them. Either both the patient and co-manager tracked separately and then shared their observations in an attempt to collaboratively make sense of the tracked data, or I found that co-manager took on majority of the tracking burden and then shared their observations and understanding with the patient for them to act upon. Thus, I see potential in supporting varying levels of collaboration in health tracking. Existing health tracking apps, specifically period and fertility tracking apps such as Clue and Glow offer the ability to add collaborators and share information with them but *"not necessarily all information"* [70]. While I imagine the patient having complete advocacy and confidentiality over their data, designers may consider allowing patients to share varying levels of information with different co-manager(s) depending on the nature of their relationship, type of information, and sensitivity of the information and context within which it is being shared. Additionally, following from my findings, patients can grant co-managers access to contribute directly to their health tracking, allowing them to add their own notes and observations. Patients and co-managers could even choose to make, and possibly even hide, their separate observations until they decide to share those with each other to collaboratively make sense of the data. The other extreme in which only the co-manager takes the load of tracking

can also be facilitated by collaborative tracking applications wherein the patient is able to see what their co-manager is tracking while not having to track any data themselves. However, similar to what I found in our previous work on living with PCOS (also a stigmatized chronic condition) [8], there might be a tension between sharing and collaboratively tracking a lot of personal and sensitive information with co-manager(s) and maintaining the privacy and comfort of the patient. Future work can tap deeper into understanding these boundaries in collaborative tracking and take those considerations into account while exploring the design of collaborative tracking applications. Similar to social networks, collaborative tracking applications can allow patients to specify their privacy settings, allowing different co-managers access to different types of information and varying their ability to directly collaborate in the patient's health tracking. Patients could also edit permissions for individual variables, giving them more nuanced control over their health data.

I also found other factors that influenced participants and their respective co-managers' choice of tracking. One reason for choosing physical or paper-based tools for tracking was the flexibility they provided, including the ability to add detailed and contextual notes. Thus, an important design consideration for collaborative tracking tools could be to allow users to add detailed notes and specify varying contexts along with making data entries. Secondly, participants, such as P1, also appreciated the ability to dynamically visualize their tracked data as a means to supporting collaborative sense-making. Patients and their co-managers could also choose to create different visualizations depending on what they aim to understand from the individually or collaboratively tracked data. Such visualizations could

further be used by patients to provide evidence for their medical records while communicating with providers, as also discussed in previous works [71, 72]. Moreover, as seen in my previous work [8], these visualizations could be used for directly sharing health data with doctors or even co-managers, bypassing detailed conversations around sensitive health variables (e.g., menstrual blood flow). Thus, dynamic and interactive visualizations can be useful in supporting collaborative tracking, including individual and collaborative sense-making, while simultaneously bypassing any stigma associated with conversations around sensitive health details. Visualization designers can also explore the possibility of letting patients and co-managers interact, highlight, and comment on different portions of the visualizations and further use those annotations as feedback for adjusting the patients' care and treatment.

Chapter 6:   Conclusion

In this thesis, I presented the results of a qualitative study to understand people's co-management practices to manage their stigmatized chronic health conditions and affected daily life activities with people in their close circles and found their relationship with co-managers and the physical or virtual space within which they co-manage to be key in shaping their experiences and current practices. I found that co-managers had varying levels of awareness and engagement in managing the patient's health depending on how much support the patient desired, which also impacted the nature of the tasks that co-managers helped participants with. I also noted the effects of stigma associated with having a chronic health condition on how participants disclosed, sought support, and communicated about their health in varied environments, such as the workplace or at home. I identified opportunities for designing co-management technologies that address people's diverse range of needs and support their current co-management practices while adapting to varied environments they co-manage their health in. I described the potential role of chronic health co-managers as allies and advocates and discussed strategies for navigating stigma around disclosure to facilitate workplace co-management. I also provided recommendations for technologies that can support coordination in co-located

and virtual setting, including collaborative tracking and computer-supported coordinated care. Lastly, I contribute to a growing body of HCI and CSCW research by contextualizing my findings in light of recent works on designing for stigmatized health topics, chronic health management, and collaborative care.

Appendix A: Recruitment Text

Title: Participants needed for design study on chronic health management and collaboration

Are you interested in using technology to manage your health? Would you like to make a contribution to research on how to improve tracking and collaboration for chronic health management? We would like to invite you to participate in an online/remote interview study at the University of Maryland on the management and collaboration practices of individuals living with chronic health conditions.

