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# Collaborative Self-Management of Depression

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## ABSTRACT

Depression is a challenging mental illness that requires individuals to manage their moods and emotions over time. While past mental health literature describes how individuals seek and share support on social media and within online communities, the ways that offline and one-on-one supportive interactions unfold is less clear. To address this literature gap, in this dissertation, I explore the *collaborative self-management* work of individuals managing depression across two studies using semi-structured interviews and visual elicitation techniques. I focus on how these interactions are mediated by technologies across individuals' technology ecosystems.

In Chapter 1 (Introduction), I present the three research questions guiding this dissertation. In Chapter 2 (Related Work), I provide an overview of relevant literature on self-management, collaborative self-management, sociality, and social support. In Chapter 3 (Methodology), I discuss my methodological approach to the studies in this dissertation, utilizing interview and visual elicitation procedures as well as Braun and Clarke's thematic analysis process [30]. In Chapter 4 (Preliminary Study), I present an analysis of my preliminary interview and visual elicitation study (n=30), showing the key importance of sociality for self-management of depression. I describe how individuals connect with specific others to achieve expected support and how these interactions are mediated through locations and communication channels. I discuss how factors including roles, culture, and locations influence participant collaboration. Next, in Chapter 5 (Main Study), I share my remote interview and cognitive mapping elicitation study (n=28). Through this main study I present a deeper understanding of the collaborative self-management practices of individuals managing depression. I describe *who* participants turn to for day-to-day collaborative support, *how* collaborative self-management activities occur (across both

'mood-focused' and 'preventative' practices), and *where* these often technology-mediated interactions take place. I discuss the technology ecosystems utilized in collaborative self-management, highlighting factors influencing channel selection and periods of engagement with support technologies. In Chapter 6 (Discussion: Collaborative Self-Management), I extend the concept of collaborative self-management from the chronic disease domain to mental health. In doing so, I discuss key characteristics — agency, reciprocity, time, and interaction, present a four-step model of collaborative self-management, and discus implications of the COVID-19 pandemic on participant collaborative interactions. In Chapter 7 (Discussion: Implications for Design) I share approaches to future design from an assets-based perspective, describe key technology features that enable collaborative self-management, and consider future technology solutions. Chapter 8 (Limitations) discusses the limitations of the dissertation studies. Finally, Chapter 9 (Conclusion) reiterates the contributions of my research.

The findings from this dissertation make several novel contributions. First, I extend the concept of collaborative self-management from the chronic disease clinical literature to the mental health domain in Human-Computer Interaction. In doing so, I provide deeper conceptual understanding about the characteristics, processes, and roles involved in this critical work from the perspectives of individuals managing depression. Second, I contribute a detailed understanding of the breadth of everyday technology tools and services used to support collaborative self-management. I describe beneficial features, contexts of use, and challenges. Finally, looking across current support technologies and practices, I contribute an understanding of opportunities for designing technology improvements and future collaborative interactions that are sensitive to the needs of individuals managing depression.

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# 1. INTRODUCTION

## 1.1 Motivation

Depression is a major contributor to the global burden of disease. In 2017, 264 million people worldwide experienced major depression disorder [124]. Individuals who manage depression often experience feelings of sadness, negative thoughts, lack of enjoyment of activities, lack of motivation, and agitation and sleep disruption [19]. A key symptom of depression is the tendency to isolate oneself from others, yet social interactions are important for self-managing the condition over time. While previous literature has underscored the importance of social support for individuals managing mental health needs (e.g., [10,273]), we still need to better understand, from the individuals managing depression themselves, how they collaborate with others to support their mental health, across the variety of their day-to-day interaction contexts.

In this dissertation, I extend our understanding of self-management of depression. The "self" in self-management practices implies that these are solitary activities, which is reflected in many individual-focused mental health support tools (e.g., [15,178]). However, as shown in my preliminary study [80] as well as other recent research [83,195] self-management often happens within a social context and involves other people. For instance, in my preliminary study with individuals managing depression, participants connected with trusted people to express their feelings to an empathetic ear, collaboratively develop solutions to ongoing issues, and reduce the intensity of their mood. In this dissertation, I contribute to our understanding of these practices by unpacking the self-management work that individuals managing depression conduct collaboratively with others (e.g., family members, friends, coworkers), which I conceptualize as *collaborative self-management* [167]. Through this dissertation, I describe and discuss this concept

to help us understand the nature of these collaborations and generate knowledge about how we might design to support these essential activities.

In the following chapter, I describe several reasons underscoring the need for knowledge regarding collaborative self-management of depression. These include the need to acknowledge the role that others play in self-management activities, the need to further understand the interactional experience of these collaborations, and the need to address the lack of current mental health support tools that account for collaborative support processes. In filling these literature gaps, this dissertation seeks to provide avenues to better support these collaborative interactions.

### *1.1.1 Collaborative Self-Management of Depression*

Approximately 16.2 million U.S. adults experienced a diagnosable depressive episode in 2016 [284]. Individuals with depression can experience difficulty establishing and maintaining social relationships [231,251]. Feelings of isolation and loneliness may lead to reoccurring challenges in symptom management [125]. Addressing these challenges requires individuals to self-manage their condition to prevent or reduce the intensity of future depressive episodes.

While we know much in the field of Human-Computer Interaction (HCI) about individuals self-managing chronic disease (e.g., [168,169,189,225,238]), we know less about these activities for individuals managing depression. Lack of understanding regarding mental illness self-management makes it difficult to develop solutions to support their work. Further, HCI research studying self-management of mental illness often focus on individual activities. This perspective is reflected in current individual-focused self-tracking and skills practice technologies for depression self-management (e.g., [15,178]). Yet, my preliminary work [80] points to the importance of collaboration and social interaction as a key ingredient of self-management for

individuals managing depression. However, collaborative work in this context can be challenging. Supporting mental health and ongoing management through collaborative means raises concerns about issues such as reciprocity [113] and burden [137]. Therefore, while social connections are clearly important to people managing depression, these same relationships can also be the source of conflicts. Understanding the benefits and challenges of collaborative self-management will be important for future design to support these activities.

While previous literature has underscored the importance of social support for individuals managing mental health needs (e.g., [10,80,273]), we still need to better understand, from the individuals managing depression themselves, how they collaborate with others to support their mental health across the variety of their day-to-day interaction contexts. To do this, I extend the concept of *collaborative self-management* from the chronic disease management literature [14] as a way of capturing the details of these collaborative interactions. Collaborative self-management as discussed in the clinical chronic disease literature largely focuses on patient-provider communication and teaching strategies to manage physical effects of chronic disease (e.g., pulmonary disease [14,69], asthma [66,74]). However, in contrast to this physical symptom orientation, individuals managing mental health needs are likely to have different collaboration goals to support mood and emotion management.

In addition, the individuals who support collaborative self-management in the mental health context often extend beyond a clinical care team to include friends and family members, among others [17,84]. Depression is an important context to explore this work because key symptoms include social withdrawal (the tendency to isolate oneself from others) and lack of

energy and motivation [10]. These symptoms create barriers to collaboration yet also show the importance of collaborative engagement to combat these symptoms.

### *1.1.2 Social Support*

The psychology literature regarding social support underscores the importance of collaboration to support individuals managing depression. This literature has primarily focused on measurement of social support [57,58,216,242], key support roles [31,118] and high-level support activities [57,216]. For individuals managing depression, key roles that provide essential ongoing support include spouses, family, and friends (e.g., [216]). The social support literature also categorizes broad types of social support activities (emotional, instrumental, informational, and appraisal support [57,216]). I provide more detail regarding these categories in Chapter 2.

While the current literature helps us to understand some key support roles and broad support activities, we still need to better understand the granular details of how these supportive interactions take place. Specifically, beyond friends and family, *who* else in individuals' social networks support their depression self-management? *How* do these broad categories of support (e.g., emotional, instrumental) take place in day-to-day interactions? Finally, *where* do these interactions occur, particularly through which mediating technologies? Understanding these situated, contextual experiences will start to provide us the detail necessary for the development of specific technological supports, educational training, and other future solutions.

For instance, based on current literature we know that emotional support from family members is likely to be important to an individual [31,216]. However, it is not as clear how an individual determines *who* to connect with for support. For instance, do they consider issues such as 'Mom is at work during the day,' or 'my friend Alex knows jokes that make me laugh'? *How*

is day-to-day support undertaken, particularly when people are not physically co-located? In addition, *where* does the interaction happen? Collaboration could occur via a variety of technology channels or in-person. Understanding interrelated aspects regarding *who, how*, and *where* will start to provide us with the granularity necessary to create technologies grounded in the lives of individuals managing depression.

### *1.1.3 The Role of Technology in Supporting Collaborative Self-Management of Depression*

HCI researchers have recently begun to examine the ways that people managing mental illness share and receive social support (e.g., [11,273]). However, there are gaps relevant to my dissertation research in the current literature. First, this research, which is largely focused on social media platforms (e.g., [11,35,66,92,106]) and online communities (e.g., [112,155,273]), misses the perspectives of people who are uncomfortable communicating online about their depression as well as in-person and one-on-one digital communication support activities. Indeed, Newman et al. [185] note in their study titled "*It's Not That I Don't Have Problems, I'm Just Not Putting Them on Facebook*," deriving understanding of health and technology discussions solely from posted online content is unlikely to show us the full picture of an individual's health-related activities. Second, while much of the current HCI work in the mental illness self-management context investigates one-to-many communication contexts including Facebook [66], Twitter [247], Instagram [11,92], online health communities [154], and online support groups [273], we still need to understand the role of one-to-one communication including face-to-face interactions, texting, phone calls, video chats, and picture-sharing. These one-to-one methods act as key conduits connecting people for the purposes of collaborative self-management.

Furthermore, while many HCI and CSCW (Computer Supported Cooperative Work) studies have investigated the mental health support potential of technologies (e.g., online health communities [112,155,273], chatbots [107,217]), most studies focus on the impacts of a single technology. However, people routinely use many technology tools in their day-to-day lives. Specifically, given the diversity of technologies that individuals described using for self-management support in my preliminary study [80] (e.g., music, online multiplayer and phone games, texting, phone calls), it is clear that individuals use configurations of tools – often simultaneously and over time – to manage their mental health. Therefore, in order to understand how collaborative self-management is supported by technologies, we need to also better understand how individuals select and use these technologies in the broader context of a technology ecosystem [72]. For instance, do individuals prefer a certain communication channel (e.g., text, video chat) to accomplish this work, or do they select from among different channels depending on contextual factors? Types of support and stigma are likely contributors to the decisions people make regarding technology choice for collaboration, but there may be other issues that we as researchers are not considering yet that push people to use certain tools over others.

Consequently, this dissertation extends our understanding of the ecosystem of technologies individuals use to enable collaborative self-management, and why they use specific technologies within their ecosystem to achieve their collaborative self-management goals. I describe critical enabling features of technologies (particularly direct communication technologies) and where current technologies could be redesigned. For instance, my preliminary study uncovered issues of privacy that make phone or video calls less appealing as avenues of support, especially in workplace contexts or home environments where others could overhear.

Below, I describe the goals and the three research questions I address in this dissertation.

## 1.2 Goals and Research Questions

Given the research gaps outlined in the above section (see Table 1. below, for a summary), I address three goals and related research questions. My first goal was to understand how people conceptualize the work of collaborative self-management. I unpack this work by examining questions of with *who, how,* and *where* these interactions occur. My findings highlight factors that affect these activities and interactions. Factors identified in my preliminary study [80] include relationship roles, mood, and location. In my main study, I show the importance of cognitive state and the preferred channel of the person the individual managing depression is trying to reach.

My second goal was to investigate how technologies shape these interactions, looking at the broader set of tools that individuals use in day-to-day life. I describe how individuals use their technology ecosystems [72] to access support, particularly the ways that certain channels and related features enable and constrain desired collaboration. I also surface challenges where current technologies do not meet individual's goals and desires.

Through gaining insights from the first and second goals, for my third goal, I develop sociotechnical design insights regarding how we might better support collaborative self-management, with a focus on communication technologies. By better understanding the tensions surrounding the use of social technologies (e.g., media "interruptiveness" [184]), we can better support ongoing collaborative self-management through informed design.

My research questions are as follows:

Table 1. Literature Gaps, Dissertation Research Questions, and Areas of Contribution

| **Research Gap** | **Research Question** | **Field Contribution** |
|---|---|---|
| In HCI, self-management, particularly of mental illness, is often viewed as an individual activity. To support individuals and their day-to-day broader health practices and goals, we need to better understand the work of collaborative self-management.<br><br>In Psychology, social support researchers describe who individuals managing depression turn to and their high-level activities. However, we know less about who they conduct this work with, how they carry out these day-to-day collaborative interactions, and where individuals are conducting these practices across technology-mediated and in-person environments. | **1. How do people conceptualize collaborative self-management of depression?**<br><br>▪ Who do they conduct this work with?<br>▪ How do they conduct this work?<br>▪ Where do they conduct this work? | CSCW, HCI Digital Mental Health |
| In HCI, researchers have investigated social media and online communities as sites for collaborative self-management, observing these as standalone support technologies. However, we know less about how people utilize their larger technology ecosystems to gain support, particularly through direct communication tools (video, texting, etc.). It is also currently unclear why people might choose not to use one-to-many online environments (e.g., concerns around stigma, fear of contagion). | **2. How does an individual's technology ecosystem enable or constrain collaborative self-management of depression?** | HCI, CSCW, Digital Mental Health |
| Self-management of mental health is often viewed as an individual activity, and this perspective is reflected in current individual-focused self-tracking and skills practice technologies. However, self-management solutions that focus solely on the individual miss recognizing and incorporating the important support provided by social circles around the individual. Yet simply making support technologies "social" is unlikely to solve current challenges, especially as these individuals may experience negative moods while using social media. Social connections are clearly very important to people managing depression; however, these same relationships can also be the source of conflicts. | **3. How might we redesign technology-mediated supportive experiences to better fit the needs of individuals managing depression and those they collaborate with for self-management?** | HCI, CSCW, Digital Mental Health |

## 1.3 Dissertation Layout

This is the layout of the dissertation:

Chapter 2 – Related Work. I provide an overview of related work relevant to my topic of collaborative self-management of depression.

Chapter 3 – Methodology. I discuss the methodological approach to my research at a high level.

Chapter 4 – Preliminary Study. I share the findings and discussion of my preliminary study.

Chapter 5 – Main Study. I present the findings and discussion of my main study.

Chapter 6 – Discussion: Collaborative Self-Management. In this first discussion chapter, I conceptualize the characteristics and process of collaborative self-management and highlight implications of the COVID-19 pandemic influencing these collaborations.

Chapter 7 – Discussion: Implications for Design. In this second discussion chapter, I discuss ways to approach design, technology features, and future ideas to support collaborative self-management.

Chapter 8 – Limitations. I address the limitations of my preliminary and main study.

Chapter 9 – Conclusion. I answer my research questions, reiterate contributions, and present possibilities for future work.

# 2. RELATED WORK

In this chapter, I overview relevant literature from HCI, CSCW, and Psychology. I first introduce collaborative practices in health management as a long-time area of interest to the field of HCI and CSCW (2.1). Much of this research has focused on chronic disease self-management, and I review this literature, focusing on concepts, support technologies, and the role of collaboration within self-management (2.2). More recently, researchers have begun to explore mental illness self-management, the area of focus for this dissertation. I describe collaboration to support mental health self-management, briefly discussing depression, sociality, social support (from Psychology & HCI/CSCW), and recent mental health support technologies (2.3). I conclude with a summary of the literature gaps that I will address in this dissertation (2.4).

The literature overview presented in this chapter is not meant to be exhaustive, but rather to focus on key concepts relevant to collaboration and self-management.

## 2.1 Self-Management Introduction

Collaborative practices to support health-related activities have long been of interest to the computer-supported cooperative work (CSCW) and broader HCI community. As Fitzpatrick and Ellingson [96] highlight, CSCW researchers have investigated work practices and technologies (i.e., use of electronic health records) within clinical settings for many years. Researchers have detailed collaborative practices among various clinical roles [97,206], as well as between patients and providers [20–22,158]. More recently, the research space has expanded to include health management contexts beyond the hospital including the home [87,105,176], and a focus beyond acute injuries and chronic disease to encompass self-care and wellness [77,189,239]. This growing

interest in how individuals manage their health in day-to-day life highlights opportunities to explore health conditions that often have to be self-managed by individuals [87].

### *2.1.1 Self-Management*

Broadly defined, self-management involves engaging in activities that protect and promote health, monitoring and managing the symptoms and signs of illness, managing the impact of illness on functioning, emotions and interpersonal relationships, and adhering to treatment regimens [65]. This involves disease, role, and emotion management [60,147]. Both for chronic disease and mental illness, self-management encompasses tasks to control physical aspects of illness(es) as well as psychosocial coping [147].

Self-management is a term that grew out of the clinical context where "management" implied care provided by clinicians to patients. Self-management, by contrast, shifts some of the responsibility of day-to-day care to patients and their family members as they carry out health-focused activities at home, at work, and in communities [54]. The term is also a key domain in Wagner's chronic care model [285]. Wagner notes that, "effective self-management is very different from telling patients what to do. Patients have a central role in determining their care, one that fosters a sense of responsibility for their own health" [255]. Battersby et al. echo this sentiment, noting that "central to self-management is the notion of rights and responsibilities and how these are shared" [147]. However, the ability to conduct and adhere to recommended self-management is tempered by levels of access to information and resources.

In the following section, I discuss previous HCI and CSCW research regarding self-management of chronic disease, the topic focus of the bulk of prior work investigating self-management.

## 2.2 Self-Management of Chronic Disease

Much HCI research has focused on understanding health self-management practices in the context of chronic disease (e.g., [12,16,54,115,151,189,234,235,238]). Individuals living with chronic illness such as diabetes or heart disease accomplish much of the daily work of maintaining or improving their health outside of clinical environments. However, the ongoing labor of self-management, happening largely beyond the confines of the hospital, has historically not been well understood and indeed has been called "invisible work" [4,143]. Therefore, to better understand day-to-day self-management practices and to build people-centric technologies, several HCI studies have sought to unpack and examine these self-management activities. In this section, I first describe ways of conceptualizing self-management including through information work and temporal trajectories. Then, I describe previous tools created to support self-management, and overview previous discussions of collaboration to support chronic disease self-management.

### *2.2.1 Information Work and Temporal Trajectories*

Many HCI studies focus on conceptualizing aspects of self-management within the experiences of individuals (and their caregivers [162,225,267,269]) managing chronic conditions. While not an exhaustive list, conditions investigated include diabetes [168,239], cancer [86,88,123,143], chronic kidney disease [81,234,253], rare diseases [166], and chronic physical injuries [115]. These studies serve as an important first step toward building effective self-management supports (technological, service-based, or others).

An important aspect of self-management is accessing and understanding needed information. Consequently, a number of studies [39,49,81,138,139,143] discuss *information work*. Strauss et al. [240] define information work in the healthcare context as "the quest for, the

receiving of, and the passing of information." This broad definition encompasses a variety of self-management activities that occur over time for individuals managing a chronic disease, including identifying problems [221], sensemaking [197,250], and collaborating with providers and caregivers [205]. Researchers have shown that information work in healthcare contexts is a critical practice carried out in the context of relationships including patient-provider conversations [158], nurse navigator connections [121], family information-sharing [14], and management of verbal and written communication [143]. While communication in these relationships is often important for maintaining ongoing care and self-management, it is also common for misunderstandings to arise. I discuss the benefits and challenges of these collaborations in more detail in 2.2.3.

Other research related to self-management has investigated how people experience and learn about their condition over time. For cancer patients experiencing a disease group with a complex treatment path, Eschler et al. [17] noted that information work activities were often tied to the stage of treatment (e.g., pre-diagnosis, in-treatment, survivor, among others). Similarly, recent work by Suh et al. [241] discovered that patients managing co-morbid cancer and depression often struggle to manage them simultaneously, given the different treatment trajectories. Thus, the authors advocate for conceptualizations of treatment through a parallel journey framework to support "whole-person care." Other researchers present information behavior models that cycle through stages of patient learning and processing but are not specifically tied to stages of disease. For example, Büyüktür and Ackerman [39] describe stages of crisis, steady states, and transitions in the information work activities of bone marrow transplant patients. Their conceptual view highlights how information work activities are tied to the medical and emotional experience of treatment and often do not fit a specific routine of daily practice. In addition, my previous work

with chronic kidney disease populations [81] described how patients shifted between periods of "Learning" – actively seeking and considering information to address ongoing questions about their care and self-management, and "Living" – maintaining practices. Through these studies, it is clear that self-management activities can be both routine and also change over time.

### *2.2.2 Tools to Support Self-Management of Chronic Disease*

HCI researchers have created and studied technologies to support chronic disease self-management. At a high level, these tools target areas including (1) learning from clinicians and peers, (2) tracking and making sense of health data, and (3) reflecting on data and self-management practices. Tools to support self-management are often introduced and used in the context of ongoing collaborative relationships within the healthcare system. This provides an avenue for individuals to ask questions about the functions of technology tools and services, and if relevant, about their health data and needs over time. These collaboration processes can support ongoing accountability regarding the use of self-management support technologies.

**Learning from Clinicians and Peer***s.* An important step in effective self-management is learning about one's condition and the healthcare system. This involves learning about the disease, learning best practices for managing and reducing the impact of symptoms, and learning how to move through the healthcare system as the disease progresses. HCI researchers have developed educational technologies to support these processes [95,244]. For instance, Jacobs et al.'s [121,122] technology design for individuals with breast cancer enabled patients to interface with the care system through connecting with a cancer navigator. The authors describe the importance of 'just-in-time' education to target relevant information to the current illness trajectory stage of each breast cancer patient. Knowing when to provide information to patients to help them prepare

for upcoming treatment stages without overwhelming them is an important aspect of education to support self-management [181].

Another important way that people learn about their condition is through connection with peers also managing the same condition. Through connecting with others with shared illness experiences, individuals can ask questions and share their own thoughts. Tools supporting peer communication include online health communities [114,154,169] and other more direct interactions (e.g., face-to-face, texting). I will discuss peer support technologies in detail in the mental health support tools section (2.3.4).

**Tracking and Making Sense of Health Data.** Health data tracking is a rapidly expanding area of interest for HCI researchers. Several studies have investigated the ability of ubiquitous and pervasive sensors and data collection avenues to help individuals and their clinicians to better understand and monitor day-to-day health [3,64,152,257]. For instance, telemonitoring (e.g., [12]) may provide easier access to clinician advice about self-management practices, and potentially enable earlier detection of health deterioration [200]. Yet, in doing so, these technologies expand the scope and reach of healthcare into the home, which presents the need for ongoing discussions about autonomy and privacy. Ancker et al. [3] detail concerns regarding technology-enabled tracking for individuals managing multiple chronic conditions. These patients considered tracking their own data to be burdensome. In addition, interacting with health-related data can be emotionally difficult for individuals with deteriorating health. An added challenge the authors note is that patients may perceive that providers are not interested or cannot offer useful insights from tracked data. Indeed, research regarding tracking to support individuals managing irritable bowel syndrome [53,134,135] has shown the importance of thoughtfully selecting types of data to best

facilitate patient-clinician conversation. Specifically, taking pictures of meals was easy to capture on a smartphone versus prior methods of filling out tedious paper logs of consumed nutrition content. Image data was also seen as a better way to talk about not just the consumed food itself, but also the wider context in which the food was consumed (e.g., a relaxed sit-down meal versus a meal consumed hurriedly in a car on-the-go).

**Reflecting on Data and Self-Management Practices.** Third, researchers have developed technologies to help people understand and reflect on their health data to adjust daily behaviors. For instance, Mamykina et al. [168] created MAHI to scaffold reflective thinking for individuals managing diabetes. The authors' motivation for this tool was the realization that for new patients who do not have prior experience looking at and making sense of health data, "engaging in reflective analysis of the collected data may be challenging." Therefore, the MAHI application assisted both analysis of collected biometric data and collaborative reflection on this data by prompting patients to have deeper conversations with diabetes educators. Through this process, the tool established the perception of an "internal locus of control" where users managing diabetes realized their efficacy and important role in self-managing their condition.

### *2.2.3 Collaboration in Self-Management of Chronic Disease*

Individuals managing chronic disease often learn about and refine their self-management through working with other individuals including healthcare providers, patient peers, and family members [147,243]. A term from the medical chronic disease literature that encompasses these activities is *collaborative self-management* [167]. This literature describes collaborative self-management activities largely in the pulmonary rehabilitation context including clinician-led education to promote adherence to medical recommendations, improve patient self-efficacy, and

discuss care plans [24,25,153,153]. However, one of the challenges these papers raise is how we conceptualize self-management. For instance, as Kendall et al. [124] argue, we need to move beyond current conceptualizations of self-management as a static set of best-practice activities taught by clinicians to passive patients. Instead, they argue, we should move toward a verb-tense of "self-managing," which encompasses evolving activities influenced by one's external environment especially one's social network. Specifically, collaboration with other patients and caregivers can help patients to make sense of complex illnesses and to locate healthcare system resources. For example, a survey of HIV patients found that 80% of patients had experience giving advice to others about where to find care-related information [194]. Similarly, cancer patients reported the importance of bringing another person (often a family member or a friend) to the clinic with them to ask questions and take notes on their behalf when they felt ill [143]. However, practices can differ depending on whether the individual is working with a healthcare worker, a caregiver/family member, or another patient.

**Relationship Roles and Collaborative Self-Management**. HCI studies have investigated patient-provider and patient-caregiver relationships as key avenues for collaborative self-management. Peer support is also important, and I discuss this literature in section 2.3.

Several HCI studies focus on the patient-provider relationship (e.g., [20–22,123]). Within a patient's network of collaborative relationships, healthcare providers are a key source of information. In this context, both patients and providers share information, and patients gain access to healthcare system resources. However, recent studies have found that communication within this relationship can be challenging. For instance, Lim et al. [158] note that patients often disclose to their primary care doctor only information that they perceive as pertinent to share. Relatedly,

patients may not share information if they are worried about the consequences of sharing that information. For instance, one of their participants described not wanting to disclose symptoms of psychological distress for fear of being prescribed medication. Similarly, Büyüktür and Ackerman [39] discuss the importance of collaboratively aligning the information work practices and perspectives of bone marrow transplant care providers and patients who often have different needs and expectations.

CSCW researchers have also explored the challenges of caregivers supporting patient's self-management. Depending on a patient's illness, collaborative interactions may become difficult. For example, researchers have illuminated some social interaction challenges for caregivers supporting individuals with illness(es) including diabetes [138,225] and dementia [249]. These caregivers may experience reduced ability to communicate face-to-face with their care recipient(s). This coupled with shifts from previous routines of social interaction with others outside care settings can be particularly exhausting for caregivers. Chen et al. [50] note that for their caregiver participants, "socializing is an important aspect of life that has been deeply disrupted by the work of caregiving." These studies highlight the reality that supporting an individual's self-management can be challenging work and often involves ongoing efforts to problem-solve and self-care.

In summary, in the section above I highlighted findings from research regarding the self-management of chronic disease. While much of the current literature has focused on this topic, more recently, researchers have begun to investigate the self-management work of individuals managing mental illness. In this dissertation, I extend the concept of collaborative self-management from physical chronic condition management to mental health management. In doing

so, I focus on mood and emotion management, extending beyond the information (e.g., [26,39,81,143]) and physical maintenance activities (e.g., [102,134,140,168]) detailed in previous self-management work. The following section overviews current research in HCI about self-management of mental illness, with a focus on depression research.

## 2.3 Self-Management of Mental Illness

HCI researchers have investigated mental illness contexts including bipolar disorder (e.g., [15,43,254]), anxiety (e.g., [73,182]), eating disorders (e.g., [45,94]), addiction (e.g., [224]), and depression (e.g., [66,178,273]). Many of these studies investigated online contexts to understand the activities of these individuals, looking particularly at the use of online communities [155,273] and social media [11,68,170] to seek and offer support. The following section will first introduce the specific mental illness of depression, and then discuss current HCI literature regarding collaborative self-management of mental illness. Then, I provide a brief overview of the social support literature from Psychology and HCI, drawing on insights relevant to collaborative self-management of depression. Following that, I overview collaborative support tools for mental illness and conclude by summarizing gaps in the literature addressed by this dissertation.

### *2.3.1 Depression*

Depression is a common mental illness affecting millions of people worldwide. In the United States alone, in 2016, approximately 16.2 million U.S. adults experienced a diagnosable depressive episode [284]. While common, depression is often a difficult illness to self-manage. Symptoms of depression include negative thoughts, feelings of sadness, lack of enjoyment of activities, agitation, sleep disruption, and lack of motivation [19]. At a basic level, these symptoms can make achieving self-management more difficult, because motivation and energy are required,

for instance, to conduct the self-management activity of a brisk walk [213]. Adding to the complexity of self-management, individuals often experience depression alongside other mental and physical health conditions, most commonly anxiety. To overcome difficulties associated with the condition itself, individuals develop strategies to accomplish their self-management activities.

My preliminary study [80], presented in Chapter 4, shows that connecting with other people is a key component of self-management activities for participants managing depression. However, managing these interactions can also be challenging. Previous psychology studies note that individuals with depression can experience difficulty establishing and maintaining social relationships [231,251] and that feelings of isolation and loneliness may lead to reoccurring challenges in symptom management [125]. In addition, while participants did not explicitly describe aspects of stigma in relation to their collaborative self-management, other publications [273] have discussed this as an ongoing issue. Depression therefore presents a critical and complex context to further study collaborative self-management, given the benefits but also the challenges of collaboration in the context of individuals self-managing this illness.

### *2.3.2 Sociality*

The role exerted by mental illness regarding an individual's ability to self-manage is generally little researched or understood [46]. Chapman et al. [46] describe how self-management is difficult for any individual to sustain, but they note that others can play a key role in a person's motivation to self-manage long-term. Below, I introduce the concept of *sociality*, a useful lens through which to understand collaborative self-management in mental health. I will first describe how HCI researchers have studied sociality in health and wellbeing-focused research and then discuss how it is understood in mental health research.

**Sociality for Health and Wellbeing**. Wellbeing is impacted by the ability to access desired forms of social interaction. Within health and wellness-focused HCI research, sociality is discussed as the various ways that people interact socially, their social goals, and their challenges in achieving those goals [11,91,93,157]. Sociality is mediated through verbal and nonverbal cultural cues (e.g., norms of conversation) and artifacts including computer-mediated communication tools [174,175]. Sociality is connected to individual and community wellbeing [104].

Much of the current research on sociality in HCI has focused on direct interaction explored in three ways: activities of deliberate communication, activities of spontaneous communication, and the location of social interactions. First, researchers have studied how deliberate communication activities (e.g., conversations, messages) promote health. These activities are usually intentionally sought out by an individual to reach certain goals and often result in conversation to share information and support. Researchers have investigated these activities within contexts of face-to-face conversations with peers [224] and healthcare providers [21,22,158], mobile communication [18,122], and online interactions [25,169] including interactions within online communities [36,114,155,185,208,273].

Second, there is growing interest in understanding how "accidental" encounters can also be beneficial to individuals. In research focused on older adults, Light et al. [156] describe the importance of protecting and maintaining social aspects of one's life and engagement in meaningful activities in retirement. The authors extend our understanding of sociality from deliberate direct communication to include "serendipitous sociality while out and about," for

example, unexpected interactions with others while out for a walk. These incidental connections made with others throughout the day are also important for wellbeing.

Finally, recent work has started to shift our focus by exploring where these interactions are taking place. In the context of individuals with autism, Ringland et al. [211] critique the presumed superiority of face-to-face social interaction and show the critical need for digital play spaces for children with autism. Their work shows the importance of attending to people's social interactions in both physical and online locations and asserts that these online social interactions have the same meaning and importance as those made face-to-face. Together, the studies described above highlight how sociality encompasses both direct and indirect social interactions, which may be spontaneous or deliberate and may occur in physical or virtual space.

**Sociality for Mental Health**. HCI research looking at the sociality of individuals managing depression has largely used digital traces of communication activities to detect signals of (worsening) depression. However, few studies have investigated how to manage or treat depression. Previous detection studies have used data from social media and online forum activity [48,51,66,160,218,233,247,264,277], multimodal behavioral signaling [13,74,131,270], and device sensing [42,52,145,193,220,258,265] (e.g., smartphones) to try to determine if individuals were suffering from the condition. Several studies used social media scraping to gather and classify the activities of individuals managing mental health needs. For example, researchers have created classification algorithms to detect activity potentially indicative of depression on Twitter [67,247] and Facebook [66]. Other studies have investigated disclosures of mental illness on social media using computer vision techniques [170], machine learning algorithms [68], and content analysis methods to investigate images, text, and commenting behaviors. However, Feuston and Piper [93]

critique these approaches to behavior classification, highlighting that to understand the nuanced goals of expression by individuals managing mental illness, we need to speak to the individuals themselves. While early detection of depression can be useful, we still have more to learn about approaches to support individuals to manage and reduce their symptoms of depression over time.

Understanding sociality as a key element of wellness encourages us to expand our current views of self-management to include planning and enacting regular and meaningful human interactions. While sociality encompasses a broad set of social interactions, social support is a more specific form of interaction, often sought by individuals managing depression particularly when dealing with a negative mood. I conceptualize social support as a specific set of activities within an individual's broader practices of sociality. In the following section, I first describe social support research from psychology and then will focus on HCI research regarding social support for those managing mental illness.

### *2.3.3 Social Support*

**Social Support Research in Psychology**. Much of the psychology research about collaboration between individuals managing depression and others in their social network draws on the broad concept of *social support*. As described by Rueger et al.'s recent meta-analysis [216], this literature primarily focuses on the people supporting individuals with depression, high-level collaborative activities, and how to measure social support (e.g., [58,242]).

For individuals managing depression, key roles that provide ongoing support include spouses, family, and friends [216]. Intimate relationships are key to many social support networks. Furthermore, researchers delineate social support activities into several high-level categories: emotional, instrumental, informational, and appraisal support [58]. Emotional support includes

expressions of empathy, love, trust and caring within intimate confiding relationships [185,251:9]. Instrumental support includes tangible aid and service with practical services or resources [185,251]. Informational support includes advice, suggestions, and information. Appraisal support includes information that is useful for self-evaluation (e.g., a close friend letting another friend know about personal qualities that will enable her to reach her goal) [208]. Studies distinguish between effects of the structure of social support networks (e.g., how many friends do you have?) and the functions of the network (e.g., do you have someone you can talk to about personal problems?) [57]. Measurement of social support ranges from simple counts of close friends to larger indicators of the quantity, quality, structure, and nature of an individual's social network and social interactions.

However, there is a disconnect between the broad work categories and structures identified in previous research, and the interaction-level understanding we need regarding the day-to-day support experiences of individuals managing depression. So, while the psychology literature underscores the importance of collaboration, we still need to better understand the granular details of how these supporting interactions take place. By understanding people's lived experiences, we can build better types of support for these collaborative activities. Specifically, beyond friends and family, *who* else in individuals' social network support their depression self-management? *How* do these broad categories of support (e.g., emotional, instrumental) take place in day-to-day interactions? Finally, *where* do these interactions occur and through which mediating technologies?

The challenges to asking for and managing social support in the mental health context are also unclear. Individuals managing depression can have difficulty establishing and maintaining

social relationships [64,74] and feelings of isolation and loneliness may lead to reoccurring challenges in symptom management [38]. In addition, some researchers (e.g., [77]) discuss stigma around mental illness as an ongoing issue influencing individuals' considerations about collaborative support activities. On one hand there are numerous reasons why individuals might seek support. Confiding relationships can provide protective factors that support mental health including intimacy, social integration through shared concerns (e.g., similar goals), reassurance of worth, the opportunity to be nurtured by others, a sense of reliable alliance, and guidance [57]. However, on the other hand, supportive individuals can become embroiled in a crisis themselves (e.g., miscarriage, the passing of a loved one). Consequently, a social support relationship does not mean it is always positive or that a particular individual is the right person to turn to in all situations. Some relationships can be more demanding than supporting and can actually increase psychological distress [201]. For example, these type of role-based relationships can disproportionally affect women, particularly lower-income women, because of additional expectations of support they will provide for children or sick family members [137]. Depression, therefore, presents an important context to understand these considerations.

**Social Support Research in HCI.** Much of the previous HCI wellness research has focused on the concept of social support [29,133,162,203]. CSCW researchers have explored social support within varied contexts including parenting [2], gender transitioning [106], and grieving and loss of a loved one [32].

Research focused on mental illness has examined peer support enacted through online forums and other technologies. For instance, peers with shared experience managing mental health concerns are often a key resource for discussing problems and sharing information [191]. Within

online support contexts, researchers observed behavioral differences between individuals managing depression and their non-depressed peers. In a Facebook study of college-aged participants, Park et al. [196] found that depressed individuals had smaller networks of comments and likes and a tendency to be "more passive in communicating with others." Similarly, Homan et al. [112] in their study of TrevorSpace, an online community for LGBTQ youth, found that individuals managing depression were not as well integrated into the social fabric of TrevorSpace. Other researchers found that online depression support groups were important conduits for support. Zhang et al. [273] and Li et al. [155] studied online depression support groups in China, finding that these were key avenues for information-sharing and collective support in a context where users had few other resources and high stigma around sharing their depression status. In another example, women with concerns about postpartum depression used public forums to seek emotional support and to ask and answer questions related to symptoms, diagnosis, treatment, and care [89]. These communities also extend onto social media sites. For example, Andalibi et al. [10] investigated picture-sharing activities on Instagram for support, establishing the importance of visual imagery as a vehicle for expressing aspects of depression. Instagram users managing depression sought spaces to interact, express positive emotions, and provide support.

Overall, while these studies show the importance of collaboration through public and semi-public technologies, how collaboration unfolds in-person and through one-on-one and small group technology interactions (e.g., texting, voice calls) is less clear. Indeed, as Newman et al. [185] note in their study titled "*It's Not That I Don't Have Problems, I'm Just Not Putting Them on Facebook*," deriving understanding of support discussions solely from posted online content is unlikely to show us the full picture of an individual's health-related activities.

Critically, little research so far has focused on understanding the social interactions of individuals who are managing mental health needs with their support networks. A few studies have shed light on the sociality of family members and caregivers of individuals with depression [248,267,269]. For example, Yamashita et al. [268], describe the challenges of caregivers supporting depressed family members in Japan. They highlighted how caregivers sought information about how to best support their loved one who was managing depression and how the caregivers created some boundaries to support their own mental health and wellbeing. However, while caregivers can provide some perspectives on the self-management work of individuals, they cannot speak to the breadth of considerations for the individuals managing depression. Therefore, there needs to be more focus on how these individuals conceptualize their *own* collaborative self-management.

Park's study [195] and Lattie's investigation [83] of young adults' practices of social support for mental health start to explore how individuals conceptualize their own self-management. Park found that college students reach out to close friends, parents, and acquaintances expecting different types of interactions such as empathetic listening or reassurance of unconditional support. Lattie et al. discuss the important role of "known and unknown peers" in supporting mental health and suggesting resources. The focus of these studies was managing general mental health needs during college. For bipolar disorder participants sharing personal informatics, Murnane et al. [183] also noted the importance of connecting to different roles (e.g., healthcare providers, family members) to understand and take action regarding their data. This dissertation builds upon these findings to investigate the breadth of social network individuals who support the collaborative self-management work of people managing depression.

### *2.3.4 Toward Collaborative Self-Management Tools for Depression*

Most current tools for depression self-management have limited, if any, social interaction features. Current technologies focus largely on individual psychoeducation and skills practice such as cognitive reframing using smartphone apps [178,227]. A few technologies offer occasional interaction with clinicians, but this is usually for crisis support or as an extension to therapy. For example, Internet-based Cognitive-Behavioral Therapy (iCBT), delivered through module-based online programs, has demonstrated efficacy in reducing symptoms of depression, both with and without clinician guidance [127,136]. Similarly, Schueller and Mohr [228] and Doherty et al. [76] have created multiple iterations of coach-supported web-based depression treatment, and Stawarz et al. [236] studied a recent intervention combining face-to-face and technology-mediated psychotherapy approaches. Chatbot applications including the popular Woebot [286] as well as other recent chatbot tools [107,217] are also being tested. Researchers have also explored context sensing to help predict episodes of depression with tools such as Mobilyze! [38]. Other tools encourage novel visualizations of the mind such as neurofeedback [40] or through gameplay [70], or enable individuals to monitor emotions over time [75,152]. However, many of these tools adapt techniques used in therapeutic practice to online and smartphone applications and, therefore, lack support for broader social interaction (e.g., [172,212]).

Furthermore, despite the growing number of tools for depression support, adherence to and long-term engagement with digital mental health tools remains a major challenge. Many of these resources have been developed and delivered in a “top-down” manner following clinical practices that may not align with the day-to-day routines, needs, or motivations of users [246]. While many of these tools have been shown to be efficacious, adoption has been low [177,179]. Consequently,

there is a need to better understand how individuals managing mental health needs conceptualize their own self-management activities to improve the design of these tools.

In other areas of digital mental health, researchers have begun to investigate the potential of social features integration into support technologies. For example, HORYZON [1] uses peer-to-peer social networking and expert moderation features to support first-episode psychosis recovery. Similarly, in a twist on common tracking features, the MONARCA system [15], designed for individuals managing bipolar disorder, captures not only biometric data such as hours slept, but also collects data regarding an individual's amount of texting and social activities to recognize early warning signs of a manic or depressive episode. One-on-one peer support applications including the Buddy Project [6] and O'Leary et al.'s [192] peer support chats also showed the importance of collaborative support, especially how individuals wanted to both talk with others about health needs and questions but also to get to know the other person's interests and life story. Finally, Yu et al. [272] created a "Mobile Mediation" tool to allow depressed individuals and caregivers to share mood and availability information for support connections.

Beyond these applications developed specifically for mental health support, recent literature has started to explore the emergent ecology of technologies for everyday self-management. Technologies used in the depression support context include social media, online communities, one-on-one calls, music, online multiplayer and phone games, calendar apps, journals, texting and messenger apps, and phone and video calls [80,130]. For example, Kornfield et al. [146] and my recent work in collaboration with Eschler et al. [130] observed day-to-day practices of individuals managing depression. This research describes how people appropriate a

variety of technologies (e.g., calendars, music, notes) to self-manage in ways that support the ebbs and flows of depressive episodes, motivation, and energy.

Social features integration is a promising future avenue for depression self-management support. However, further research is needed to deeply understand current contexts and conceptualizations of self-management to create effective tools sensitive to the needs of these individuals. Additionally, it remains unclear how individuals select from among these tools and services in the context of a technology ecosystem [72] to facilitate collaborative self-management. Types of support and stigma are likely to contribute to decisions regarding which technologies to use to connect with others, but there may be other issues that we as researchers are not considering, that push people to use certain tools. Consequently, as part of examining collaborative self-management, in this dissertation, I help us understand the role that the ecosystem of technologies plays in enabling and constraining desired collaboration.

Overall, the majority of current self-management technologies for depression (e.g., [40,75,178,227]) do not support the social interactions and nuances of relationships within an individual's wider support network. This is a missed opportunity because connecting with close relationships has been shown in the chronic disease literature to be key to sustainable self-management [189,238,253] and in numerous social support studies shown to be beneficial for mental health [29,31,59,195].

## 2.4 Chapter Summary

While in HCI we know much about collaborative self-management in chronic disease contexts (e.g., [12,16,54,115,151,189,234,235,238]), we still have much to learn about collaborative self-management for mental illness. Specifically within social support literature,

psychology research has outlined the broad activities of self-management, role categories of some supportive relationships, and a few contextual factors relevant to collaborative self-management (e.g., [57,58,216,242]). However, we still need to know more about specific, granular interactions in these contexts. In particular, understanding *who* people are interacting with, *how* they are interacting, and *where* these interactions take place is still unclear. Within HCI research, social support has been studied in multiple contexts, however, beyond a few studies [64,150], researchers have not yet fully examined the role of social activities for individuals with mental health challenges from their own perspective. Further research is needed to deeply understand current contexts and conceptualizations of self-management to create effective tools sensitive to the needs of these individuals. Current technology tools for self-management of depression were designed to deliver mental health support services based on clinical best practices, however these tools have not yet fully envisioned the role that the user's support network can play in the self-management process. Therefore, my dissertation research addresses these gaps by presenting conceptualizations of collaborative self-management analyzed from speaking with individuals managing depression. I describe how technologies mediate and augment this work, and detail areas for future redesign to support the needs of individuals managing depression.

In the next chapter I discuss the methodological approach to my research.