We are looking for participants who are (a) diagnosed with one or more chronic health conditions and (b) have experienced stigma associated with their chronic condition(s) for a single hour-long online interview. Through this interview, we want to understand your symptoms and the measures you take to track and manage your health alongside the conditions. We also want to understand how you may be collaborating with people in your close circles (e.g., family, friends) to manage your chronic condition(s). To participate in this study, you must be at least 18 years of age and be officially diagnosed with one or more chronic health conditions. Participation in the study is completely voluntary. You will be compensated with $30 for participating in the interview.

Participants will be contributing directly to understanding how to design tracking and collaboration technologies to better support people living with one or more chronic health conditions. Your personally identifiable information will be kept confidential and will not be shared with anyone outside the members of the research team.

To participate, please indicate your interest by filling this screening survey (https://forms.gle/3avbcePTDeP3BLJN8). If you have any questions, please contact Shaan Chopra at schopra7@umd.edu.

Please also feel free to share this to other eligible individuals you think might be interested to participate in our study.

Appendix B: Screening Survey

1. Are you 18 years old or above?

   - Yes

   - No → end survey

2. What is your gender?

   - Male

   - Female

   - Other ──────────

   - Prefer not to say

3. What is your age? ──────────

4. In which country were you born? ──────────

5. Are you White, Black or African-American, American Indian or Alaskan Native, Asian, Native Hawaiian or other Pacific Islander, or some other race?

   - White

   - Black or African-American

- American Indian or Alaskan Native

- Asian

- Native Hawaiian or other Pacific islander

- From multiple races

- Some other race (please specify) ——————

6. Do you have one or more chronic health conditions?

  - Yes

  - No → end survey

7. Which chronic health condition(s) do you have? Please list all. ——————

8. When were you diagnosed with the condition (s)? Please enter the year or age of your diagnosis for each of the conditions. ——————

9. Have you ever personally experienced or are experiencing stigma in relation to one or more of your chronic conditions?

  - Yes

  - No → end survey

  - Don't know

10. I manage my condition:

  - By sharing SOME responsibility with one or more close people

  - By sharing MOST responsibility with one or more close people

- By sharing ALL the responsibility with one or more close people

- I manage my condition(s) all by myself

- Other, please specify

11. Please select any of the following tasks, on which you get help from others. (multiple select)

  - Medical-related tasks (e.g., come to a doctor appointment, assist with self-care, ensure they are comfortable after surgery, help with keeping track of medications and following treatments)

  - Everyday practices and lifestyle measures (e.g., help with household chores, make sure they eat, exercise, sleep, do everyday chores...)

  - Coordinating tasks – more logistical side of things (e.g., booking an appointment, make sure I get to the doctor on time, help with transportation, arrange outings, organize calendar, sorting out billing and insurance logistics)

  - Provide emotional support (e.g., being there with them in good and bad times, talking/conversational support, motivating, mourning...)

  - Other ways to help (e.g., send cards and flowers, come visit me, help sort out work issues, spend time with me)

  - Other(s), please specify ——————

  - I manage my condition(s) all by myself

12. Please provide your email address. We will use this to schedule an interview with you. ——————

Appendix C: Interview Protocol

Introduction Thank you for agreeing to participate in this study. [Introduce self if haven't already]. I am interested in learning about your experiences with managing your chronic health condition(s) and why you feel your condition(s) are stigmatized. In particular, I am looking to get a sense of how you may be sharing the responsibility of managing or what we call "co-managing" your conditions and how self-monitoring and/or collaboration technology can be designed to support you through your experiences.

I'd like to know about your health history and how you were diagnosed

- Can you tell me a little about yourself, including what you do (e.g., studying, working) and your living situation (e.g., living alone, with family, etc)?

- Can you tell me a little about your chronic health conditions?

    – When did you discover that you have [name of chronic condition(s)]? How was it diagnosed? (If needed) What kind of challenges did you face during the diagnosis?

    – What symptoms have you faced in relation to your [chronic condition(s)]?

- What all you do to manage your health condition? (e.g., medications, lifestyle, regular doctor appointments, emotional/mental support, etc)

- What kind of challenges have you been facing in managing and following treatments required for maintaining your health, if any? How would you want to improve your management practices or bypass these challenges?

- In general, how have your [chronic condition(s)] been affecting your daily life? (If needed) What kind of support do you feel is lacking in terms of managing your health, if any?

• In the survey, you mentioned feeling stigmatized by your chronic condition(s). Why do you feel your condition is stigmatized?

- What, for you, is this feeling of stigma? Is it something from within (internal) or caused by others around (external) or both?

- Would you feel comfortable narrating a personal story/incident where you felt that you faced stigma?

- What would/do you do in the case of facing such stigma? How would/do you deal with it? (If needed) Do you share/have you shared such incidents with someone else or do you deal with them on your own?

I'd like to know about your practices of managing and collaborating around your health

• Can you name or tell about the people who you are co-managing with?

- Can you describe your relationship with the person or people with whom you share the responsibility of managing or "co-manage" your condition(s)? If there are multiple people involved, feel free to describe them all.

  – Did you know/bond with your co-manager(s) before your diagnosis or did you start bonding with them only post that?

  – How did you open up about your chronic condition with your co-manager(s)?

- Why do you co-manage your chronic condition(s) with this person/people?

- What all aspects/parameters of your health do you co-manage?

- What mediums do you use to communicate and/or co-manage with them?

- What kind of tasks do you co-manage with them?

- Do you use any tools or technologies to co-manage your chronic health and everyday activities? (e.g., tracking apps, collaborative calendars)

  – Can you elaborate on what health or everyday life aspects you have been using these technologies for?

  – Can you tell me about a time your co-management technique or tool did not work the way you wanted it to?

  – What kind of support do you feel is lacking in the technique or tool you used for co-managing your chronic condition(s)?

  – Have you ever shared your health data or data from co-management tool with anyone?

- Have you ever tried using an online forum or social media to seek/provide support? If yes, how is your co-management experience similar/different from any sort of online support?

- Has co-management in any way helped you in coping or dealing with the stigma associated with your chronic health condition(s)? Why or why not?

- Is there anything you haven't shared yet that you would like to add?

Appendix D: Codebook

Themes	Codes	Example
Reasons for disclosure or non-disclosure at the workplace	Need to seek reasonable accommodation	*"I needed to be able to go home at certain times a day and get rest and just sort of be off the clock" (P9)*
	Driven by co-worker's inquiries	*"I do have a male coworker who I work with very closely... and he's like, 'some days you just don't see well...' and I finally told him" (P7)*
	Not wanting to lose jobs or being seen as incapable	*"[People at my previous job] were forcing me to... officially disclose, which means that they can say, 'you're not fit to perform the duties of this position"' (P11)*
	Made uncomfortable by past negative experiences	*"My direct supervisor was like, 'Oh well, you're gonna have a lot of stress here... you should just be able to deal with it" (P6)*
	Felt condition to be too personal to share	*"It feels very awkward and weird to bring it up... it's like a very personal thing I would say" (P7)*
	Felt no need to disclose in virtual environment	*" I have a new coworker who was hired during the pandemic and we're at mandatory telework right now. So I haven't had the conversation with her because well, I don't need to" (P9)*

Impact of disclosure at the workplace	Receiving reasonable accommodation	*"I more or less got a promise of no overnights, no all-night exercises" (P9)*
	Finding understanding co-workers and creating co-management relationships	*"My colleagues at work... like I have sort of a set of people who are like on the lookout to help me" (P1)*
	Losing their job or being seen as incapable of doing it	*"I made one small mistake that could be fixed very easily... I did end up losing that job because of that incident" (P6)*
Effect of workplace co-management on stigma	Accommodating patient's needs to combat their internal stigma	*"Surrounding myself with people who like who get it is definitely helpful and makes me feel less stigmatized, less down, less depressed, makes me feel like I can be more of like, you know, a healthy human being" (P1)*
	Empathizing with and normalizing patient's internal frustrations	*"she said that 'even your thoughts with brain fog are more valuable than not having your thoughts' which was like very sweet and empowering" (P1)*
	Bolstering external stigma by performing physical tasks in front of others	*"he [my co-worker] saw that I was about to have an issue and he sort of grabbed my shoulder to bolster me... I did get some quizzical looks" (P9)*
Ways co-located co-managers assist patients	Physical management tasks and active service	*"he's picked up my prescriptions... brought food or... whatever I need when I'm not feeling well" (P6)*
	Logistical support and family management	*"I don't do a lot of driving because you don't want to fall asleep on the road... my wife does the driving... getting the kids from point A to point B throughout the day or in the evenings" (P9)*