# 3. METHODOLOGY

This section presents a high-level view of the methodology employed in my dissertation work. My focus here is to talk about broader strategies, values, and processes. Then, in chapters 4 and 5, I provide specific methodological details pertaining to my preliminary and main studies. Below, I discuss my research population of individuals managing depression, researcher stance, data collection, and data analysis approaches.

## 3.1 Research Population

The research population for my studies is individuals diagnosed with depression (Major Depressive Disorder (MDD) [287]). Depression is a common mental illness that affects millions of people worldwide. Symptoms of depression include negative thoughts, feelings of sadness, lack of enjoyment of activities, agitation, sleep disruption, and lack of motivation [19]. Individuals often experience depression alongside other mental and physical health conditions, most commonly anxiety. Depression can be particularly challenging in how it affects an individual and their interactions with other people. Individuals with depression can experience difficulty establishing and maintaining social relationships [231,251], and related feelings of isolation and loneliness may lead to reoccurring challenges in symptom management [125]. Addressing these challenges requires ongoing work to prevent or reduce the intensity of future depressive episodes.

My research population of interest includes individuals across the adult age span (18+). Given my focus on self-management, it is important to talk to people who have been managing depression for various lengths of time. While the first episode of depression most often occurs in young adulthood [144], a person's age does not necessarily signify how long they have been living with depression. For example, a 22-year-old and a 51-year-old could both have been managing

depression for the past two years. However, age diversity can present varied societal, occupational and/or relationship roles that may influence how they self-manage and interact with others. For instance, college students may have certain practices that differ from others employed in 9am-5pm jobs. Each individual will therefore have their own story with the illness and their previous clinical or self-led treatment experiences.

### 3.2 Researcher Stance

As an individual who does not live my life with a mental illness, there will be aspects of the lives of my participants that I cannot empathize with personally. I choose the research methods for my studies (semi-structured interviews; elicitation and design methods) to best support my participants in expressing their lived experience, their goals, and their daily activities. I believe it is important to speak directly with these individuals to create actionable design insights for this population.

My thoughts about design in the mental health support context are inspired by *Positive Computing: Technology for Wellbeing and Human Potential* by Calvo and Peters [41]. They introduce the idea of intentionally selecting and combining a diversity of perspectives when we design for wellbeing. These perspectives may include those from medicine, neuroscience, hedonic psychology, subjective wellbeing, Buddhism, and eudaimonic psychology. This last perspective – eudaimonic psychology – captured in the phrase, "wellbeing as engagement with meaning and the fulfillment of potentials" particularly speaks to the type of work I seek to do with my participants. I am also informed by the extensive clinical psychology literature about depression and depression (self-)management. Therefore, my research and design approach to depression support is to both draw from the clinical research view of depression as well as the user-centered perspective of

helping people to reach their desired goals. These perspectives may be oppositional at times and designing in this space is likely to raise these tensions. When tensions arise, I ask further questions like: *could there be harm in supporting people's goals over the clinical best practices, and vice versa*? as well as, *what designs are people likely to actually use?* Throughout this process, I draw on the perspectives of my participants as well as the perspectives of my colleagues and research partners who have deep background in clinical treatment and clinical research.

In my overall work in healthcare, I have investigated different facets of health management. I have led interviews, usability studies, and participatory design sessions with fire fighters [33] , individuals with hearing disabilities [288], healthcare providers [78,81], and patients [81]. These projects have provided background training for my dissertation work.

## 3.3 Data Collection

My primary goal in data collection is to help make participants comfortable as they tell me about their experiences. My second goal is to enable participants to share their experiences in a variety of different ways. In my dissertation studies I use multiple means of data collection (e.g., interviews plus visual elicitation) to enable triangulation of findings. In the section below, I first discuss the methodological choice of semi-structured interviews and then visual elicitation methods.

### *3.3.1 Semi-structured Interviews*

Semi-structured interviews are a standard method in HCI work, particularly for qualitative health researchers seeking to understand people's thoughts and life experiences (e.g., [39,81,139,143,168]). Semi-structured interviews often follow an interview guide used to gather information on key themes of interest in the research. However, the strength of this method lies in

the ability for the researcher to react during the interview to what a participant shares. For instance, the researcher can probe to understand more about topics as they emerge throughout the interview without constraint from a formal interview script.

I have conducted semi-structured interviews in several studies including my research in the United Kingdom with chronic kidney disease patients, caregivers, and clinicians [81], research with care managers [149], and most recently in my preliminary dissertation study, published at CSCW 2019 [80] as well as co-authored work at CHI 2020 [130]. To me, semi-structured interviews are a natural fit for research with patients/members of the public who often hold diverse views about (their) health and preferred self-management practices. Because these individuals do not always describe aspects of their health experience using similar language, analysis of these interviews can be more time-consuming than, say, analyzing the transcripts of conversations with physicians. However, to understand a participant's conceptualizations of health, I believe the semi-structured interview allows participants to articulate concepts in their own words and evince the important goals in their life, making it one of the best methods to conduct my dissertation work.

### *3.3.2 Visual Elicitation*

Qualitative researchers have a long history of using various types of elicitation to gather reactions and explore new lines of questioning with participants [55,102,108,289]. Visual elicitation in particular is used as a constructionist and emotionalist [252] approach to gather information from individuals about how they see and interpret elements of the world and how they think about relationships between those elements. Particularly important for individuals managing mental illness, these techniques can reduce perceived power imbalances between interviewers and

respondents and, critically, “enhance participants’ ability to elaborate on their own conceptions of the world, rather than limiting them to categories derived from theory or previous research” [17].

In my preliminary study, I used a specific form of visual elicitation called graphic elicitation [63] which involves “presenting interviewees with a diagrammatic representation of the domain with which they are involved.” Diagrams can provide a “common conceptual foundation” [63] to guide discussion in qualitative research. This method provided a common framework in my preliminary study (see Fig. 2. in the Preliminary Study chapter for reference) to help participants think through the interrelated aspects of their self-management. The graphic also enabled the research team to compare across participant responses. Next, the main study utilized a different type of elicitation: a cognitive mapping exercise. The Nielsen Norman group [90] defines cognitive maps as “any visual representation of a person’s (or a group’s) mental model for a given process or concept.” Cognitive maps enable participants to externalize knowledge, aiding cognitive processing. Visually laying out and connecting concepts can enable identification of themes across different concepts and surface new patterns and connections. In HCI, researchers have used cognitive maps to understand people’s lived experiences in a city [119], and to design for organizational environments [214]. Recently, DeVito et al. [72] used cognitive mapping to investigate how participants decided to share queer content across their technology ecosystem (see Figure 1., above for a participant example). Within health services research, Burgess-Allen and Owen-Smith [34] found that using

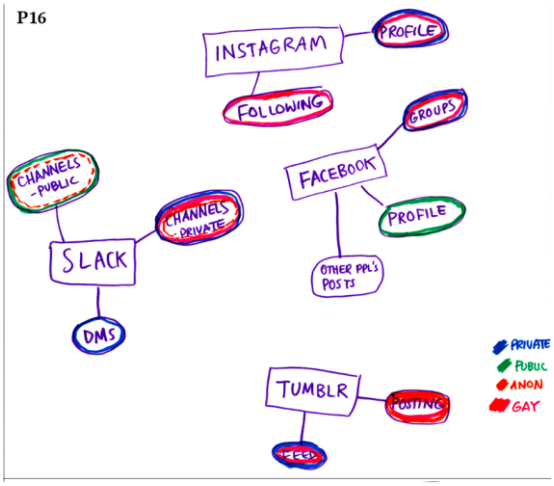


Fig. 1. Cognitive Map of Technology Ecosystem from DeVito et al., 2018

cognitive mapping within a focus group was helpful in stimulating discussion, enhancing transparency, and supporting group ownership of data analysis. Finally, and perhaps most importantly in the context of my research, cognitive maps assist researchers in understanding mental models of a system or of a process. This is particularly helpful for complex systems and when thinking about the design of novel products [90]. Across both of my studies, once a participant created their map, it then represented a tangible artifact and served as a conversation prompt for the rest of the interview.

## 3.4 Data Analysis

Of the many methods of analysis for qualitative data including Charmaz' grounded theory [47], content analysis [290], narrative analysis [278], and framework analysis [99], I choose to use thematic analysis. In this section I will first discuss thematic analysis following the approach outlined by Braun and Clark [30]. Then I will discuss aspects of credibility and transferability of qualitative research and the thematic analysis approach.

### *3.4.1 Thematic Analysis*

My key analysis approach is thematic analysis, described in detail by Braun and Clark [30] (see Table 2.). In brief, the process of analysis involves first reading through several of the collected interviews (or other types of data) to (1) familiarize oneself with the data corpus, and then (2) create an extended set of open codes. Once the breadth of open codes is developed, the researcher (or research team) moves to (3) create axial codes – a higher level of abstraction that better captures the breadth of the data than the often fine-grained open codes. In my practice, I usually make this transition visually by writing down my open codes onto separate post-its, and then forming categories relevant to my research question.

Table 2: Braun & Clarke's Six-Phase Thematic Analysis

| Phase | Description |
|---|---|
| (1) Familiarize yourself with the data | Transcribe field notes and interview, then read through transcriptions to ensure a general understanding of the data. |
| (2) Generate initial codes | Label segments of data in a systematic way across all the data. |
| (3) Search for themes | Review individual codes and identify preliminary themes. |
| (4) Review themes | Review preliminary themes to ensure they make sense across the entire data set. |
| (5) Define and name themes | Continuously refine each theme, identify a name for each theme, and define the theme's boundaries. |
| (6) Produce the report | Present themes with interesting examples that illustrate the individual themes. |

Sometimes, however, it may become clear through this process that participants described other issues of importance not captured in the initial motivating research question. This is where thematic analysis shines – the researcher can see what participants focused on instead and use this to guide her ongoing analysis.

The researcher then (4) reviews the themes by applying the axial codes across other interviews to see if the axial codes fit. If not, the axial codes are revisited and revised until they work across the dataset. If working with other coders, the researchers may create a codebook to clarify each axial code and ensure uniform coding across the dataset. After applying axial codes to the data corpus, the researcher then moves to (5) define and name the overall themes from the data which then guide (6) writing the results and discussion, positioning the paper for publication.

### *3.4.2 Credibility and Transferability*

Quantitative research is usually conducted to make findings reliable, valid, and generalizable. However, while for qualitative research these broad concepts are also important, they are addressed in different ways. According to Wittemore et al. [260], when evaluating

qualitative research, we should instead seek to understand quality through its credibility and transferability.

*Credibility* regards the researcher's accurate interpretation of the meaning of the data. I think of credibility-building in my work through my analytic method which includes sharing findings with others and gaining feedback through an iterative process. Specifically, thematic analysis seeks patterns within a dataset. Thus, findings rest not on the word of a single individual but show important similarities and contrasts across the dataset. The coding process is rigorous and involves constant comparison to ensure that the developing codes indeed fit the concepts within the dataset. Another important aspect is the use of representative quotes in the manuscript to continue to show credibility by presenting the words of the participants as evidence supporting the researcher's analysis.

Next, *transferability* does not equate to generalizability, but according to Gasson [100], the point is to show to what extent findings and conclusions of a study might be transferred to other contexts, particularly when derived into a useful theory. For instance, the concept of sociality introduced by Miller and Sinanan [175] is applicable across a wide variety of physical and digital contexts. However, in the type of qualitative research I conduct, the researcher is the research instrument responsible for collecting and analyzing data. This means that my findings will likely differ slightly from those of another researcher if they also conducted a study with the same participants. Thus, I seek to be as clear as possible regarding the process of my studies, while understanding that it would be impossible to fully "replicate" a qualitative study. The aim of qualitative research is not to be generalizable per se, but to present an account grounded in the experiences of the participants, an important research outcome in its own right. Finally, when

presenting the findings of qualitative work, we connect them with findings of other work in the field. For my work, I connect my findings and discussion to related literature in the areas of health HCI and CSCW and Psychology research. By looking across related studies, we can see areas of similarity and areas of difference that enable us to build a picture of human activity across studies in varied contexts investigated by many different researchers.

In summary, in this chapter I described my research population of individuals managing depression and my researcher stance in conducing qualitative research with this population regarding potentially sensitive topics. I shared my data collection processes at a high-level, discussing both semi-structured interviews as well as visual elicitations. Finally, I shared my data analysis approach. I now turn my attention in the next chapter to the preliminary study.

# 4. PRELIMINARY STUDY

The following chapter details the preliminary study of my dissertation [80][1]. The following chapter starts with an introduction to the study (4.1) and details the methodology (4.2). I then share the findings of the study (4.3) and conclude with a discussion of how these findings begin to address my research questions (4.4) and the gaps that I fill with my main study (4.5).

## 4.1 Study Introduction

To support the self-management practices of individuals managing mental illness, researchers and designers in CSCW, HCI and Psychology have begun to investigate the potential for technology-based approaches to mental health treatment (e.g., [40,75,178,227]). However, current tools do not yet integrate well into the daily lives and routines of users and have so far not been sustainable [246]. To start to address these issues of integration and sustainability, I undertook a "bottom-up" investigation to understand how individuals conceptualized their depression self-management activities. My colleague and I conducted interviews and visual elicitations with 30 individuals managing depression living in a large city in the U.S. Midwest. The study protocol encouraged participants to build a holistic picture of the values, behaviors, and preferences that informed their individual, day-to-day activities managing the symptoms and effects of depression. I primarily draw on the visual elicitation activity for this study and provide more details about this activity in the methods section.

I found that a key ingredient for effective self-management is *sociality*. Sociality refers to the social interactions and relationships within an individual's life [175]. Within CSCW,

[1] This chapter is drawn from the CSCW 2019 paper, "I think people are powerful": The Sociality of Individuals Managing Depression. I would like to acknowledge that the data collection, analysis, and writing was a collaborative process.

researchers are beginning to investigate the role that social relationships play in the self-management of mental health conditions, particularly the supportive practices that individuals enact through these relationships (e.g., sharing personal health data to support bipolar disorder management [183]). By using the lens of sociality to understand our participants' day-to-day activities, I highlight how social relationships factor into mood and symptom self-management.

I use sociality to better understand and unpack the social self-management activities of individuals managing depression. I present the professional and non-professional ties with whom they connect and detail locations where they conduct these activities. I also analyze the in-person and technology-mediated communication channels they select to enable their sociality. In my discussion, I address my three research questions through unpacking factors influencing participant sociality including relationship roles and expectations, mood state and communication channel selection, location and privacy, and culture and society.

## 4.2 Detailed Methodology

In the following section, I describe participants and recruitment practices as well as the data collection, data analysis procedures, and positionality of the research team.

### *4.2.1 Participants*

This research and my recruitment practices were approved by my university institutional review board. Participants were recruited through four means: (1) online posts to local Facebook groups; (2) flyers posted to local libraries and public spaces; and (3) a study recruitment email from a patient registry through a partner research group in the University's clinical psychology department; and (4) via an email to a local Meetup group for depression peer support.

My colleague and I recruited participants who were comfortable conducting the interview in English, were 18 years or older, and were currently managing depression or had received a diagnosis of depression within the last 12 months. All participants lived or worked in the geographic area of the large Midwestern city where the University is located. From a demographic survey of participants, 57% of the sample self-reported as white, 43% were mixed race or people of color, and 30% indicated Hispanic origin. Participants ranged in age from 18 to 72. Less than half (40%) reported full-time employment, 20% were full-time students, 17% worked part-time, 13% were unemployed or underemployed, and 10% indicated "other" (e.g., retired, or on disability). As highlighted in Table 3, participants had been self-managing depression for varying lengths of time. Some were newly diagnosed, and others had been managing depression for many years – the minimum was a few months, and the maximum was 25 years of self-management.

Table 3. Preliminary Study Participants

| **Participant** | **Age** | **Gender** | **Years managing depression** | **Participant** | **Age** | **Gender** | **Years managing depression** |
|---|---|---|---|---|---|---|---|
| P01 | 22 | Male | 5 | P16 | 51 | Female | 16 |
| P02 | 32 | Female | 3 | P17 | 18 | Female | 1 |
| P03 | 32 | Male | 6 | P18 | 52 | Male | 1 |
| P04 | 24 | Female | 7 | P19 | 21 | Female | 1 |
| P05 | 44 | Female | 12 | P20 | 72 | Female | 10 |
| P06 | 36 | Female | 15 | P21 | 34 | Female | 6 |
| P07 | 32 | Female | 1 | P22 | 28 | Male | 3 |
| P08 | 48 | Male | 19 | P23 | 52 | Female | 25 |
| P09 | 31 | Male | 2 | P24 | 21 | Male | 1 |
| P10 | 40 | Male | 1 | P25 | 33 | Female | 17 |
| P11 | 29 | Female | 8 | P26 | 44 | Left blank | 1 |
| P12 | 21 | Female | A few months | P27 | 48 | Female | 2 |
| P13 | 20 | Female | A few months | P28 | 31 | Female | 2 |
| P14 | 20 | Female | 2 | P29 | 18 | Left blank | 2 |
| P15 | 54 | Female | 25 | P30 | 36 | Female | 22 |

### *4.2.2 Data Collection*

My colleague and I coordinated via email to meet with each participant for data collection in a location of their preference. The aim was always to maximize participant comfort. We met some participants in public libraries and coffee shops, some came to our lab across our two campus locations, and we also conducted a few interviews in participant homes. Compensation for each participant was $25. Study session lengths among participants ranged from 75 to 90 minutes.

**Study Session Process**. After completing a short demographic survey, each participant completed a 45-minute semi-structured interview. The interview protocol included a variety of questions about technology and self-management routines. After the interview, participants took part in a visual elicitation activity for the final 30 to 40 minutes of the session. The visual elicitation data is the main focus of the analysis for this chapter. The visual elicitation for each participant consists of two structured worksheets, completed in response to prompted scenarios.

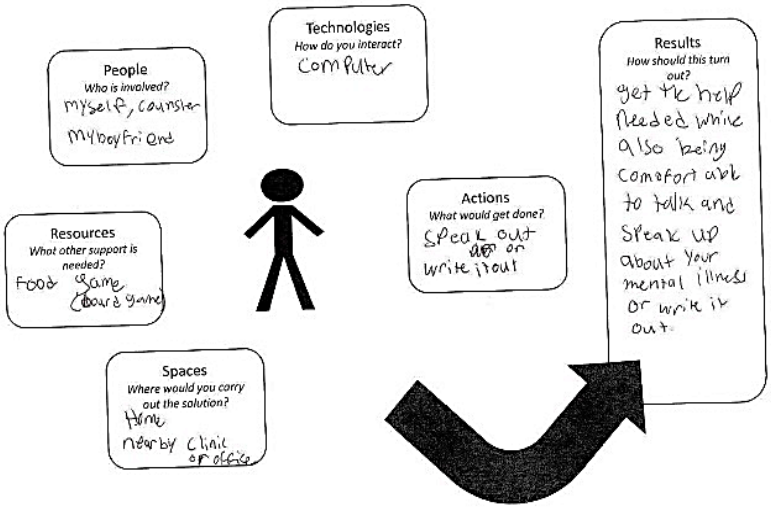


Fig. 2. Scenario 2 Worksheet for P01

**Structured worksheets.** Each participant completed two worksheets, each with 5 boxes labeled Spaces, Resources, People, Technologies, Actions, & Results (see Figure 2.). These boxes provided data to help me understand systems for supporting self-management. I did not expect comprehensive coverage but used the worksheet structure to obtain a consistent "picture" of activities as described by participants. I was particularly curious about the Outcomes section because I wanted to understand what goals and outcomes look like from a participant perspective. Clinical outcomes and participant-perceived outcomes may be different or overlap, but critically they are often expressed using different language (i.e., clinical vs. patient). Therefore, I sought to capture their activities and management expectations in their own words. The visual elicitation created a reliable avenue to gain diagrams of daily management support while allowing flexibility for participants to define their own "success" in the outcomes space. The worksheet was offered as a space for participants to respond to two scenario prompts, given in the following order for each participant. Below, I provide more details about each scenario.

**Prompted scenario 1.** "Imagine you're having a bad day, feeling anxious or tired. How do you best take care of yourself in that situation? How would you try and improve your day and your feelings using the worksheet to illustrate your solution?" This prompt investigated participant's current self-management routines (e.g., their response to a problem situation *without* access to clinical resources, or a mental health expert).

**Prompted scenario 2:** "On days you're struggling with your moods or motivation, you are given the opportunity to get instant, on-demand support from someone who can provide you expert counseling. What would you like that support to be like, using the worksheet to illustrate it?" This scenario investigated how participants would conceptualize a management routine *with* access to

clinical resources (e.g., connection with a mental health expert; I left the concept of "expert" vague, as individuals with depression may view a member of the clergy, or other influential person in their life, a preferable source of support than a clinical expert).

Participants completed their response to scenario 1 before moving on to scenario 2. Participants responded to the scenarios by writing text on their worksheets. Some participants spoke aloud during the exercise, and other participants who were silent as they completed the worksheet were prompted to walk the researcher through each section, providing more detail. One participant was not willing to put his handwriting on study materials other than the consent form; in this case I used his audio transcript in lieu of the visual elicitation document.

After both scenarios were completed, my colleague and I placed the scenarios side by side, facing the participant. At this point, the participant answered questions to compare responses to each scenario. Such questions included: *What are some differences between the two solutions you made up? Looking at the results box, how do you know when you achieve good results? What is the most important element of the scenario?* Participant interview and visual elicitation descriptions were audio-recorded and transcribed, and scenario worksheets for each participant were scanned and digitized for analysis alongside the transcripts.

### *4.2.3 Data Analysis*

Four members of the research team used qualitative data analysis methods to analyze the last two questions of the semi-structured interview component (*Who do you consider to be an expert about managing moods or emotions?* and, *Who do you consider to be an expert in managing your moods or emotions*?), the visual elicitation documents, and audio transcripts of the visual elicitation activities. I describe our process below.

Beginning with a sorting exercise to examine initial patterns across the visual elicitation documents, with my colleagues, I organized all the documents within Scenario 1 and then Scenario 2 separately developing several categories including types of technologies, and how many people were involved in desired social interactions, among others. We recorded these categories in Excel. During the sorting process, we realized that there was significant overlap in many aspects of the documents, and therefore conducted our following analysis across both scenarios.

In analyzing the data, my colleagues and I followed the Braun & Clarke thematic analysis process [30], starting with open coding of the elicitation transcripts across both scenarios examining 40% of the data corpus. We followed a consensus process among the multiple coders. All reviewers independently coded all of the transcripts and met to compare coding to arrive at consensus judgments through open dialogue [71,110,111]. Consensus coding captures data complexity, avoids errors, reduces groupthink, and circumvents some researcher biases. To conduct our coding, we utilized Dedoose, a qualitative coding software system [291].

Through a collaborative process, my colleagues and I developed a consensus set of axial codes such as “past and ongoing relationships,” “locations,” and “creating action plans and learning tools,” among others. We then applied these axial codes across the dataset. This coding process resulted in the main themes explored in the following section.

#### *4.2.4 Positionality*

In this work, the research team represented a variety of backgrounds including behavioral scientists and human-computer interaction researchers; all who had prior experience working with individuals with mental health concerns. The other HCI researcher and I were attuned to common understandings of technology and routines of technology use. The other two researchers had a

psychology background, and, therefore, were able to explain issues that participants raised that had a clinical nature. At least one author has a mental health condition. These varied perspectives allowed us to be more sensitive to the nuances in our participants' data.

## 4.3 Findings

In this section, I present the results of our analysis of participants' descriptions of their self-management of symptoms of depression. First, I describe participant socially focused self-management activities, with whom they interact, and related expectations. I then describe characteristics influencing these activities, including locations and selected technology channels.

### *4.3.1 Role of Sociality in Participant Self-Management Activities and Expectations*

Participants described a variety of self-management activities to help mitigate negative emotions or deal with challenging situations. I detail three common activities below: expressing moods, creating solutions, and de-escalating moods. While I separate these activities in the findings for analytical purposes, in practice, participants often interwove a variety of these activities in their daily lives. They also had differing expectations of their self-management activities. These included changing feeling state, achieving a specific outcome, and learning about or enacting control over symptoms. Below, I describe each of these major categories of activities, followed by a brief discussion of participant self-management expectations.

**Expressing Moods**. Participants expressed their moods through sharing stories and conversations about their issues and feelings. Being able to put words to an internal mood and describe a challenging situation helped participants to feel better, especially when speaking or writing to a sympathetic listener. Although a few participants journaled their moods individually, the majority expressed their moods to other people. By expressing moods to others, participants

felt heard and validated in their emotional experiences, such as, "*letting my frustrations out and venting…hopefully I will gain a little peace of mind. It is never healthy to keep it all in*" (P07).

During their sharing process, participants expected to receive understanding and empathy from the person listening to them. Importantly, while expressing their moods, participants explicitly stated that they did *not* want to receive advice or solutions; they simply desired to "vent" and be heard. P14 highlights what she is looking for in this type of interaction, "*have someone just listen and not interrupt or tell me what they think I should do*." Expressing feelings and moods to others helped to normalize participant experiences of dealing with symptoms of their condition and to "*feel supported*" (P19) in their condition management.

Participants expressed moods primarily to others with whom they had an ongoing relationship. These individuals possessed knowledge of the participant's life and circumstances, particularly through knowledge developed over time. They included close family, friends, and those who shared similar experiences with depression. Therapists also built relationships over time with participants, but these interactions were viewed as a different relationship context by participants because of their professional knowledge and formal relationship.

P27 describes that shared history is an important reason why she is comfortable expressing her moods to her long-time friend: "*[My best friend] and I have known each other for 20 years, so I can tell her something, and she has enough history to get it without me even saying it the right way*." Similarly, P09 described how his therapist used the knowledge developed over the course of their clinical relationship to know when to probe further to help him to express his feelings, "*one time when I tried to just say everything's fine, and then he could tell – he's like, 'I don't think everything is fine*.'" Relationships that build over time, such as described by P27 and P09 enable

a trusting and predictable connection. Predictability is important, providing participants the ability to better expect the response that they will receive when connecting with supportive others for self-management. This also means that lack of history may be viewed as a barrier. For example, P16 contrasted the idea of connecting with supportive individuals she knew versus someone new such as the on-demand expert in scenario 2: "*well, I trust these people. I don't trust this [expert]. And I have a history with them, so I know they will respond in a way that will help*." P16 exemplifies the frequent wariness of participants when considering connecting with a new person for support.

Participants were comfortable expressing their moods to individuals who had a shared experience of depression and believed they would receive appropriate support from them. P07 described her perceived benefits of connecting based on shared experience of depression: "*Just knowing somebody that has been there done that, that may be able to offer me solutions, maybe not, but also will just be like, 'Oh, girl, I've been there.*'" P07 found the empathetic understanding from someone who has also experienced depression to be particularly meaningful. An additional benefit of receiving support from others with depression was knowing that they are not alone through access to a supportive community. This aligns with findings of previous research about online peer support for depression [192].

**Creating Solutions**. Some participants wanted to connect with others to help them identify a solution to issues underlying their negative mood(s). Through conversation, participants shared details about their mood with others and asked for help coming up with solutions. These solutions ranged from advice, personalized tools, and strategies, to detailed next step plans. For example, if she is struggling to self-manage, P13 would connect with others to develop "*a plan of [a] series*

*of things to do that'll get you back on track.*" Solutions meant different things to different participants. Some participants sought to understand what caused or might have triggered their current mood. Others knew what caused their mood and wanted to know how to address the issue, for example, how to resolve a fight with a friend.

Across these different solution-seeking approaches, people who knew participants well were seen to offer better solutions than others because of their knowledge of the participant. However, weaker connections including work colleagues were also helpful to a few participants. For example, over lunch breaks, P08 frequently would "throw" problems to his work colleagues, get feedback from them regarding what he should do next, and then recompose himself: "*If it's a lunch hour, I've managed to get it down to a mad science*."

Although participants turned to their non-professional network for general help, they sought professionals with mental health training for best-practice solutions to challenging issues. For example, P23 wanted to receive a prioritized list of next-step tasks for her mental health management through connecting with a therapist. While most mental health professionals were described as therapists, others had a variety of backgrounds (e.g., wellness/life coach). The perceived benefits of connecting with a mental health professional for support included knowledge of best practices and the ability to provide unique support for creating solutions e.g., *"offer tools or insights that I may not have on my own*" (P02). Participants expected professionals to offer solutions and plans beyond the validating and comforting activities largely conducted with family members and friends. They often expected professionals to possess better knowledge and advice about depression management than other people in their social circle:

> *"if I, right now, am feeling anxious or depressed, I can reach out to my wife, my brother, my friends, etc., and just tell them – and they can empathize with me, but they can't say 'try*

> *this.' And if they do, I'm like, 'You don't know what you're talking about.' They're not experts. And so, I think [connecting with an expert] would make my life easier by providing at-the-ready solutions to some of the biggest problems I deal with day in and day out."* (P03)

Some participants discussed how their therapist could be warm, but at the same time be an effective change agent, "*[my therapist] calls me out on my shit but is also a really kind person and so that helps me manage my stuff*" (P19). Therapists managed their professional relationships with participants to support and encourage ongoing self-management. However, participants voiced frustrations about timelines for connecting with therapists. P24 discussed how the timeline of therapy did not match when he experienced challenges, "*you have to take all your problems that you have during the week and then address them in 50 minutes*." Instead, he said, "*you want real time advice*." Therapists were not always available when desired or needed by participants and having to wait and ruminate on issues over the course of a week or longer meant that participants were not able to act on issues as quickly as they would desire.

**De-escalating moods: Distracting & Self-Soothing**. Participants often reduced acute feelings of distress through distracting and self-soothing activities. These activities helped to create distance from the troubling problem or emotion. Participants used distracting activities such as going out to dinner with friends or watching a comedy show on Netflix to help them "get out" of their heads and take a break from their negative thoughts and mood. For example, "*Focus on one thing, instead of what's going on in my head*" (P01).

Other research has shown that distractions can be perceived as meaningful or a waste of time depending on the user's intentions [164]. This research describes how people might perceive using social media to pass the time as "mindless" or without deeper meaning, but the activity may also hold benefit as a "micro-break" from larger tasks. Additionally, psychology literature shows

there are instances when distraction can offer a positive respite, especially to de-escalate intense moods when they occur [69,129,132,207,230]. Some participants described that they distracted themselves when they could not deal with a mood in the moment, for example, if experiencing a negative mood at work, "*Compartmentalize; assure self that the issues will be attended to later"* (P08). In tandem or in complement to distraction, participants engaged in self-soothing activities such as meditation, going for a walk, practicing reiki (a Japanese energy healing practice), getting a massage, taking a nap, or listening to music. P26 described self-soothing activities including a calming inner voice narration, "*I would first exercise/meditate, drink water, calm myself down by thinking through things slowly, smile at other people instead of frown, talk to myself 'it's not the end of the world."*" Some activities served dual distracting and self-soothing purposes, for example, sharing a meal with friends.

During mood de-escalation activities, participants' social responses were varied. Some sought interactions with others, and others explicitly sought solitude. Participants described hanging out with friends or family, cuddling with a significant other, scheduling meals with friends, playing video games together, or otherwise interacting without discussing their mood or problems as a way of distracting themselves. Conversely, others spoke about the importance of being able to tackle their own problems to start to calm themselves without waiting for others to help. In both cases, participants wanted to distract themselves from their current mood.

**Expectations of Self-Management Activities**. Many participants conducted self-management activities to achieve a change in feeling state, such as reducing stress or anxiety or becoming relaxed. These expectations or hoped-for outcomes motivated participants to engage in activities to self-manage their depression symptoms. For example, one participant wanted to "*feel*

*more grounded and less frantic*" (P19), and another wanted to "*[gain] confidence to get through the day*" (P30). Being able to move from a negative mood to a calm mood led to an improved state that allowed participants to carry out their other daily activities such as getting out of bed, grooming themselves, and going to work. Improving their own productivity was a major goal, such as, "*finding some peace or energy to keep doing my things or activities"* (P10). P03 described specific outcomes of his socially-oriented self-management – to first achieve self-care, and then work toward improving his psychological health:

> *"I'd be motivated to apply these self-care tips as they're needed with the promise of accountability keeping me on top of things; I'd be able to get over the hump, so to speak, and get back on more level psychological ground"* (P03)

Finally, a few participants expressed a desire to manage their condition longer-term. While this was not the expectation for most participants, for individuals who already knew many self-directed activities, for example deep breathing, and tracking daily positive behaviors, this was the next step. P25 felt that gaining input and solutions from others as "*tools to deal*" with her condition would help prepare her for future self-management. Others desired "*control over emotions*" (P06), "*not using maladaptive coping mechanisms, e.g., self-harm*" (P13), and "*in the future, be able to control my depression more effectively*" (P17). These participants were particularly interested in gaining a better knowledge of their condition and long-term self-management skills through conversations with therapists and other trained professionals.

When asked about the most important element supporting her self-management, P15 noted that it was the people she connects with, saying, *"I think people are powerful."* Through connecting with others, participants felt heard and understood, validated in their emotions, and assisted with reframing or deciding to let go of a situation. To achieve the expectations described

in this section, individuals, as part of their self-management, reached out to others to express moods, create solutions, and enable distraction from feelings. Some participants described employing one or more of these activities, often mixing and matching depending on the situation.

In summary, these findings present a nuanced picture of the variety of participant expectations of self-management and their activities in pursuit of these expectations. Interestingly, most participants, even when responding to a scenario prompt (Scenario 2) that included an on-demand expert, did not seek long-term management of their condition. Instead, participants focused much more on mood alleviation, mood expression, and shorter-term (more immediate) problem-solving.

In the next section, I describe characteristics of locations and their impact on sociality.

### *4.3.2 Locations of Sociality*

Participants had specific ideas about where and how supportive interactions should occur. As has been found in other HCI research (e.g., [109,209,223,263]), location is a key component in participants' descriptions of social activities. Participants chose locations in which they could regroup, reflect, and engage in their preferred sociality. They described a variety of locations including home, work, and public areas where they conducted self-management activities. The ability to control their location improved their interactions and helped them reach their expected outcomes, as stated by P25: "*if I was uncomfortable in a setting, I would want to change that as much as possible with like what I'm wearing, where I'm sitting, so that I could just be receptive to whatever they and I were gonna talk about*." Four key themes were important to participants in choosing their location: privacy, comfort, a new perspective, and social interaction.

**Ensuring Privacy.** Participants often cited privacy as a reason for choosing a particular location for self-management. For example, "*I would wanna be somewhere, whether that's home, or at work, or even driving home in my car, or whatever, I would want it to be private*" (P21). This desire for privacy is unsurprising given the sensitive nature of discussions about one's moods and circumstances and was important in helping participants reach their expected outcomes. Participants largely associated their homes and vehicles with privacy.

However, for participants living with roommates, partners, or spouses, the ability of nearby individuals to potentially overhear conversations had to be taken into consideration. This was a particular consideration when preparing to talk with others for self-management support because of the likelihood of sharing private and sensitive information. Specifically, being in an intimate relationship, a friendship, or living with another did not mean that participants were automatically comfortable with them overhearing conversations about their mental health. As such, participants sought privacy to safeguard against unwanted disclosure of their mental health.

**Enabling Comfort**. Participants often cited comfort as a reason for choosing a particular location. Being comfortable and feeling relaxed and safe allowed individuals to lower their inhibitions and interact more freely with others. Comfort was closely related to helping individuals achieve self-soothing activities, but also was often a pre-requisite for undertaking the work of understanding moods and coming up with solutions. Home was most often the place participants wanted to be as they carried out self-management activities. When at home, they could more easily connect with a significant other, or call parents or friends. For example, P18 said, "*My comfort zone, other than my car, is my home*." For some participants, safety was closely linked to comfort, "*An escape, I guess, from everything from the outside world, going somewhere else were you feel*

*comfortable and safe*" (P01). Comfort could encompass feelings of safety, familiar surroundings, and the ability to feel relaxed and secure.

**Shifting Perspective**. Because certain environments or social situations were described as triggering or exacerbating of their negative moods, several participants described a need to get away from their current location and change context, particularly to de-escalate their moods. Going outside, sitting in one's car, or taking a walk were common activities, and connecting with supportive others helped to enhance these context shifts. For example, participants described talking with others during perspective-shifting walks to express and de-escalate their mood through conversation and change in location. Participants described wanting to go "*away from work, house, stuff. And just be somewhere else*" (P08) or to just "*get the hell out of the situation*" (P05) that was triggering or worsening their mood. However, shifting perspective did not always have to be accomplished by physically moving. A perspective shift could also involve simply changing activities, for example, from doing homework to watching a show on Netflix and brushing one's hair. Therefore "location" for depression self-management can mean an individual staying in one location but shifting activities, or an individual moving between multiple locations to enhance and enable their self-management activities.

**Managing Social Interactions**. Participants chose their location based on their desired social interactions with others. In some cases, they wanted to be around other people in busy, public places without directly engaging with them. I label this "diffuse sociality." For example, P19 explains frequently working on homework at a coffee shop chain: "*I put in my headphones and I like being surrounded by people but feeling like not hearing any sounds*." P19 is still engaging in a social experience but not explicitly interacting with others. Importantly, she does

this when she is experiencing a negative mood to accomplish her required tasks. Being in public and busy places helped several participants to focus on their work while avoiding negative mood spirals and unwanted behaviors.

P13 described how the public nature of her favorite coffee chain helped her to avoid isolating herself and attendant unwanted self-harm behaviors, "*I'm in public, so it's a little easier to resist.*" Diffuse sociality also occurred in other locations. P01 liked to sit next to his boyfriend while playing games but did not need to directly interact with him to feel the comfort of his presence. Being near other people but not necessarily needing to interact with them was important to some of our participants. Being near others allowed participants to accomplish their own tasks, but also enjoy the benefits of a social location. Consequently, while direct interaction was certainly a major component of sociality for our participants, so was diffuse sociality – focusing on their own activities while being around others.

In summary, these findings prompt reflection on how locations influence interactions for social support. The ability of people to participate in self-management and to interact in ways where they can feel safe and secure relates to how well their environment matches the intent of their interactions. In the following section, I describe ways participants adapted technology use to meet their needs.

### *4.3.3 Collaborative Technologies and Sociality*

Technologies enabled participants to connect with their supportive network. Participants selected technologies according to their desired type of interaction, using different options depending on their location, their mood, and their expected outcomes. They communicated with others through a variety of technologies including texting, phone calls, voice calls, social media,

and online games. Technology offered an opportunity for in-the-moment support. This is important because addressing a bad mood earlier is often beneficial for mental health management [19].

No single mode of communication was preferred; participants were flexible and multimodal in their use, making choices about technology use based on the need for privacy, the content of the interaction, or the locations of those with whom they were communicating. For example, P02 described texting for support if she was having an issue with her boyfriend: *"If I'm complaining about my boyfriend and he's sitting right next to me, I'm not going to want to say it out loud."* Current moods and emotions guided other participants' technology choices. For instance, if someone was anxious, "*typing things out…lets them say what they want to say without using their voice"* (P01). Similarly, not wanting to cry led P02 to switch communication modes to something less likely to evoke that response. Flexibility in their mode of communication was important for handling participants' multiple different situations and communication desires.

At times, participants also switched communication medium during a conversation with other people, based on the subject matter. For example, to communicate via *"instant messaging with an option to escalate to video chatting"* (P13) if a richer connection experience was desired. Others desired visual communication for better communication of emotion with their listener. P30 thought that FaceTime would be best for interaction because, *"you can see and hear what people are feeling."* P10 concurred, *"texting takes too much more time than actually talking and can be so much colder than a visual interaction."*

While technology was used to mediate direct interactions, participants also used technology to plan physically co-located interactions and to de-escalate their moods. Participants would often text their social support network to arrange face-to-face meetings or to call a therapist

to arrange an in-person appointment. For example, P06 explained how she would contact her friend via *"messenger, and we are potentially [going] to make plans to go out to dinner or have drinks."* P22 described more broadly searching for social connection by looking for upcoming Facebook events, Meetups, and using OKCupid to set up interactions with others. Participants also used technology for mood de-escalation. They used headphones for music, computers and TVs for streaming services, and gaming consoles for games with others online. P01 described often having *"headphones on because I like the music of the games...It gives me something to focus on, rather than focusing on how I'm feeling."* Therefore, technologies were used both to support social and individual-focused self-management.

Although technology was crucial to successfully being social in the ways that our participants desired, a few participants mistrusted technology-mediated communication. They viewed technology as potentially leading to less honest connections with others, *"It's kind of easier to lie behind technology...you can convince someone you're fine via text so easily"* (P13). Others found technology-mediated communication to lack the warm personal qualities of in-person interactions, *"I rely more on the person experience, rather than the virtual experience"* (P10). Finally, some participants were skeptical that technology-mediated support could work in an immediate way. P27 described how on-demand therapy would need a prohibitive amount of background information to work, in her perspective:

> *"you can't give your life story in an instant. And unless they have enough of your back story, they can't give you a good answer to go forward. So, the technology – the idea is good, but the input from the individual would need to be massive"* (P27)

Technology clearly played an essential role in mediating sociality for the majority of participants, however, technology also created challenges for some participants.

In summary, participants connected to their support network through a diversity of channels, including technology-mediated channels and physical face-to-face channels. Additionally, these channels were often used in tandem or in sequence with one another. This variety allowed participants to choose which social activities to engage with in any given situation.

## 4.4 Discussion

In the findings above, I unpacked how sociality is interwoven into individual's self-management practices. These findings begin to present a picture of the work of collaborative self-management of depression. Previous literature has found that social interactions can be challenging for individuals managing depression [175]. While this is true, and my study participants did talk about their challenges, I also found that they turned to others for several reasons and in a variety of ways as a key aspect of their self-management. When faced with a bad day or a negative mood, many participants reached out and connected with others through texting, video chat, or face-to-face conversations. This is similar to social media use research that found connecting online to close others improved symptoms of depression [35,37]. Direct human connection enabled participants to feel heard, understood, and validated in their emotions and the experience of their condition, helping to lighten their load of managing depression. Connection with others largely centered on conversation (empathetic listening, some problem-solving), resonating with the social support literature [31,195], but also encompassed affectionate physical contact. My findings regarding the collaboration activities of the participants resonates with previous conceptualizations of sociality as highlighted in Chapter 2.

The following section is organized to present a discussion of the three research questions guiding the dissertation: (1) how do people conceptualize collaborative self-management of

depression, (2) how does an individual's technology ecosystem enable or constrain collaborative self-management of depression, and (3) how might we redesign technology-mediated supportive experiences to better fit the needs of individuals managing depression and those they collaborate with for self-management? The conclusion section highlights the aspects of the research questions that are explored further in the main study.

### *4.4.1 How do people conceptualize collaborative self-management of depression?*

a) Who do they conduct this work with?

b) How do they conduct this work?

c) Where do they conduct this work?

This study helps us begin to understand (a) who individuals managing depression interact with to help to manage their depression, and (c) where individuals managing depression conduct collaborative self-management. Below, I present a variety of interrelated factors that influence collaborative self-management of depression. These include first, relationship roles and culture (particularly stigma), and second, location, privacy, and emotion and communication channels.

**Relationship Roles.** Participants selected who they wanted to connect with based on both the expertise of and their ongoing relationship with individuals in their social network. Reaching out to particular individuals for specific supportive reasons resonates with findings from Park [195] and Lattie's [83] college student participants and Murnane et al.'s participants managing bipolar disorder [183]. To aid self-management, participants in our study sought social activities with close supportive relationships including friends, significant others, family members, and others also managing depression. For example, participants socialized with people who shared experience managing depression to receive empathetic listening, similar to findings of O'Leary et al. [191].

Participants also sought interactions with individuals with professional training, (e.g., therapists) to gain solution-focused support based on clinical best practices. Many participants viewed interacting with professionals as particularly beneficial because it did not require reciprocal sharing. For individuals managing depression who may have limited energy and motivation, the tiring nature of managing relationship challenges including burden and reciprocity can influence to whom they reach out [31]. Furthermore, for some participants, hearing problems shared by others made them feel worse, similar to findings of depression symptom contagion [128]. Consequently, while supportive relationships are generally beneficial to participants, there are issues that affect who participants want to turn to for support.

Specifically, trust played a critical role in these supportive relationships. While participants viewed topic-based expertise as important (e.g., perceptions of expertise motivated people to connect with trained professionals), I found that other factors also encouraged trust within supportive relationships. Participants' support networks included people who were close to the participant and who had built a deep understanding with them over the course of their relationship. Thus, while some supportive individuals had mental health expertise (e.g., a sister who is a trained social worker), importantly, these individuals also had participant-specific expertise. They knew the participant's preferences, past activities, and common ways of thinking. Participants trusted the ability of these individuals to provide useful support based on their background knowledge of the participant and their ability to deliver support in comfortable and pleasant ways.