	Emotional support through direct physical actions	*"I believe that if it wasn't for my partner, I probably wouldn't eat like three square meals a day. Um, I don't do very well on like feeding myself all the time due to the stress and anxiety"* (P13)
Asking (or not) for help from co-located co-managers	Receiving assistance without explicitly asking for help	*"My dad is great at like being in the background and seeing where holes are or like seeing where needs aren't being met, and just swoop in and take care of those, even if I don't necessarily realize that I need help with something."* (P8)
	Feeling guilty asking for (extra) help	*"I would love for that to not be his [P1's partner] responsibility because I do kind of feel bad like continuously asking like, 'Can you do this? Can you do this?"'* (P1)
Easing burden on co-located co-managers	Avoiding asking for help unless absolutely necessary	*"Sometimes I can get dressed by myself but sometimes I can't... it just depends on how I feel and so when I can do things independently, I try to do them but a lot of times, I just end up having my parents help me."* (P4)
	Keeping co-managers informed & contributing to tasks when possible	*"If I'm noticing like a trend in the data that I'm collecting, I'll be like, 'I'm realizing I'm entering like my five-day window of no pain. So like, anything we want to get done should be done between these dates, because I have a feeling after that nothing much is gonna get done."* (P7)
Types of virtual co-management support	Providing emotional support and performing other activities together	*"We spend a lot of our time on Zoom, just having Zoom open and doing whatever tasks we need to do.... just so we don't feel quite so alone"* (P12)

	Checking-in and keeping regular tabs	"a friend will check in on me like once a week, just to see how I'm feeling" (P16)
Challenges in virtual co-management	Panic caused by ill-timed support-seeking messages	"Sometimes I'll send a message to multiple people to see who's up... if it is at two in the morning... I'll message a couple of people and finally, someone will help and so I won't respond to the other people... so the other people will be left wondering like, 'Are you okay?' 'please let me know when you get home' or... 'are you in need of anything else?"' (P1)
	Lack of quick responses to support-seeking messages	"So I'll text him when something comes up... I think a month ago when I was sleeping with the machine... it didn't work. So the next morning, I felt horrible, I just wanted to go to bed all day... So I just kind of sent him a message that I feel like shit, I don't want to do this at all and he was kind of like, I'm sorry... like, I don't expect a quick response" (P14)
	Hesitation in reaching out	"I don't like to burden her [P14's friend] too much because what she is going through... a more severe kind of condition" (P14)
Co-manager's varying levels of awareness and engagement with the patient's health	Tracking and detailed monitoring of patient's health	"My partner tracks my exercise, food, water, what was my average dizziness for the day, your maximum and average nausea, amount of water I drink, what medications I took, blood pressure, and heart rate" (P1)
	Occasionally checking in and monitoring overall well-being	"My parents just kind of monitor how I'm doing overall" (P4)

	Supporting patient when reached out to	*"Every time I reach out to a friend... they always reach back and like say, consider doing this, think about this, take a walk... maybe we should do a Zoom call... but I do have to like... reach out for help" (P13)*
Who takes initiative and has control in the co-management relationship?	Co-manager as a direct initiator of health monitoring	*"My partner helps me track my symptoms... I just find tracking very frustrating because you put a lot of effort into it... He will every day just sort of go down the list and like actually store the data for me and he'll play around with visualizations because he wants to see me get better and understand these things" (P1)*
	Co-manager as a receiver of health information (no direct involvement with health monitoring)	*"I talked to my grandparents and especially my mother in law about the journal that I keep to kind of track my chronic illnesses" (P5)*
	Co-manager as a collaborative sense-maker	*"We look at it [tracked data] visually together and like, talk through it because I was like, trying to... see whether the medication was working in the way I wanted it to." (P16)*
	No direct health data sharing data with co-manager	*"I don't have anyone else on my health records that can speak to my doctors for me... I don't tend to like formally share data with people" (P11)*
Co-management tasks facilitated by physical and paper-based tools	Coordination in a shared space	*"We used to do everything on a paper calendar in our kitchen... who has what or who is doing what, who's taking which kid where... and knowing when one of us makes an appointment for the kids..." (P9)*

	Paper-based health tracking and collaborative sense-making	*"My mother always used to keep track, she used to mark it [P2's periods] on her calendar" (P2)*
Co-management tasks facilitated by digital tools & technology	Coordination within shared and virtual spaces	*"I have like two or three different Google Calendars. So like, I'll write something down, and then I'll just add her [P13's partner] to it, and then I'll send her an invite, and then she'll accept it..." (P13)*
	Digital health tracking and collaborative sense-making	*"He keeps it all in a spreadsheet... he has a Jupyter Notebook with a bunch of scripts for visualizing like, 'how has your nausea changed?', 'What was your running 50 day average for nausea?' or something like that" (P1)*
	Communication with non-co-located co-managers	*"When I lived on my own in college... I just like texting, FaceTiming, talking on the phone with them [P8's parents]... if I was FaceTiming them, I was probably feeling overwhelmed" (P8)*

Table D.1: Codebook generated from thematically analyzing the interview data.

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