**Culture.** The important social needs of our participants to maintain productive self-management influenced the many ways they actively sought out human connection. In many cases, participant's networks were able to support their needs. However, participants also spoke about

some social challenges they experienced including both the tiring nature of self-management work and relationship aspects of burden [137] and reciprocity [113]. When designing future tools or new supportive social connections for this population, it is important to keep in mind that the concept of "mental health" is socially constructed and, as such, the definitions and meanings of labels such as "depression" are fluid and situational [79,208]. In creating new systems of support, these complex interplays between how labels and/or identities are interpreted, reified, and redefined will influence design and deployment of these new systems.

Furthermore, the term depression also has certain power within the culture of these participants. For example, a study examining online support groups for depression in China [273], highlights that cultural contexts and societal understandings of depression strongly affect an individual's goals and behaviors of social connection. The importance of saving "face" both for oneself and one's family prevented many people from being comfortable disclosing and discussing their mental health needs. Cultural understanding mediates and shapes the conversations participants have when they connect with others and where self-management activities take place. We need to be sensitive to this issue because tools and technologies for mental health become a part of the larger societal "conversation" about depression. As we integrate tools into people's lives, this conversation about their mental health is influenced by and in concert with the different interactions they have with medical professionals, friends, family, and cultural artifacts. Therefore, understanding the social activities and social goals of individuals managing mental health needs is essential to properly support the nuances of human connection for these individuals and their support networks.

**Location.** Location influences the collaborative self-management of individuals managing depression. To carry out interactions either in-person or mediated by technology, individuals seek out private and comfortable locations. As shown in previous HCI studies, location impacts interactions with technologies, as well as interactions with others (e.g., [109,209,223,263]). However, much of the prior CSCW literature has not focused on location in the context of mental health. For example, work analyzing social media communication and expression (e.g., [11,66,67,112,170]) may be "severing [posts] from other aspects of life and experience" [94]. In contrast, my findings deepen our understanding of participant experiences of self-management across a variety of locations in physical and technology-mediated environments.

For individuals seeking support, locations can take on new dimensions because of the social stigma associated with mental health challenges [61] and the difficultly in managing moods and emotions. For example, as described in the findings, location can affect an individual's sense of security. A person may feel more or less secure disclosing to others about their challenges depending on their location (e.g., therapist's office, workplace, public setting). Similar concerns have been raised in online environments. Previous research by Andalibi et al. [7] regarding disclosure of mental health and other sensitive topics on social media has also shown that privacy can affect intent to disclose [8,9,11] and others's response(s) to disclosure.

Participants described the challenges of being in certain locations such as their workplaces when experiencing negative moods. An important way they self-managed in these locations was to seek comfortable and safe environments to communicate within places where they could avoid being overheard. For example, while at work, some participants headed to their car, went on a short walk, or connected with friends over lunch to talk through issues. Others used technology

such as mobile phone games and music to reduce the intensity of their mood until they could manage it later. While the use of distraction as a self-management strategy to remediate low mood is often reported by individuals with depression [69,129,132,207,230] understanding more deeply what prompts people to 'transport' themselves physically and mentally in order to manage their mood is less understood. Comfort, privacy, and moving one's body and/or mind to a new location (through physical movement or technology use) enable the difficult work of self-management.

In the following section, I discuss how this study addresses my second research question.

### *4.4.2 How do individual's technology ecosystems enable or constrain collaborative depression self-management?*

To help them self-manage, participants used multiple forms of technological mediation including social media, texting, video conferencing, and video games in distinct ways and in specific combinations. Technology-mediated channels to connect with others were often selected based on a collection of considerations such as location (e.g., work or home), emotion state (e.g., sad, anxious), and the availability and location of the person with whom they were connecting. Participants' emotional states often influenced their interaction and technology choices. Technology allowed participants the flexibility to receive in-the-moment support through different channels. Indeed, in-the-moment context-based channel-switching enabled by technology-mediated communication has also been found useful beyond the mental health context to enable communication with deaf and hard-of-hearing individuals [256]. These social interactions can take place both in physical and digital spaces.

Technology channels were critical to support collaborative self-management by enabling flexible connection with others and in-the-moment support. Participants' ability to interact and

feel safe and secure related to how well their channel and location matched the intent of their interactions. My findings described how participants used technology to enable and augment their social interactions. While the literature reports a lack of user engagement with current individual-focused tools to support user mental health [177,179,246], I found that participants creatively appropriated mainstream technologies to support their desired sociality. Technology ecosystems [72,211,259,261] (e.g., SMS, Facebook Messenger, and video chat) provided essential access to supportive relationships and social network resources. These tools were unlikely to have been created with supporting user mental health in mind and indeed some have been correlated with negative trends in mental health [117]. However, as shown by research investigating the well-being of social technology users, meaningful connections within these social technologies including directly writing to others [35,37] and showing effort in communication [141] beyond simply "liking" content can positively influence mental health. Thinking toward future technologies for depression self-management, we need to consider incorporation into existing management routines and communication structures where people are already sharing support.

As highlighted in other areas such as assistive technology [210,232], we can learn much from user appropriation. Understanding how users are appropriating technology can provide insight regarding what users want or need. For example, many participants described selecting among different channels of communication including texting, voice, or video calls, depending on their mood. A few participants noted that texting was particularly attractive when they were having difficulty regulating their emotions because even a voice call seemed too difficult to manage. My findings align with other CSCW literature on selecting between multiple channels of

communication [5,256]. However, channel selection was not only based on static individual preference, but also on the dynamic needs of our participants in the moment.

In the next section, I discuss how this study addresses my third research question.

### *4.4.3 How might we redesign technology-mediated supportive experiences to better fit the needs of individuals managing depression and those they collaborate with for self-management?*

This study surfaced the key importance of designing to support user privacy, especially contextualized to the variety of locations an individual might be in when they desired to connect with others for support. For the participants, even though technology was useful to quickly connect to people in rich forms (e.g., video chat), these uses still suffered from privacy challenges. For instance, while video chat was prioritized by some participants, privacy of conversations at work and on the go (e.g., between classes), and in shared households was not a given. Technology solutions that enable in-the-moment adaptation, for example, by allowing switching between text, voice, and video-based channels might be one way to enable users to adapt their sociality to their current environment.

One way that researchers and designers have begun to use location information to support mental health management is through the use of smartphone sensors and passive tracking (e.g., [163,257,275]). A potential design direction from my research relates to passive sensing solutions. For example, a hypothetical application could combine sensed location data with user input, allowing sensors to detect frequent locations [219], and request users to annotate them (e.g., work, coffee shop, home), noting channels that are socially acceptable and most useful for the user to connect with others for support. For example, using texting but not video chat during work hours.

However, such solutions have limitations and require more nuanced thinking before implementation. First, as shown in my findings, locations are not necessarily used for the same social activities all the time. For example, a home might be used sometimes to have alone time away from people and at other times to host a gathering of friends. Given the diverse interactions of daily life, mood management, location, and other people, it is difficult to predict a person's social needs in any given moment solely based on sensing data.

Furthermore, location-based technologies necessitate privacy considerations. For many reasons, a user may not want to disclose their location. Indeed, vulnerabilities from this type of data are cited as a concern regarding many digital mental health technologies [224]. In their study with individuals managing depression and anxiety, Nicholas et al. [186] noted distinct differences in individuals' comfort sharing "health data" including sleep, mood, and physical activity versus "personal data" including communication logs, location, and social activity. Further, safety is an important concern for many individuals and was brought up by participants. We need to consider who has access to location and other personal and sensitive data. The case of domestic violence exemplifies a need for great care to be taken in the design of these technologies [98]. The concept of "safety" is deeply intertwined with how each person chooses to be social, where they are being social, and who they are being social with. Future work needs to address these more nuanced concerns when designing digital mental health technologies, particularly if they involve tracking sensitive personal data such as location.

## 4.5 Conclusion

This study identified several collaborative activities conducted by individuals managing depression and their support networks, and the importance of collaboration through technology

mediation. The main study extends on this foundation to better understand how individuals conceptualize this collaboration, how collaborative activities are mediated by technology, and where we might design to better support the needs of individuals managing depression.

First, while this preliminary study provides an initial understanding of with whom and where individuals conduct collaborative self-management work, I still needed to further understand the larger social network of people *who* individuals connect with to manage their mental health, granular details about *how* this work is conducted, and *where* this work occurs across technology-mediated and in-person environments. Understanding interrelated influencing factors is important for developing solutions that are sensitive to a user's current context.

Second, while this study showed the breadth of technologies used by individuals, it did not investigate challenges or unmet needs regarding communication technologies. Therefore, I still needed to know more about how people conceptualized their technology ecosystem for collaborative self-management (*how do you get in touch with people when you've had a bad day?*), how they selected from among available technologies to enact their work, and challenges they encountered conducting this work. I sought to better understand the perspectives of people who were uncomfortable communicating online about their depression, as well as support activities carried out in-person and through one-on-one digital communication.

Finally, in their recent book, *Positive Computing* [41], Calvo and Peters write that "there is obviously much we need to learn about which technologies can support wellbeing, when, in what circumstances, in what combinations, and why." Their work highlights the need to understand the connections between social interactions, technology use, and relationships. Therefore, I needed to further identify potential design avenues to consider for supporting self-

management. This preliminary study showed the importance of considering how to design for privacy during collaborative interactions while adapting to a changing set of locations and contextual factors. However, unexplored factors included the collaboration preferences of individuals managing depression and areas where they experienced challenges conducting this work.

In the next chapter, I describe my main study which investigates these gaps in our understanding of collaborative self-management.

# 5. MAIN STUDY

The following chapter details the main study of my dissertation[2]. I undertook this study to address the gaps raised in the preliminary study conclusion section. In the following chapter, I begin with an introduction to the study (5.1), and I describe the specific methodology (5.2). Then, I share the study findings (5.3) and conclude with a discussion of technology ecosystems and collaborative self-management (5.4).

## 5.1 Study Introduction

Depression is a major contributor to the global burden of disease. In 2017, 264 million people worldwide experienced major depression disorder [124]. Individuals who manage depression often experience feelings of sadness, negative thoughts, lack of enjoyment of activities, lack of motivation, and agitation and sleep disruption [19]. A key symptom of depression is the tendency to isolate oneself from others, yet social interactions are important for self-managing the condition over time. While previous CSCW literature has underscored the importance of social support for individuals managing mental health needs (e.g., [10,80,273]), we still need to better understand, from the individuals managing depression themselves, how they collaborate with others to support their mental health, across the variety of their day-to-day interaction contexts. To do this, I extend the concept of collaborative self-management from the chronic disease management literature [14] as a way of capturing the details of these collaborative interactions.

Self-management is often conceptualized in HCI and clinical literature as a set of individual activities undertaken to support one's health (e.g., taking medications, exercising). Within mental

[2] Currently under review at CSCW as a paper titled, "I Just Can't Help But Smile Sometimes": Collaborative Self-Management of Depression.

health this perspective is reflected in many individual-focused digital mental health support technologies (e.g., smartphone apps [15,178]). While individual self-management work is important, this perspective fails to capture the breadth of collaborative activities that individuals engage in with others as part of their self-management. Recent HCI work has begun to show the importance of collaboration and social interaction for individuals managing mental illness, for instance, through interactions on social media [5,7,85,92] and in online communities [24,45,155,273]. Other research has investigated the roles of caregivers, friends, and family members in supporting ongoing mental health self-management [80,83,146,248,268].

Collaborative self-management as discussed in the clinical chronic disease literature largely focuses on patient-provider communication and teaching strategies to manage physical effects of chronic disease (e.g., pulmonary disease [28,173]; asthma [167,180]). However, in contrast to this physical symptom orientation, individuals managing mental health needs are likely to have different collaboration goals to support mood and emotion management. In addition, the individuals who support collaborative self-management in the mental health context often extend beyond a clinical care team to include friends and family members, among others [31,216]. Depression is an important context to explore this work because key symptoms include social withdrawal (the tendency to isolate oneself from others) and lack of energy and motivation [19]. These symptoms create barriers to collaboration yet at the same time also show the importance of collaborative engagement to combat these symptoms.

In this chapter, I explore the characteristics of collaborative self-management of depression with particular focus on the ways that individuals collaborate using one-on-one or small group social technologies (e.g., texting, phone/video calls, social media). To do so, I conducted remote

semi-structured interviews with an associated cognitive mapping activity with 28 individuals managing depression who live in the United States. This data, collected from May-July 2020, includes participant collaborative experiences both prior to and during the COVID-19 pandemic. I discuss my approach in greater detail in my Methods section. I describe the network of people who individuals managing depression collaborate with to support their mental health, how collaboration unfolds through a variety of practices (both mood-focused and preventative), and where this often technology-mediated work occurs through channel-switching between text, phone, video, picture-based and in-person interactions.

This chapter deepens our understanding of the everyday technology individuals use in their technology ecosystems to support their mental health. I discuss factors influencing technology channel section: the preferences of the person or group that the individual managing depression wants to connect with, as well as in-the-moment cognitive state. I also describe varied periods of use across these everyday technologies for the purpose of mental health support. I present this contextual understanding to guide the development of future digital mental health tools, educational resources, and services sensitive to the needs of these individuals and their support networks.

## 5.2 Detailed Methodology

I conducted a qualitative study with 28 participants managing depression, consisting of remote semi-structured video interviews aided by a cognitive mapping elicitation. All research was conducted in the United States and received ethical clearance from the Northwestern University Institutional Review Board. Participant compensation for the study was $25.00 sent through Paypal.

### *5.2.1 Participants*

I recruited participants who were at least 18 or older, lived in the U.S., had previously received a diagnosis of depression, and had experienced symptoms of depression within the past 12 months. I considered interviewing friend/family/caregiver dyads but decided for this study to identify the breadth of supportive connections from the perspective of the individual managing depression. Another reason for this methodological decision was to ensure that participants felt comfortable discussing any collaboration challenges.

28 people participated in this study. 75% of my participants were White/Caucasian. Of the remaining 25%, two participants were Hispanic (from Guatemala and Mexico, respectively), two participants were White and Hispanic (Puerto Rican; Mexican), one participant was White and Asian, one participant was African American and Asian, and one participant was Mixed Race. 64.3% of the sample were Female, 32.1% of the sample were Male, and one participant (3.6%) left the gender question blank. Participants ranged from 21 to 66 years of age, with 36 as the mean age. Participants had managed depression from a few months to 35 years (Table 4.).

Participants lived in many different U.S. states. Regarding education, 71.4% of my sample had completed college or more, 21.4% had completed some college, 1 participant (3.6%) had completed high school or GED, and 1 participant (3.6%) had completed 1st grade – 11th grade. Regarding employment, 46.4% of my sample worked full-time and 21.4% worked part-time. 14.3% were not currently working but were looking for work. One participant (3.6%) was not currently working and not looking for work, and one participant (3.6%) was retired. Three participants (10.7%) indicated that they fit the “other” category, one as an undergraduate student, one laid off due to COVID-19, and one on very part-time work due to COVID-19 and disability.

Table 4: Main Study Participant Information

| Participant Number | Age | Gender | Years Managing Depression* | Participant Number | Age | Gender | Years Managing Depression* |
|---|---|---|---|---|---|---|---|
| P01 | 21 | Female | 2 | P15 | 30 | Female | 12** |
| P02 | 66 | Female | 21 | P16 | 33 | Male | 4 |
| P03 | 28 | Female | 9 | P17 | 60 | Female | 33 |
| P04 | 38 | Male | 10 | P18 | 24 | Female | 5 |
| P05 | 34 | Female | 20 | P19 | 26 | Female | 20 |
| P06 | 38 | Female | 23 | P20 | 23 | Female | 8 |
| P07 | 38 | Male | 11 | P21 | 24 | Female | 3 |
| P08 | 35 | Male | 19 | P22 | 25 | Female | 10 |
| P09 | 36 | Female | 9 | P23 | 33 | Female | 11 |
| P10 | 32 | Female | 9 | P24 | 54 | Male | 35 |
| P11 | 28 | Female | 6 | P25 | 36 | Male | 10 |
| P12 | 25 | Left blank | 5 | P26 | 25 | Male | 10 |
| P13 | 62 | Male | 21 | P27 | 62 | Male | 27 |
| P14 | 39 | Female | 25 | P28 | 23 | Female | A few months |

* 'Years managing depression' was in response to the question "When were you diagnosed with depression?" Participants may have managed depression before their official diagnosis, so this number gives us some idea but not necessarily the full period of management. ** P15 noted that she had been managing "since high school" so this is our estimate given current age.

Participants managed their depression in several ways and often combined strategies (e.g., medication and therapy). In their responses to the background questionnaire, 67.8% of participants noted that they used medication and 42.8% of participants participated in therapy (including cognitive behavioral therapy, talk therapy, EMDR Therapy, and group therapy). One participant (3.6%) reported using psychiatric care. Four participants (14.3%) noted that they did not formally manage their mental health.

### *5.2.2 Data Collection*

Recruitment and data collection occurred from May to July 2020. Due to the COVID-19 pandemic, all recruiting for this study occurred online. Recruiting occurred primarily through a research registry database operated by a behavioral health group within Northwestern University.

The lived experiences of non-white participants can often be distinct, and I wanted to gather this diversity of experience managing depression. To do so, I sought participant diversity through connecting with a community organization focused on peer-based mental health support to share our study recruiting materials. I also shared recruitment materials with student organizations at Northwestern University focused on supporting individuals in minority populations and was able to interview a few people through those connections. However, while I tried these different methods to increase diversity in my sample, the recruitment occurred just as the U.S. was experiencing racial justice protests. In consideration of this I did not request further send-out of recruitment materials so that my partner organization could attend to emergent priorities in supporting the mental health of their members during that distressing time.

**Study Process**. Potential participants filled out a short study screener on REDCap a browser-based software for designing clinical and translational research databases. I then directed potential participants to the online consent form and e-signature followed by a background questionnaire asking about demographics, current depression treatment routines, and technology device and online platform use. Participants received a Zoom login link along with instructions: a request for the participant to have a piece of paper and a pen or markers for the upcoming activity (cognitive mapping exercise) and to gather mental health management tools near their computer.

Semi-structured interviews are a standard method in CSCW research, particularly for qualitative health researchers seeking to understand people's thoughts and life experiences (e.g., [5,18,33,52,96]). During the interview, the webcam was on for both for me and the participant, but depending on internet connection quality, either the participant or I could turn our video off. I followed a semi-structured approach coupled with an interview guide. Major topic categories

included: a) mental health management, b) support network experiences, c) the mapping activity, and d) design questions. Sample questions included: "*Can you tell me a story about a recent time someone in your support network was able to help you out with a bad mood or an emotional issue?"; "Which technologies do you use the most often to connect with others?"* Some participants shared artifacts including showing their phone screen for a visual of a game or app or showed a smartwatch technology or a journal. When this occurred, I asked the participant to hold the artifact steady and took a screenshot.

After about 30 minutes of discussion came the mapping activity phase. The Nielsen Norman group [38] defines cognitive maps as "*any visual representation of a person's (or a group's) mental model for a given process or concept*". Laying out and connecting concepts can enable identification of themes across different concepts and surface new patterns and connections. The mapping instructions included the following: "*Please map out the people or groups who you feel help support your mental health as well as the people who you help to support, leaving some space between them for connections*." Participants were instructed to follow a talk-aloud protocol. Then, I prompted the participant to note their communication channels, "*Now, what are the ways that you connect with these people? Feel free to create links or note however you'd like to show these connections*." As Figure 3. shows, individuals detailed their support networks by using circles, stick figures, arrows, links, different colors, and text in creative ways.

Further prompting included asking about in-person groups, online communities, and group texts. Once the participant finished, I took a screenshot of the participant's map as they held it up to their webcam. Then, using the picture as a shared visual artifact, I asked follow-up questions. These included asking about the frequency of communication with each person/group, whom the

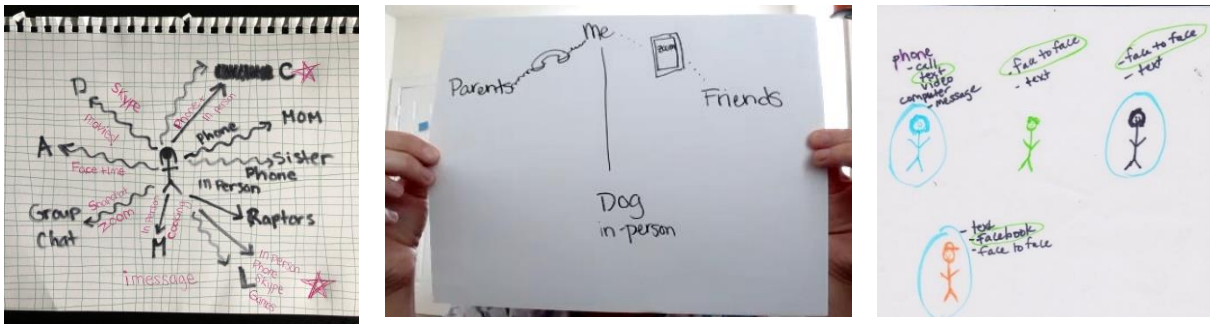


Fig. 3. Selection of Participant Cognitive Maps

participant would turn to if they had a bad day, which communication technology they used the most frequently and the perceived strengths and challenges of the technologies noted on their map. I probed both specific challenges and potential solutions to current connection routines as well as "blue sky" questions, "*if you had a magic wand and could make anything happen, even outside the realm of current science, how would you change this map?"* Macadamian [279] defines a blue-sky approach as "a chance to validate design ideas that are not limited to current notions of what is practical or feasible." Through these open-ended, exploratory questions, I gathered a diversity of ideas from participants ranging from creative solutions to current challenges to futuristic technologies for connection which I discuss in Chapter 7. Video and audio files of the interviews and screenshots were recorded locally and then stored in our secure password-protected and HIPAA-compliant University server.

### *5.2.3 Data Analysis*

I led the analysis process and regularly discussed ongoing analytical approaches and emerging themes with faculty members advising me on the project. The data collected for this study included examples from both prior to and during the COVID-19 pandemic. Overall, participants did not report many new routines or technologies for connection and collaboration during the pandemic. Instead, the technical infrastructure was largely already in place between

participants and their social support networks. I describe a few specific collaboration practices shifts due to the pandemic in 6.3.

The cognitive maps were primarily used to elicit greater detail from participants regarding their social support network and the technologies they used for communicating with members of their network. I analyzed the maps by numbering the individuals and groups on each map as well as the number and type of communication channels. For the interview transcripts, I followed Braun and Clarke's thematic analysis method [16]. I began by open coding several participant transcripts to gain familiarity with the data. I primarily coded at the sentence level, but some coding took place at the paragraph level because I was interested in understanding sequences of collaborative interaction(s). Through a process of iterative analysis and comparison I arrived at a set of axial codes reflected in the themes of this paper (Table 5.).

Table 5. Example Open Code to Axial Code Transitions

| **Open code** | **Axial code** | **Theme** |
|---|---|---|
| She saw that watching the movie helped her roommate reduce emotionality and get ready for bed | Reflection on the collaborative interaction | Collaborative Support Practices |
| Marco Polo for awareness & Zoom for actual support call | Channel-switching | Technology Use |

### *5.2.4 Study Ethics and Reflexivity Statement*

I took care to build trust and to develop a process that prioritized participant comfort in discussing the sensitive nature of their depression management and social relations. The research team included an experienced clinical psychologist who provided guidance throughout all stages of the study design and data collection and offered clinical guidance when needed. Participants selected a time for the interview that best fit their schedule, with opportunities to carry out the

interview on weekends and after work hours. While the remote nature of the interviews meant that participant privacy was not something I could control, through study emails, I recommended finding a quiet, private place for the interview, noting that there would be a discussion of potentially sensitive mental health topics. A few participants rescheduled the interview due to unexpected events. When this occurred, we rescheduled together for a better interview time.

I do not live with a mental illness and there are aspects of the lives of the participants that I cannot empathize with personally. To understand their experiences, I took a user-centered approach to support participants in expressing their lived experience, their goals, and their daily activities. I tried to frame questions to enable individuals to reflect as they saw fit on potentially sensitive past experiences.

## 5.3 Findings

To support their mental health, participants described a diversity of collaborative self-management interactions. These interactions could occur frequently or infrequently depending on the participant. For instance, some participants worked with others on a daily basis to support their depression self-management, but for others this happened every few weeks or months. In the following sections I describe the diversity of people *who* participants connected with to accomplish this work, *how* these interactions occurred, and *where* the interactions occurred (e.g., via technology or in-person). I conclude by overviewing the diversity of everyday tools used for mental health support.

### *5.3.1 "Who": Roles Supporting Collaborative Self-Management*

Below, I describe participants' selection criteria for supportive connections, the role categories with whom participants collaborated, and their collaboration challenges.

**Selecting Collaborators**. Participants described criteria guiding the decision of who they turn to for support: (1) how well the individual(s) understood them as a person, (2) whether they were in physical proximity, (3) whether the individual(s) had experience or knowledge of managing mental illness, and (4) how frequently they communicated.

First, participants described the importance of turning to individuals who understood them well as a person – their common behaviors, their values, how they think, and effective support approaches. Many participants used the phrase "*know me well enough to [do X]*". For example, P02 discussed how her family members noticed cues when she might be struggling. In one instance, she left a video message for her brother using the Marco Polo video messaging application to congratulate him on a new job. Her brother noticed that something was wrong from her facial expression and voice in the message. Later that day, she received a message from him asking, 'what's going on?' which led to a phone conversation. During their call, she realized that she was experiencing emotional issues from recent pandemic-related experiences.

A second factor was physical proximity. Many individuals had supportive interactions with people they lived with. When in the same physical location, participants described how others could see their need (and they could see other's need) without even asking for help. For example, one evening when P01's roommate (who was also managing mental health needs) had been having "*a really shit day*," P01 spent her evening supporting her friend. She made a plan for them to eat food, have drinks, and watch a funny TV show:

> "*We fixed ourselves two G&Ts and put on Miranda which is our favorite cheesy British sitcom and made ourselves a bowl of popcorn…I was like, 'You can cry if you like. We're going to put this on, and you don't have to watch. You can just curl up in my lap and cry but we're going to do it in a way that's slightly less, um, depressing and just feeding the mood than alone under our duvet.' And, I was like, 'I don't mind if you cry, I don't mind if it's the worst night ever but I'd rather we do it together and not by yourself*.'" (P01)

Watching a show together did not necessarily solve the issue, but P01 felt that in these situations, "*it's just nice to have someone else sitting there*." After the show, P01 observed that her roommate was not crying as much and seemed to be feeling better.

Third, participants collaborated with others who understood the challenges of managing mental illness. Some of these individuals were also managing depression while others were managing conditions such as anxiety, attention deficit hyperactivity disorder (ADHD) and obsessive-compulsive disorder (OCD). These friends often suggested strategies that worked for their own mental health management. P21 described that her friend who also had depression and anxiety could understand her thought processes: "*We'll talk to each other about things that are sort of like the irrational things that we do, or that we think, and we definitely have different conversations about it. It's a lot of laughing about it*." This shared experience with depression and anxiety enhanced their ability to understand and support each other. Many HCI researchers have observed similar types of peer support (e.g., depression [77,78], cancer [37]). Other collaborators learned how to provide mental health support either by having a close family member who experienced mental illness or through job-related mental health support training. For example, P03's mentor at work had a younger brother who had died by suicide. Furthermore, both P03 and her mentor were in child protection services and in that capacity, they had also received crisis training for mental health. Her mentor, through that devastating experience and her training, had learned to recognize signs of crisis and to provide useful support.

Finally, participants considered the frequency of communication with people. For P18, it was easier to be honest about how she was doing when she frequently communicated with her grandmother who was up to date with what had been happening in her life:

> "*I think also, especially because she checks in on me a lot. It's very easy for me to just kind of be like, 'Today's kind of been a rough day.' Or 'Today's been a good day.' And I know that if I do say that today's been a rough day, she just always knows the right thing to say back to me to make me feel better*." (P18)

Support can often be more usefully targeted or delivered more quickly when others are aware of ongoing issues. These collaborators therefore did not require as much background context of a participant's life and ongoing stressors, resulting in a supportive interaction focused on taking action on a mood or issue instead of catching up with the background details.

Therefore, when considering who to reach out to for support, participants considered the interrelated criteria of familiarity, location, knowledge of mental illness, and frequency of contact. In the next section we describe key role categories for depression support.

**Role Categories and Collaborative Self-Management**. Resonating with previous social support literature on depression [80,191], my participants connected with family, significant others, friends, medical professionals, and peers managing depression. For space considerations, in this section, I first describe my findings regarding the experiences of peer support from participants who attended group therapy. Then, I describe findings regarding roles less frequently discussed in the literature: support from coworkers and strangers.

First, peers managing depression provided a unique support perspective for those who attended group therapy. Some group therapy, like P23's group, was led by a therapist, whereas P27's support groups were entirely run by individuals managing mental illness. P27 described the difference between "*old-timers*" like him in his peer-run mental health support groups and new members who had often been recently diagnosed. Old-timers would offer best practices to the new members, suggesting experiences with various medications, the importance of sleep hygiene, and

other advice. Pre-COVID-19, after meetings, a smaller group of support peers would get together and enjoy drinks at a coffee shop where they would discuss larger life events and other topics.

Second, participants described the importance of coworker support in the workplace. Participants relied on some coworkers for mood-focused support (e.g., P03's mentor helping her through an anxiety attack) and others for preventative support (e.g., going out to eat together). I describe the distinctions between mood-focused support and preventative support in greater detail in section 5.3.2. Relationships with coworkers were particularly important because many participants described negative moods triggered by work-related stress and negative experiences.

Third, strangers provided support in unexpected ways. To leave the house for a while during the pandemic, P16 drove to a coffee shop in a nearby town and had an affirming interaction with the coffee shop staff. When he pulled up to the drive-through a staff member asked, if he could select to be a part of a TV or movie cast, which one would he choose? P16 replied, "*Parks and Recreation,"* a popular TV-show. Then, 3-4 other staff members joined the conversation, and he heard the staff members yell "*yes*!" and other statements saying how great that TV show was. P16 said: "*that made me feel so good, just that one little act of positivity and kindness. It lifted me, you know? It filled me with such light*."

In summary, participants drew on a wide variety of connections including family, significant others, friends, medical professionals, and peers managing depression, as well as individuals less frequently discussed in prior literature: coworkers and strangers. Next, I describe how participants managed collaboration challenges.

**Challenges with Collaborative Self-Management.** While many collaborative experiences were helpful, collaboration could sometimes be challenging. To collaborate,

participants needed people in their support networks who were available and could be relied upon to provide support in ways that were effective and sensitive to their needs. However, participants described challenges including dealing with small support networks, fear of burdening others, unmet expectations, and ineffective support.

First, small support networks can be a particular challenge. From past experiences, P06 knew that she is likely to upset her mom (or vice versa) if she turns to her for support. "*I mostly talk to my mom about emotional stuff. Unfortunately, she's not in a great space herself, so a lot of times we end up upsetting one another*." She described how she also tried to talk about things with her friend who has a new baby:

> "*She and I are probably the closest as far as what we're experiencing, but she's also had a baby screaming at her for 3 months and trying to teach. So, we've been kind of trying to lean on each other, but it's not exactly the same experience. And, while misery loves company, it's not always good to have both of you dig yourselves into a hole. So, we've been kind of limiting our conversations to more superficial stuff just to avoid upsetting each other*." (P06)

P06 also recently had a falling-out with her previous best friend, so she described that she does not have anyone to turn to who would provide good support. For now, she keeps her moods and needs to herself. Her small support network means that even if she wanted to engage in collaborative self-management activities, she would need to undertake the difficult work of making new connections or try to repair other relationships.

Second, some people felt that their problems were too severe and therefore would burden others. For P17, after several negative experiences attempting to discuss her past with others, she concluded that her past experiences were too much to put on another person's shoulders. She

therefore maintains her support interactions with others at a "superficial" level to avoid getting hurt. In this situation, P17 supports her mental health through her religion and regular prayer.

Third, challenges can also occur when support requested does not match one's expectations. For instance, when P16 was in Europe, he asked his girlfriend at the time to send texts to him while he was traveling. When she did not do so, he had several panic attacks. Asking her to send him a supportive text was something P16 perceived as relatively easy to do that he knew would be helpful in supporting his mental health while away from home. However, it was devastating when that did not happen and resulted in the pair eventually breaking up.

Finally, participants also had to manage situations where people tried to provide support but were ineffective. Many participants described that some people in their networks did not "*get it*" regarding how to effectively support their needs as someone who was managing depression. Participants discussed aspects that others did not understand about depression, including signs and symptoms and what it is like to feel sad and not be able to "*get over it.*" This meant that participants sometimes had to exert tiring effort to try to teach others about the experience of depression. Without the personal experience of managing mental illness, participants described how they perceived it was difficult for others to have true empathy with their needs.

In summary, for some participants, part of the experience of collaborative self-management was dealing with challenges including small support networks, fear of burdening others, unmet expectations, and ineffective support. In the next section, I describe practices of collaborative self-management.

### *5.3.2 "How": Practices of Collaborative Self-Management*

Participants collaborated with others in a variety of different ways. Below, I describe a selection of collaborative activities (see Table 6.). While I separate them here conceptually for clarity purposes, in practice, they could occur simultaneously or overlap with each other. I separate collaborative self-management practices into two categories: mood-focused support and preventative support. I distinguish these below and note the importance of both as part of collaborative self-management.

Table 6. Key Collaborative Self-Management Practices

| **List of Practices** | |
|---|---|
| Mood-Focused Support | Checking-In |
| | Sharing Stories, Venting & Empathetic Listening |
| | Making Sense of Situations Collaboratively |
| | Sharing Advice |
| | Affirming, Encouraging & Calming |
| Preventative Support | Engaging in Shared, Group & Community Activities |
| | Sharing Humor |
| | Setting Boundaries |

**Mood-Focused Support**. Participants described a variety of stressors, often related to work or interpersonal relationships, that could trigger a negative mood or emotion. When either the participant or someone around them became aware of the (potential) need to address a mood, they engaged in mood-focused support practices (Table 3.). The practices of sharing stories, venting & empathetic listening, and sharing advice are similar to findings of previous mental health CSCW literature [5,33], so for space purposes, I focus on the three other practices.

***Checking-in*** often happened when an individual noted that another person's emotional state or behaviors differed from the norm. For example, P16's mom talked to him because he had been waking up very late and watching TV shows all night. P16 assured her everything was okay

and that he was doing this to help him to cope during a time when his community artistic pursuits were inaccessible due to COVID-19: "*And she goes, 'Oh, good. Okay. So, I don't have to worry about you if you're up at 3:00 [am] still watching TV shows?' Like, 'No, it's actually – That's fulfilling*". By checking in, P16's mom was able to find out if he was struggling or needed support, and he was able to explain that he viewed his actions as important coping during the pandemic.

Participants also described ***making sense of situations collaboratively***. Events in participants' daily lives could sometimes feel overwhelming or difficult to figure out on their own and this affected their mood. When this happened, participants talked through the situation with others whom they trusted. These individuals helped them to better understand the distressing situation. For example, P04 was accused of a human resources violation at work. This caused him intense emotional distress and he took a leave of absence from work. He connected with his brother to interpret the confusing situation to understand if he was at fault. Through several conversations, their discussions led to the point that P04 said he began to "*feel like we're getting a handle on it to address it*."

Participants also described the importance of ***affirmation and encouragement*** and actions to exert a ***calming presence***. Affirmative words helped participants to counter negative thoughts like feeling worthless or unlovable. P17 shares words of affirmation with her daughter and vice versa, "*My one daughter, she's always telling me when I get really down that her kids love me and that I'm loved, and I'm needed and useful because she knows that's what I need to hear to keep moving forward*." Similarly, P18's grandmother sent a nice message and a video via Facebook Messenger to support her when she had messaged to say that she was feeling down:

> "*Because I think when I get super anxious and stressed, my brain just takes over and I can't think of anything else…When I get anxious, it's just almost like a whirlwind of emotions.*

> *And I can't think about anything else at all…I found myself on several occasions when I do get that nice text from a friend or my mom or my grandma, I just can't help but smile sometimes. And it brings me back to reality again*." (P18)

People could also act as a calming presence. This included providing hugs, cuddles, and having calming conversations. When P16 noticed that his co-worker was struggling with a work task he knew what to do because he recognized being in "panic mode" himself: "*So, I stepped in and tried to be the calming presence and say, 'We'll get through this. Yes, this is shit right now, but if we can look past that, let's just do what we can do and say what we can say*.'" Many other participants also provided affirming, encouraging, and calming support to others in their social networks.

Overall, the mood-focused practices described by participants included (1) checking-in, (2) sharing stories, venting & empathetic listening, (3) making sense of situations collaboratively, (4) sharing advice, and (5) affirming, encouraging & calming. Next, I describe preventative support practices not directly tied to a negative mood or emotion.

**Preventative Support.** Participants also described engaging in "preventative" practices. I use this description to mean that they did not engage in these interactions to address a specific negative mood or emotion. Rather, they engaged in these activities to help maintain their mental wellness. In these practices, unlike for mood-focused support, the other parties may not even be aware that the participants were managing depression.

The most frequent practice was ***shared, group, and community activities***. Examples of shared and group activities included having meals, sharing drinks, and participating in group exercise. For many participants, it was important that they felt they were part of the community through social activities. They described the positive benefits of going to a restaurant or a bar after work with colleagues. Other participants participated in community classes, group exercise, church

events, or volunteered. For example, P02 volunteered locally, started her own business, and joined a photography class to combat her tendency to self-isolate. For P28, joining a new church during the pandemic was a wonderful source of community support. She attended weekly sermons hosted via Facebook Live, participated in discussions via live commenting, and joined group discussions after the sermon. As a Black and queer woman, she found companionship and shared experiences with others in her church focused on supporting a predominately Black and LGBTQ congregation.

Participants also ***shared humor***. For example, P09 often called her mom. Her mom would listen to her and then make her laugh with her humorous responses. This practice also included sharing funny and stupid memes. P12's friends' group chat was a place to "*talk about the dumbest of things*" and to comfort each other. Similarly, P21 described sharing memes with her friend who was also managing depression. They would often share dark or black humor about mental illness. In addition, P16 described how he could tell that his friend who is a police officer in a large city in the U.S. was doing okay emotionally because his friend consistently sent wrestling memes and videos. P16 was worried about his friend's wellbeing during a time of continued protests against police brutality and calls to reduce police department funding. Therefore, this consistency in communication showed P16 that his friend was still able to spend time keeping up with a shared hobby that they both loved.

Finally, participants ***set boundaries*** to support their mental health. This practice recognizes that not all interactions were helpful. For example, after many years of exhausting work to emotionally support her parents, P15 recently set firm boundaries to preserve her emotional energy and not let the issues that her parents were dealing with upset her mood day-to-day:

> "*Being able to say to them, 'I need this time to work on myself and work on my own mental health. And I don't have the mental energy to necessarily process your beef with my aunt, so to speak, or to process your fear over having to go to the pharmacy*.'" (P15)

Her interactions with her parents occurred primarily through Facebook Messenger, so she also set boundaries by alerting them when she would be muting the group chat for a day or longer for this purpose. Setting boundaries also sometimes occurred in response to specific moods. P11 described how she could feel a depressive episode coming and told this to her boyfriend. He asked her a number of questions, including: *"Is there anything I can do? Can I listen? Can I give you a hug?"* Her answer to all of these was "*no*." After their conversation, she went to her room (thereby creating a physical boundary) to cry and then reflect on her feelings. As she thought through her mood, she was able to use her boyfriend's phrases to combat her negative thoughts. Similarly, after a bad day, P07 preferred to zone out with TV rather than talk to his wife about his mood. Coming home and turning on the TV signified a boundary and P07's preferred coping strategy at that moment. Through these examples, I show that there can sometimes be overlap between preventative and mood-focused practices, depending on the issue and resulting behavior(s).

Therefore, preventative support practices such as (1) engaging in shared, group & community activities, (2) sharing humor, and (3) setting boundaries are an essential complement to mood-focused practices. Next, I describe the technologies used to mediate these practices.

### *5.3.3 "Where": Technology Channels and Collaborative Self-Management*

Participants used a diversity of technology channels within their technology ecosystem [72] to support collaborative self-management interactions: text, voice, video, and picture-sharing technologies. Each channel afforded different types of support, ways of expressing oneself, and speed of response.

**Text-based technologies**. These included native SMS technologies such as iMessenger and Android messenger and text-based social media technologies including Facebook Messenger, Instagram Direct Messages, Twitter Direct Messages, Telegram, WhatsApp, LinkedIn and GChat. Participants also used email and letters, though much less frequently than texting. While some participants occasionally interacted with others on online forums (e.g., Facebook groups, Subreddits), most of the text-based communication involved one-to-one or small group interactions with individuals that participants knew well. Participants used text to coordinate in-person interactions, share information, and ask for and provide support. For example, P22 uses WhatsApp to keep in touch with her large family. She prefers this app because she can share what is on her mind and her family members can respond at their convenience:

> "*We have several different chat groups, and I have family across in different towns, so I've found it's really nice to – just to get it out there. Even if they don't see it right away, it's in their hands and they'll get to it when they get to it. For me, also, verbalizing or vocalizing what's on my mind really helps me to process and get a better understanding. But then, it's reassuring and – nice when they can respond*." (P22)

While participants viewed text-based applications as convenient, they also noted their challenges. Specifically, it could be difficult to interpret the tone and meaning of the words. Because of this, many participants carefully proofread their messages to ensure that their words were as clear as possible before sending.

**Voice Call Technologies**. Participants used landlines and cell phones as well as voice call technologies such as Discord and the voice call functions on Skype, WhatsApp and Facebook Messenger. A call often signified a higher immediacy or intensity of need than a text message. Phone calls provided the tonal context of another person's voice and often showed emotion. For example, during a regularly scheduled call, P11 realized from hearing her mom's voice that her

mom was upset. Hearing this, P11 was able to respond in the moment by letting her know how much she admired her. Similarly, P21 described how she feels more connected to people when she can talk to them via the phone and have conversations flow from one topic to the next. She also was able to share emotion more easily on the phone. However, participants also acknowledged that phone calls could put the other person on the spot to respond immediately and not necessarily at their convenience. This resonates with Nardi et al.'s [184] concept of media "interruptiveness." Other participants described difficulties paying attention while on the phone. P23 easily became distracted when trying to listen on the phone to her grandmother or to her friend who can be "*long-winded*." Similarly, P05 would weed in her garden, pet her dog, or play with Legos or kinetic sand to maintain attention while listening to others on a phone call.

**Video Technologies**. Participants used a variety of video technologies including FaceTime, Skype, and Zoom, the video function on other communication platforms (e.g., WhatsApp), and video-based asynchronous communication via platforms such as Marco Polo. Video was the main way that participants in support groups communicated with their groups. Many participants considered video as more authentic because it provided body language cues. P04 described how video was particularly helpful when he was in distress because he could see the support in others' faces. At the same time, video was also the most challenging channel to use. First, there were bandwidth limitations. Participants who lived or worked in rural areas, lived in high-density dwellings like apartment complexes, and worked in the top levels of city skyscrapers all experienced frequent Internet connection difficulties. Second, tele-therapy, often conducted via video, also raised some issues. For example, P23 had previously participated in in-person group therapy but because of the pandemic was attending video-based group therapy. She described the

lack of body language (the videos were focused on the faces only) and eye contact as challenging. In comparison to the previous easy flow of conversation during in-person interactions, the flow of conversation was often disrupted over video. People would either be silent or interrupt each other. P23 also described becoming very aware of her own image, a feature of many video software systems: "*I get really distracted by my own image, and I find myself staring at myself. I'm listening, but I'm really not thinking about stuff to say, I'm thinking about like, oh, what do I look like.*" Overall, while video supported visual communication unlike text and voice, it also had more challenges than other channels.

**Picture-sharing Technologies**. Participants described the benefits of using technology to share pictures (sometimes accompanied by text). This included platforms such as Snapchat, Instagram, SMS applications, and to a lesser extent, Facebook. For example, P17's son and daughter regularly send her pictures of her grandkids. When asked what benefit she gains from these photos, she said, "*hope*". Participants also used pictures to share mood status. For individuals battling a negative mood, expressing oneself can sometimes be a challenge: "*when I'm having a really bad day, I almost can't even get the words out*" (P18). When in this state, P18 will send a Snapchat of her face to her friends. She feels that the Snapchat image captures her "*true, honest self*" to share with them:

> "*I've sent a sad face selfie to my friends and been like, 'No job yet.' Full honesty that only my best friends would see. And then, seeing their face in response to that has been kind of helpful in a supportive way…They usually will just say kind of like a soft smile back usually, or [friend] will send like a photo of her dog. And they'll always say something like, 'I have my fingers crossed for you. Something will come along soon,' or they'll just remind me the job markets are really tough right now*." (P18)

Her friends responded to her Snapchat with supportive emoji, pictures, and text – sending a slightly smiling face and supportive text or by sending a picture of a cute dog. Picture-sharing platforms also facilitated easy sharing of memes and funny content. Many participants described using Instagram Direct Messages when sending memes because Instagram was the source of many of their memes and it was easier to share through the same platform than through any other tool.

Overall, participants in our study used multiple communication channels to connect with people in their social networks. Some participants even had multiple ongoing conversations. P19 describes this diversity:

> "*I'm pretty sure I have three conversations going with my one friend right now but they're all different. On Instagram it's about random food things – posts we've seen or recipes. And then, on Facebook Messenger it's whatever random news story, and then on text it's our lives*." (P19)

In addition, many participants described that in-person communication was particularly effective in supporting their moods and emotions. For example, P21 thinks of technology-mediated connections as a "supplement" to in-person interactions. Similarly, for participants for whom physical affection was especially important, in-person interaction offered opportunities that were not possible via technology-mediated interaction. P22 spoke about how she would be excited for a future where there could be teleportation to share hugs with her loved ones: "*Yeah, technology is amazing, but it definitely lacks that human connection, that physical connection*." Therefore, while technology-mediated collaborative self-management was certainly prevalent in my study, participants also valued in-person activities.

In the final section of the findings, I discuss everyday tools used by participants for mental health support. While 5.3.3 above discussed key technologies mediating the collaborative work of self-management, the following section describes the variety of tools used for individual and

collaborative self-management support, including technologies used sometimes individually and sometimes collaboratively (e.g., video games). I present this section to help us better understand the breadth of tools in participants' technology ecosystems for mental health support.

### *5.3.4 Everyday Tools Used for Mental Health Support*

Participants used a variety of support tools to manage their mental health both collaboratively and individually. Figure 4. shows common participant tools and services.

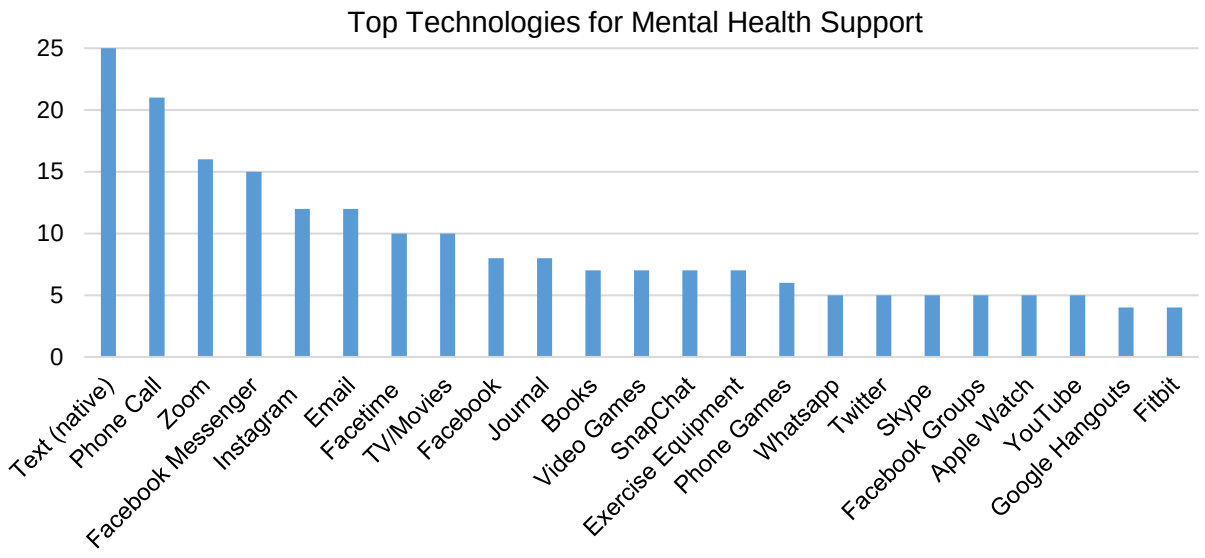


Fig. 4. Mental Health Technology Ecosystems: Most Frequently Mentioned Tools and Services

As Figure 4. shows, participants used a variety of technologies to support their mental health. Technology tools supported connection with others, entertainment and distraction, and mobile health and tracking. Below, I detail the breadth of technologies described within each of these three categories (Table 7.).

Table 7. Technology Types and Specific Tools and Services

| **Technology type** | **# of participants who used this type (%)** | **Specific tools and services** |
|---|---|---|
| Communication Technologies | 100% | Text (25), Phone Call (21), Zoom (16), Facebook Messenger (15), Instagram (12), Email (12), FaceTime (10), Facebook (8), Snapchat (7), WhatsApp (5), Twitter (5), Skype (5), Facebook Groups (5), Google Hangouts (4), TikTok (3), Discord (3), Telegram (2), LinkedIn (2), Tele-therapy – (e.g., Talkspace, Teladoc, PlushCare) (2), GroupMe (1), Slack (1), Reddit (1), Tinder (1), Twitch (1), DUO (1), Google Chat (1), GoToMeeting (1), Marco Polo (1), Paper Mail (1), Moodle (1), Duolingo Community (1), TextMe (1), Mental Health Hotlines (1) |
| Entertainment Media | 68% | TV/Movies (10), Books (7), Video Games (7), Phone Games (6), YouTube (5), Podcasts (3), Kindle (3), Online Courses (3), Digital Drawing (3), Spotify/Digital Music (3), Audiobooks (2), Alexa (2), Pinterest (1), Bible (1), Bible Verses App (1), Car Radio (1), Library App (1), Online News (1), Online Blogs (1), Business Website (1), Camera (1), Artwork (1), Kinetic Sand (1), Legos (1), Google Home (1), Musical Instrument (1) |
| Mobile Health and Tracking Tools | 75% | Journal (8), Exercise Equipment - bike, weights, treadmill, punching bag, hula hoop (7), Apple Watch (5), Fitbit (4), Planner/Calendar (3), Step Tracking App (2), Water Consumption Tracking App - (e.g., Plant Nanny) (2), Food-tracking/Meal planning app (e.g., Omada, Renaissance Periodization) (2), Medication Reminders (2), Headspace (2), Mood Tracking (2), Notes App (2), Vehicles – calming driving (2), Period/Fertility Tracking Apps (2), Breathe (1), Meditation App (1), Replika App – AI journaling app (1), Smiling Mind – mindfulness app (1), Pill Pack Service (1), Nike Run Club App (1), Nike Training Club App (1), Sleep Tracking App (1), WayBetter – fitness challenge app (1), Good Reads – reading tracking app (1), Alexia Clark – Women's Workouts App (1) |

As described previously, technologies for communication for collaborative self-management primarily included text-based, voice, video, and picture-sharing applications. Participants could achieve different collaborative support purposes even when using the same communication technology. For instance, Zoom was used to both connect with friends and to participate in depression peer support groups. A few participants utilized online communities on

platforms including Facebook Groups and Reddit threads to communicate and be a part of a group of like-minded people discussing topics as varied as memes, books, grief, history, and positivity.

Second, participants used entertainment technologies, often to distract and soothe themselves to get past negative moods or to gain feelings of accomplishment. These could be used individually or collaboratively. For instance, several participants watched online streaming movies with friends while simultaneously chatting about the film on a Discord or Skype voice channel as they watched. Other shared activities included playing video games and listening to music together. However, using tools individually was also important to re-center and relax, especially technologies including audiobooks, digital drawing, and online courses.

Finally, participants also used a variety of mobile health and fitness tracking tools. These tools were usually used individually. For example, P24 uses his Apple Watch to check his pulse rate during panic attacks:

> "*If I feel anxious or if I'm upset or if I'm feeling a panic attack coming on, something like that, I'll check my heartrate and my pulse. And then I guess I kind of mentally talk myself into calming down and then I check the heartrate and the pulse rate again a few minutes later and it makes me feel better if they've dropped*." (P24)

Other tools in this category included Fitbits and step trackers along with exercise equipment including workout bikes, treadmills, weights, punching bags, and hula hoops. Two participants discussed using tools to track their nutrition. Several participants used tools to assist their sleep. For example, P17 uses a bible auto-reader: "*And, when I'm having a hard time sleeping at night because I'm really frightened or anxious or scared, I can have it read to me on my phone and there's one specific version where the person's voice that's reading is fairly soothing*." Similarly, P11 used her Fitbit to keep track of sleep as well as her menstrual cycle.

In summary, across my findings presented above, I described *who* participants engaged with to reach their collaborative self-management goals, *how* these activities occurred, and *where* these often technology-mediated interactions took place. I then provided a view of everyday technologies used for mental health support, looking across collaborative and individual-focused tools to provide a deeper understanding of the breadth of tools in individuals' technology ecosystems for mental health support. In the following Discussion, I share how these findings help conceptualize collaborative self-management and technology use in the mental health context.

## 5.4 Discussion

This study focused on deepening our understanding of the collaborative self-management activities of individuals managing depression. I described the important interrelationship between social network individuals and mental health self-management goals that guided participants' technology selection across the ecosystem of available support technologies. In the following section, I discuss the technology ecosystems utilized in collaborative self-management. I highlight factors influencing channel selection as well as periods of engagement with support technologies. In the following chapters, I address broader questions about collaborative self-management and design using insights derived from this and the preliminary study.

Using the concept of collaborative self-management, we can start to see how technology-mediated communication practices stretch across individuals' social networks and interplay with a diversity of technology channels as individuals seek support to manage their depression. Previous work showed how individuals managing depression used social media platforms [10,66,92], online communities [112,155,273], and individual-focused technologies [130,146] (e.g., music, calendars, meditation apps) as part of their day-to-day routines. I found that the communication

technologies used by many individuals worldwide — text, video, voice, and picture applications — play a major role in the collaborative self-management work of individuals managing depression. In order to understand how these ecosystems of technologies [72] are used in concert with each other, I draw on Miller and Sinanan's [175] concept of "polymedia" — understanding each media in the context of all the others. They describe how dynamism exists not only in a diversity of communication channels but also "in respect to their changing relationship to each other." For example, this relates to how my participants often used text to determine the availability of the other person and to prepare implicated individuals for a channel shift to a more intensive phone call, video call, or in-person supportive connection. This is also similar to observations by Isaacs et al. [120] of channel-blending behaviors to create coherent conversations across multiple media. The concept of polymedia allows us to attend to why individuals use a variety of channels for collaborative self-management. Below, I discuss factors guiding channel selection, and periods of engagement with everyday technologies for mental health support.

### *5.4.1 Factors Guiding Channel Selection*

Multiple factors influenced participant selection of communication channels (technology-mediated or in-person). In my preliminary study [80], I highlighted influencing factors including relationship roles, culture, mood, and location. This study adds two more influencing factors: participants often used the channel most preferred by the person they wanted to reach, and participants often used a channel that best fit their cognitive needs in the moment. First, individuals selected certain channels because they knew that the person they were attempting to reach would respond to a message in that channel more quickly. For example, P08 knew that his friend had difficulties with a limited smartphone data plan. He chose between sending a message over

Internet-supported Facebook Messenger or cell-service supported SMS based on which one she would likely see first. Overall, when a participant initiated communication, they were more likely to adapt to the other person's preferences than to ask the other person to cater to their preferences. However, individuals managing depression are not entirely beholden to the technology preferences of the people they turn to for support. Communication channel selection could also be the result of consensus among the support network. For example, P09 used Facebook Messenger with her support network because everyone already had it and knew how to use it. Even though individual people (e.g., P09's mom) might prefer other channels, Facebook Messenger was a compromise that enabled the group to communicate.

People also adapt their communication strategies to account for the cognitive symptoms of depression, such as concentration and memory difficulties. In previous literature in the romantic couples context, Scissors et al. [229] found that individuals channel-switched to avoid conflict escalation, manage one's emotions, and attempt to reach a resolution. In my study, *cognitive state* was another contextual consideration influencing media choice. This resonates with Zhang et al.'s [274] recent work highlighting the impact of user's cognitive and motivational capacity on usage of mobile app technologies to support depression self-management. Especially when in distress, many of my participants used text to craft their message. For example, one participant revised a text message several times when she wanted to tell her work mentor that she was struggling and needed support but did not want to alarm her into calling the suicide prevention hotline. Texting also allows individuals to send a single message versus the effort required to carry on a conversation via phone call. This may be related to concentration [27] and decision-making [198] challenges especially while in distress.

Individuals managing depression can adapt their need to communicate in the moment by selecting a channel to best help them feel comfortable and receive useful support. However, technologies can also exacerbate cognitive issues [19]. For example, P03 and her co-workers used Snapchat via Wi-Fi to communicate instead of SMS texts because of the poor cell service coverage in her rural area. However, P03 would often experience what she called "brain fog," an issue with short-term memory. For this participant, past messages would disappear, and she often found herself looking at her co-worker's response with no recollection of what she had just asked them. The impacts of depression on memory and cognitive state in high-distress and often complex situations is important for researchers and designers of mental health support technologies to understand. My work with Eschler et al. [130] noted that participants used note-taking applications on their phones to keep track of important items they needed to remember. In this study, two ways that individuals managing depression adapted to cognitive challenges while carrying out collaborative self-management was by spending more time editing and crafting messages and ensuring that they had a record of past messages to refer back to over time.

### *5.4.2 Period(s) of Engagement*

Another important aspect of technology ecosystems is how tools often have different periods of user engagement. Understanding the goals which guide users' selection of tools within these ecosystems can tell us much about how technologies support health adaptation over time, a topic of recent interest in HCI. As Schraefel [292] describes, inbodied interaction "frames the body not as the site of disease (medicine) or performance (sports science) but rather as the site of adaptation" influenced by factors such as context, time, discomfort and recovery [226]. My participants adapted their use of their mental health support technologies based on ongoing needs

and goals. Below, I overview 4 usage patterns: consistent use, specific issue use, initial use and frustrations leading to disuse, and initial use and skill learning leading to emancipation.

**Consistent Use**. Some tools were a consistent complement to participants' daily routines. These include tools used track regular occurrences like menstruation or as part of daily mental health maintenance. For instance, several participants enjoyed a daily phone game for relaxation. Technologies used consistently often included communication technologies used to connect with others. However, communication technologies could be used for a variety of mental health support activities day-to-day. Depending on the need, participants could use communication channels for checking-in, expressing their moods and emotions, making sense of complex situations, sharing advice, or partaking in shared activities, among other practices (see 5.3.2). This shows the versatility of mental health self-management goals that can be accomplished through using communication technologies and their ease of adaptability to support engaging in different ways with others [72,276]. Participants who used tools consistently integrated them into their routines, using them as an extension of themselves to better understand habits over time (similar to Eschler et al.'s [130] findings of emergent self-regulation), provide daily moments of relaxation and mood-boost activities, and to gain and share support with others.

**Specific Issue Use**. In contrast to consistent use, several participants discussed using tools periodically to tackle challenges when an issue began to feel overwhelming. For example, participants used journals when they wanted to work through a larger issue, get past feeling unmotivated, or to support certain "challenge" periods of concentrated use. Technology use in this category did not need to be consistent to be helpful, because these tools offered benefit in concentrated timelines. Indeed, this periodic "pick-up" of tools for specific issues and purposes

aligns with Epstein et al.'s [84] Lived Informatics Model which shows the common cycle of deciding, selecting, tracking and acting, and then lapsing that many individuals go through when using health technologies.

**Initial Use and Frustrations Leading to Disuse**. Many participants described experiences of trying certain technologies, particularly popular ones like journals or Fitbits, and then ending their use because the tool was not helpful in supporting their mental health management. In the past, many participants had attempted to use support technologies but then had concluded that they were not helpful in managing their mental health. Relatedly, some participants experienced negative feelings about themselves while using fitness tracking tools like Fitbits and therefore stopped using these technologies. In addition, some participants experienced anxiety regarding their ability to maintain use of the tool over time. For example, P08 had a habit of downloading apps that he intended to but ultimately did not use. It was easy to download an app but then he became anxious about his ability to follow-through with using the tool, leading him to not use the app because it felt like a commitment that was larger than he could handle.

This usage category shows us that over time, individuals managing depression become aware of opportunities to try various mental health support technologies. If these tools look interesting or potentially helpful, then individuals will often purchase or downloaded these options. However, when these tools fail to meet their goals, or if they increase anxiety around starting to use the tool, then individuals end up not continuing to use them in the long term. For these practices of abandonment, beyond showing us that there was an expectations mismatch, Clawson et al.'s [56] recent study of health technology abandonment notes that rationales associated with one's social environment or physical abilities (social connections, health conditions, changes in activities

associated with the device) can also lead to abandonment. The authors note that support technologies are "used in complex dynamic social environments and need to fit within individual's existing, messy practices." Therefore, the authors argue that support for sense-making, problem-solving and experiential learning can provide fruitful avenues to push against these trends in technology abandonment. Attending to these aspects of use can help individuals managing depression to determine whether a tool is helpful or not for supporting their mental health.

**Initial Use and Skill Learning Leading to Emancipation**. Finally, some participants used technologies to build skills around a topic and then were able to move beyond that scaffold in their future mental health maintenance. For example, P16 used Headspace upon recommendation from his therapist. While P16 has not completely removed the app from his routines (he still uses it to help him sleep), he was able to practice and build his competency in meditation through use of the app and now can recall that line of thinking without app's aid. This usage category is similar to the goals of Pocket Skills [14] a mental health mobile app developed to practice Dialectical Behavior Therapy (DBT) skills over a set period of engagement. Tools developed to support this type of use often strive to support skills practice (e.g., reframing negative thoughts) with the perspective that the individual might graduate from needing the tool at some point, thereby having "ownership" over the practice. Then the tool could be deleted or referred to at a future time if an individual desired extra support. However, few participants in my study discussed this approach regarding use of their support technologies. Instead, many participants spoke about this skills-building process in relationship to past therapy – they had worked through issues in therapy in the past and now had resolved those past issues. Given the variety of technologies described in our study, one potential implication is that tools with an educational or

practice-based component might fit well into this category, whereas tools that are focused on entertaining or connecting to others might not follow this same process of use over time.

## 5.5 Conclusion

This chapter presented an investigation of the collaborative self-management practices of individuals managing depression. I explored who individuals connected with for this purpose, noting roles less frequently discussed in prior social support literature – coworkers and strangers. In the "How" section I expanded upon the practices described in Chapter 4 to include several new practices and a distinction between mood-focused and preventative practices. I then shared findings regarding the channels and larger technology ecosystems that individuals utilize to support their collaborative and individual self-management activities. My discussion presented ways to conceptualize technology ecosystems through the concept of polymedia, where each technology must be understood through its interrelationship with other tools, and through understanding periods of engagement (consistent, specific issue, dissatisfaction leading to disuse, and learning leading to emancipation). In the following chapter, I discuss implications of the findings across the preliminary and the main study to further conceptualize the work of collaborative self-management and the factors influencing the ability of individuals to carry out these activities and their comfort in doing so.

# 6. DISCUSSION: COLLABORATIVE SELF-MANAGEMENT

To manage their depression, participants across both my studies engaged in individual self-management activities, for instance, taking medicine, journaling, solitary exercise, or meditation. However, they also described interactions with others as a significant part of their mental health self-management. This supports recent CSCW research (e.g., [10,80,112,155,196]) underscoring the important role that social networks play in supporting individuals managing depression. While some participants collaborated much more frequently than others (e.g., multiple times daily versus every few months), being able to connect with others to feel soothed, see new perspectives, and enjoy social experiences were key elements in how individuals managed their depression. Thus, through my analysis, it became clear that self-management was not only an individual activity but also a collaborative one.

In this first discussion chapter, I describe how my studies extend previous literature on collaborative self-management. I extend the term to the mental health context, highlighting the characteristics of agency, reciprocity, temporality, and interaction (6.1). Next, I discuss the steps of the process of collaborative self-management (6.2). Then, I discuss shifts in collaborative interactions due to the COVID-19 pandemic (6.3) and conclude with a chapter summary.

## 6.1 Extending Collaborative Self-Management to Mental Health

While social support for mental health management has been explored previously (e.g., [31,57,58]) and researchers have described broad work activities [57,242] and roles [31] involved in these processes, we did not yet have an understanding of the granular detail of these interactions nor how they were carried out on a daily basis. In short, the social support literature presented the broad framework, but did not unpack the practices that people engage in on a day-to-day basis.

Consequently, I undertook this dissertation to better understand the work of the individual managing depression to facilitate these supportive interactions. My work builds on Kendall et al.'s [142] recent critiques of the medical literature's focus on self-management as a cost-cutting mechanism and the providence of healthcare professionals who deliver expertise to passive participants. They state, "this narrow view of self-management fails to acknowledge the importance of the complex sociocultural, political and economic contexts within which it is embedded and the relationships that make self-management possible." Instead, the authors push for an organic and dynamic conceptualization of "self-managing" that is self-defined, encompasses the lived expertise, and recognizes the diversity of individuals who support self-management processes. I build on these ideas to show that a crucial aspect of self-management is the interplay between one's social network, technologies, and goals. While collaborative self-management has been used in the chronic disease context to promote adherence to medical recommendations [28], here, I extend the term to the mental health domain. I use it to analytically focus on the work of the individual as they plan, seek, receive, and reflect on support from others, viewing it as the intentional engagement in activities with others as a part of mental health and wellness self-management. Below, I discuss four key characteristics of collaborative self-management: agency, reciprocity, temporality, and interaction.

First, I found that individuals had a great deal of ***agency*** in collaborative self-management activities. As Coyle et al. [62] state, agency is "a person's innate sense of being in control of their actions and through this control of being responsible for, or having ownership of, the consequences of those actions." To collaborate effectively with others, participants described many decisions through which they demonstrated their agency: determining when to collaborate, who to contact,

which channel(s) to use for the interaction, and what type of support they needed at a particular time. For example, the first aspect of agency is to determine when collaboration would be beneficial – moving from self-management to collaborative self-management. As described in both my studies, several participants attempted to address a mood or issue themselves (e.g., through journaling) and then would reach out to others if they needed additional support. When participants determined that reaching out would be helpful, they first identified their current need and then directly asked a person or group in their network for the support they desired. Similar to cancer patients [122,123], my participants maintained close control over how to best address their needs. For instance, there were times when others initiated an interaction in reaction to a participant's negative mood. However, participants described that it was up to them to decide to respond to other's concerns and if they did respond, what shape that response would take (i.e., a quick text or longer conversation).

Second, the characteristic of ***reciprocity*** highlights the role that many participants took on also as providers of support. While individuals managing depression are often positioned as the recipients of care [8,31], I found that participants also actively supported other people managing mental health needs. However, for some, supporting others could be emotionally taxing and required participants to actively draw boundaries to ensure that providing this support did not negatively affect their mental health. This resonates with Andalibi et al.'s [7,8] findings regarding reciprocity and decisions to offer support in social media contexts. My participants described the shared experience with what they called the "irrationality" of depression. For instance, this shared experience allowed participants to support others (and receive support in return) often through humor (e.g., sharing darkly humorous memes with friends). Being able to laugh at the experience

of having a difficult condition enabled much-needed spontaneous relief. Furthermore, having to deal with depressive episodes over time meant that individuals often developed a set of strategies that worked for them, which they could then suggest to others in need. My findings underscore the reciprocal nature of collaborative self-management, pushing back against the framing of these individuals as simply the recipients of support. While supporting others' mental health can certainly be taxing, it can also be fulfilling, enabling individuals to feel competent and an important part of their networks and communities.

Third, the ***temporal*** characteristic highlights the role that time plays in these activities. One instance of collaborative self-management can be instantaneous, can happen over the course of a day, or can unfold over multiple days or weeks. For example, in my findings across my studies, I reported several instances of participants calling or texting a friend and receiving a response that same day. However, I also presented an example in the main study where P04 worked with his brother to address an issue over the course of a week. Similarly, some support interactions occurred right after a major shock and others developed or become apparent during regularly scheduled support or catch-up time (e.g., in the main study P11 noticed her mom's distress during their weekly catch-up call). Quick issue-support timelines are common, yet also, for larger, ongoing issues, participants described the importance of time to think and to plan an interaction. This reflection work was important to address internally experienced moods and emotions (e.g., by applying new ways to view a situation) and to determine specific actions to move forward with ongoing issues (e.g., addressing a work-related issue that triggered the mood). So, for a longer-lasting mood or issue, there might be multiple interactions. Therefore, the temporal bounding of collaborative self-management between when an issue first occurs, when collaboration with others

occurs, and when the individual managing depression feels that an issue is resolved (or decides to stop trying to collaborate) can vary by a magnitude of hours or weeks depending on the issue and available support.

Finally, collaborative self-management can manifest itself through different forms of ***interaction***. For example, I distinguish in my main study between mood-focused support practices and preventative support practices. In essence, some practices are directly tied to a current negative mood and some are broader proactive practices. Building upon my notion of "diffuse sociality" [80] and the construct of "belongingness" [161] described in the social support literature, I found that participants also benefited from being around others in shopping malls or movie theaters even if they did not directly engage with them. Engaging with others in a community is one structural aspect of social support that produces a sense of bond or social identity without requiring deep personal interactions. I also distinguish between social interactions which are verbal and others that are non-verbal or action-based. Many of the examples described across the two studies, particularly mood-focused support practices, involved conversation or discussion, often about the mood or issue. Technology-mediated interactions (through text, voice, video, and pictures) facilitated much of the work of collaborative self-management. However, shared activities that involved nonverbal support usually occurred in-person so many current technologies (texting, phones) were not as helpful in facilitating non-verbal collaborative self-management. Technologies that support shared presence, for instance the always-on webcam [175], or virtual or mixed reality experiences [159], might be able to better support nonverbal shared experiences. Indeed, when envisioning the future of their support network maps, several participants described

VR technology tools and teleportation to bring them closer to their families and friends. I describe these ideas further in 7.3.

In the next section, I discuss the process of collaborative self-management.

## 6.2 Process of Collaborative Self-Management

While several recent HCI and CSCW studies have shown the importance of social network support for individuals managing depression (e.g., [11,80,83,85,130]), the *process* by which individuals determine the need for and carry out these interactions is less clear, particularly in environments beyond online communities [273] and social media [5,7,85]. Understanding this process enables us to identify where breakdowns might occur and to understand the specific types of support that might be useful depending on the immediate process goal (e.g., *Who should I reach out to?* vs. *How can I act on what I learned*?). Through my analysis across a diversity of participants' examples, I identified 4 key components of the process of collaborative self-management (see Figure 5.). This process highlights the importance of pre- and post-interaction work of the individual managing depression to facilitate and benefit from collaborative interactions. While I describe the process in a linear chronological manner, I note with circular arrows that this process can repeat and circle back to earlier steps.

I first describe the process using examples from mood-focused support activities, and then I describe the process, often playing out over longer time periods, for preventative support. At the beginning of the process, individuals will sometimes experience a trigger leading to a negative mood or emotional issue. Trigger examples in my data included stressful situations at work or at school, feelings about and impacts of the pandemic, losing valuable items, getting laid off, people moving away, and interpersonal issues (e.g., with family members and significant others).

However, not all negative moods have an identifiable trigger. For example, several participants described times when negative moods arose without warning.


Fig. 5. Collaborative Self-Management Process

The first part of the collaborative self-management process is ***awareness*** of mood. Participants described times when they could feel an oncoming "negative spiral" of emotions, felt paralyzed by a seemingly endless number of tasks, or had a negative experience. Often, participants' friends and family members would notice affect changes when participants showed signs of a negative mood or new problem. Similarly, participants also described how they could tell from a friend or family member's body language, facial expression, and/or voice pitch that they were not doing well. Crucially, people have not yet decided how to act regarding combating or soothing the mood.

Then, ***planning*** occurred to determine what supportive interaction would take place. Planning could occur both deliberatively, through a conscious, thoughtful process, or more automatically, building on processes that the individual used more habitually. Some individuals tried to work on a mood individually (e.g., through journaling) and then if that was not successful, would reach out to others. From the participant's perspective, this planning stage often encompassed reaching out to others to see if they were free to talk or do an activity together. For example, when P03 in the main study was upset with her mom, she texted her friend to see if she could go to her friend's house to have some physical space away from her family. Planning was

often technology-mediated, usually via text. However, sometimes planning was not necessary. For example, during a regularly scheduled phone call, P11 in the main study realized from hearing her mom's voice that she was upset. In this case, they did not need to coordinate and plan because they were already on a call and seamlessly moved to the next stage of the process: the interaction.

Individuals carried out supportive ***interaction*** through a variety of practices. Many practices could occur within a single phone call where individuals might, for instance, check-in, vent, share advice, and share emotional support in quick succession all within a 20-minute call. These interactions could occur in-person or be mediated by technology. During the interactions, participants often articulated how they were feeling to others. This could be challenging, because in contrast to other health-related information, for instance, data that can be captured by sensors (e.g., blood pressure, insulin level), sharing one's mood is an internal experience that can be hard to communicate. Adding to this complexity, identifying and communicating mood and emotional state can be particularly challenging for individuals managing depression [44]. My participants spoke to this difficulty and several were actively building skills in this area. For example, P20 in the main study was working on identifying her mood and articulating it to others because she did not learn how to properly do so while growing up. Similarly, when asked by supportive others, not all participants could articulate their current mood or what caused it. Managing the disclosure of feelings and the anticipated or perceived reactions of others could make collaborative support more challenging.

Finally, after the interaction occurred, participants ***reflected*** on the support, considering what the interaction meant for their mood, and what their future action(s) would be. For instance, when P15 in the main study talked with her husband about an issue with a frustrating client, talking

through the issue with him enabled her to feel empowered in her own ability to tackle the problem, but she still needed to identify further actions to reach a solution to the work issue. Participants who offered reciprocal support often looked to the other person to say whether the interaction was helpful. For example, in the main study P18's friend would often text her about issues and P18 would continue to text with her until she had evidence that her friend was feeling better. Reflection is an important part of the collaborative self-management process, and reaching this stage, participants decided what their next steps would be, including reaching out to other people, reaching out to the same person again, or taking action in different ways on the mood or issue.

Similarly, this 4-step process also helps us understand how individuals seek preventative support. For preventative support interactions, individuals described how they gained *awareness* over time of behavioral patterns such as a tendency to self-isolate [19], and realized they needed to shift their behaviors to counteract those inclinations. Instead of awareness of mood (the emotional trigger) as discussed earlier in the section, awareness for prevention is somewhat different, as there is not necessarily a strong emotional trigger. Therefore, individuals may pay attention to small shifts in mood or patterns that they know are potential indicators of risk, such as increasing social isolation or the impulse to socially isolate. Awareness and planning are often tightly coupled, where individuals remember past actions and see patterns. To structure preventative activities, *planning* could include signing up for a class or volunteer activity, setting up a group text with friends, or considering the need to state one's boundaries. Then individuals carried out a diversity of *interactions* (e.g., sending funny memes, participating in group activities, setting boundaries). The main distinction here between preventative and mood-focused activities is that the "loops" of the collaborative self-management stages are often longer for preventative

activities. For instance, there might be multiple interaction instances (e.g., volunteering over the course of several weeks) before reaching the *reflection* stage, where an individual might consider, in this example, whether the volunteer work is helping them to reach their goals of managing depression or of preventing a worsening of their depression.

In sum, these 4 stages presented in Figure 5. show a view of the collaborative self-management process. Individuals realize the need for collaboration with others, plan, carry out the process, and reflect on their experience. In the next section, I discuss how shifts in participant's collaboration routines during the COVID-19 pandemic enable us to understand how external forces influence how this work is conducted.

## 6.3 Implications of the COVID-19 Pandemic on Collaborative Self-Management

In Chapter 5, I described examples of participants' collaborative self-management work from both before and during the COVID-19 pandemic. Due to the significant overlap in practices and routines, I analyzed and presented examples across both periods. Here, I discuss some specific shifts in participants' day-to-day lives and related implications for understanding collaborative self-management activities during a period of continuous disruption [65]. Using the pandemic as an exemplar, I discuss how collaboration can shift over time because of large-scale external factors.

The 2020 Coronavirus (COVID-19) pandemic disrupted people's lives around the world. The virus outbreak began in China, but within a few months had spread around the globe. The first confirmed U.S. case was January 22, 2020 [68]. A key measure to reduce the spread of the infectious disease was "social distancing" [18]. This is a broad name for activities including but not limited to: working remotely from home (where possible), reducing activities out in public, and keeping physical distance (e.g., 6 feet or more) from other people. Authorities advised

preventative health measures including wearing masks over the nose and mouth and frequently washing hands. Starting around March 2020, at various times, local and state governments in the U.S. ordered specific disease spread prevention measures, including to temporarily close (and then, later, reopen) businesses considered "non-essential." Overall, there was a significant economic impact from these measures. The main study data were collected from May – July 2020.

In the following section, I discuss shifts in participants' collaboration. First, there was, unsurprisingly, a shift to more technology-mediated interactions, which resulted in more work to arrange support. Second, many participants used telehealth to access in-person and group therapy. Third, there were multiple considerations concerning in-person connections during this period. Finally, preventative support in community environments became inaccessible, so participants tried to re-create these interactions online.

### *6.3.1 Similar Technologies, but Different Connection Routines*

The pandemic shifted individuals' work and socialization practices. For example, with many participants' social networks working from home, social interactions became more purposeful and planned versus previous routines of seeing people and chatting organically within workplaces or other social environments. This resulted in new work for participants to schedule and arrange for support interactions (e.g., arranging specific times for a call to connect) which could be a tiring process. However, interactions with friends and family who lived further away often remained consistent during the pandemic because these interactions were already technology-mediated.

While routines shifted, participants did not report many new technologies for collaborative self-management during the pandemic. Prior to conducting the study, I thought that many

participants may have started to use technology-mediated tools (e.g., video chat) for the first time during the pandemic. Instead, I found that the communication technology infrastructure was already in place for connecting with others[3]. Many participants already texted and called individuals living nearby and at a distance (e.g., to coordinate in-person meet-ups or to check-in with each other). Therefore, while new technologies were not necessarily added, these technology connection infrastructures were used more heavily, especially to connect with friends and family members, even those who lived nearby.

Working at home highlighted vulnerabilities in communication infrastructure(s). The ability to engage in critical support, especially via rich video interactions, was reliant on the functionality of internet service providers and impacted by the behaviors of neighbors and other people in the household. While connectivity was an issue prior to the pandemic, the amount of traffic on these channels due to stay-at-home orders exacerbated these issues, making it more difficult for individuals to access essential lifelines for support. Across the U.S., the pandemic highlighted the digital divide where many people lack access for fully participating in modern, daily life, through issues such as lacking at-home Internet and computer skills, and not having essential digital tools at home [202].

### *6.3.2 Shifts to Telehealth for Individual and Group Therapy*

Many participants tried telehealth for therapist-led and group mental health support for the first time during the pandemic. These participants had previously attended in-person sessions with a therapist or with a group of peers, and then shifted to phone or video calls to connect with these individuals. Other participants decided to cancel their ongoing treatment if they could not meet in

[3] My population for the main study had high technology literacy and I recruited through digital methods. Therefore, this finding may be different for other populations during the pandemic.

person and for financial reasons. This meant that these participants were less likely to be moving forward with therapy-related mental health goals during a challenging time.

For some, therapy became more accessible. For example, group support via video platform was easier to attend for P27. He had lost his car a few years previously and since then walked several miles to attend meetings. However, while the meetings did become more accessible, due to this shift, he was not able to continue his routine of going to a coffee shop and chatting with a smaller group after the main support session, leading to less camaraderie and social experience as part of connecting with this support group.

Developing new norms around telehealth was challenging, particularly because technology-mediated environments did not replicate all components of in-person interaction. Participants who shifted to tele-therapy missed seeing the park outside a therapist's window, the plants in the therapist's office, and the ability to sense the therapist's "energy." Similarly, as discussed in Chapter 5, P14 experienced difficulties shifting to video-mediated group therapy where people would alternately be silent or interrupt each other without in-person cues to know when people would begin talking. Given these challenges, during the transition to new telehealth norms, participants perceived less personal benefit from these therapy interactions. Yet, at the time of writing in March 2021, after a year using telehealth, it is possible that participants have adapted to these shifts and created new norms of interaction in these environments.

### *6.3.3 Considerations for In-Person Supportive Interactions*

Despite frequent communication with others via multiple technology channels, many participants desired in-person connections. P17 and her family members, many of whom managed mental illness, decided to "isolate together" in quarantine "pods" or "bubbles" [54]. They chose to

do this to support the family's collective mental health, given that multiple family members managed mental illness. This decision shows that collaborative self-management decisions can operate at a level beyond the individual because this decision to potentially create more risk of catching the virus required buy-in across the families and trust in the safe practices of others. In addition, some participants sought in-person interactions outside of people they lived with even though this could potentially increase the risk of contracting the virus. Outdoor distanced walks enabled participants to see friend's eye contact, hear them laugh, and experience physical co-presence, providing positive mood boosts. In-person support interactions were clearly important and offered additional elements (e.g., eye contact, shared laughter, co-presence) that are harder to accomplish through technology-mediated interactions.

Challenges with in-person and technology-mediated support connections led participants to increase individual and mind-oriented self-management activities (e.g., reading, walking, listening to audiobooks, meditating, decluttering, creating art, planting a garden, and sitting outside) as well as interactions with pets. While not a human "collaborator," pets were nonetheless key participants in many people's self-management interactions. When participants were feeling down, pets could be a key source of soothing interactions. Participants described how dogs could provide unconditional love and not be "judgmental." In addition to the soothing nature of petting and feeling loved by an animal, a dog was also helpful in creating daily structure and providing motivation for getting exercise.

### *6.3.4 Inaccessible Community Spaces Challenged Preventative Support Routines*

While participants negotiated in-person one-one-one and small-group interactions, they had very limited interactions in the community. Whereas previously participants periodically went

shopping, visited the movie theater, or went out to eat, these avenues for distraction and group social interaction were largely removed from daily routines. Important social activities that became inaccessible included choir, dance groups, and places to volunteer. Oldenburg describes these as "third places" – "those happy gathering places that a community may contain, those 'homes away from home' where unrelated people relate" [190]. Oldenburg argues that without these spaces such as coffee shops, bars, bookstores, hair salons, and the community interactions therein, urban life is dulled as individuals miss out on informal public life. Similarly, in my study, community groups within churches, dance studios, and museums, among others, were important for many participants' preventative support interactions, and so with these previous routines removed, engaging in this type of collaborative self-management became difficult.

Participants tried to re-create these spaces for socialization and connection online. Participants connected with online communities on Reddit, Facebook, and Twitch, and described long family video chats and playing online games together. Churches delivered online sermons, some enabling live commenting from viewers, as well as group discussion after the sermon. Museums began to offer virtual tours and experiences [280,293]. However, for those who enjoyed group dancing, there did not seem to be a fruitful digital translation.

In summary, participants adapted to the pandemic pressures and safety protocols by increasing technology-mediated collaboration with friends, family, therapists, and community groups. In doing so, they had to create new collaboration norms, expend extra effort to plan and adapt interactions, and navigate Internet connection difficulties. To access in-person interaction more safely, participants created pandemic "pods" and went on socially distanced walks. Finally,

participants re-created community connections online when these previous third spaces became inaccessible during the pandemic.

## 6.4 Chapter Summary

This chapter advanced our knowledge of collaborative self-management in several ways. I explored key characteristics of the work of collaborative self-management (agency, reciprocity, time, and interaction) as well as the 4 steps of the process of collaborative self-management. These steps underscored the important pre- and post-interaction work on the part of the individual managing depression in coordinating and reflecting on collaborative interactions with others. I then discussed how COVID-19 shifted participant collaborative interactions. Together, these contributions help us to understand the rationale and goals driving the diversity of observed collaborative self-management interactions and shows the essential interconnectedness of people, technologies, and practices.

Next, in the second discussion chapter, I discuss specific design directions to support collaborative self-management.

# 7. DISCUSSION: IMPLICATIONS FOR DESIGN

A key goal of my dissertation was to better understand the day-to-day lived experiences of individuals managing depression. While previous literature drew on clinical approaches for depression treatment, to develop human-centered support technologies, we were missing an understanding of day-to-day collaborative self-management and how individuals used technologies to mediate this work. Addressing these gaps in the literature was essential because a key step in many design traditions and methodologies is to understand current user practices and needs [126,187,224,237].

A sociotechnical approach to design is essential because technologies are inherently political [262] and exist within a larger cultural milieu. For example, how we design technologies can influence people's ability to conduct tasks essential to accessing information, maintaining their livelihood, and managing their health. Technologies also often sit within existing relationships (e.g., friends, doctor and patient), and their use is influenced by larger cultural and societal views (e.g., potential stigma regarding depression). Norman [188] notes that, "difficulties arise when there are conflicts between the principles, demands, and operation of technology with the tasks that we are accustomed to doing and with the habits and styles of human behavior and social interaction in general." Therefore, understanding individuals' current practices, including the motivations and challenges driving those behaviors, is a critical part of the design process because it helps us design technologies that people will actually use.

I view design as the principled creation of new futures. Recognizing the strengths of participants is a key value in my work. In the following chapter, I first use an assets-based approach [266] to start from participants' currently functioning routines to interrogate potential future tools

to build upon current practices. Next, I discuss avenues to augment everyday technology solutions. Then I discuss implications for future collaborative self-management technologies by drawing on participant blue sky ideation. I conclude with a chapter summary.

## 7.1 Setting the Frame: Design Approaches to Collaborative Self-Management Support

Digital mental health support technologies for individuals managing depression often focus on treatment targets to improve or reduce symptoms of the condition (e.g., [172,178,227]). Indeed, when we think of these individuals as a population they are defined by their collection of symptoms. While alleviating or reducing the impact of these symptoms is certainly important, technologies developed following this view often focus on correcting perceived "deficits" of an individual in terms of mood regulation, self-management activities, and negative thoughts. I suggest we extend this approach through considering design directions starting from the strengths of these individuals, known as assets [199]. Asset utilization refers to "the extent to which an intervention recognizes and leverages resources already existing in the community, including physical and social infrastructure, skills, knowledge, networks, and environmental resources" [266]. Specifically, I encourage designers of digital mental health technologies to consider solutions that enhance individuals' current toolsets. Areas of participants' strengths that I identified from my research are their ability to support others who are managing mental illness and their creative use of technologies to support collaborative self-management.

Below, I discuss the question: *What do these strengths mean for design?* I present three ideas to guide future researchers and designers who want to support collaborative self-management: (1) integrate an individual's previous work developing self-management routines,

(2) learn the productive ways that individuals provide support to each other, and (3) support technology appropriation and adaptation work.

### *7.1.1 Integrate an individual's previous work developing self-management routines*

Digital mental health technologies should augment self-management strategies from the clinical literature with an assets-based approach. Many individuals managing depression have already developed or learned some self-management strategies (as shown in this dissertation), therefore we can consider how to integrate and learn from that expertise. For mental health support technologies, we need to do a better job of incorporating what people currently do. To "meet people where they are at," for instance, a self-management tool could begin by understanding current routines that an individual uses to manage their depression. Of course, not all practices are as productive as others, and some might even be harmful, so this is an important aspect to keep in mind when designing tools integrating these behaviors. However, given the heterogeneity of depression symptom effects [19] (e.g., one person may struggle to sleep, another might sleep too much), and the ways that access to resources make certain self-management activities easier or more difficult [23,46], it is worth understanding previously developed useful routines.

Second, we could learn where individuals managing depression want to increase or intensify current self-management. For example, when reflecting on their current collaborative routines, participants desired to increase their amount of connection with others. This included activities such as: meeting new people to increase their social networks, communicating more frequently with people they already know, and, if possible, moving distant friends closer for more in-person and more frequent interactions. When considering geographically distant friends on their support maps, participants said that it was easier to forget to reach out to them, similar to Tillema

et al.'s [245] findings that greater physical and relationship distance predicts less frequent communication. To accomplish these increased connection goals, participants discussed ideas including increasing their use of technology-mediated communication, switching from text message conversations to phone calls, and gaining confidence through becoming better integrated with their team at work or becoming more attractive.

Gathering self-management strategies from users may yield a creative corpus including emergent uses of technology tools. Moving in this direction, the MUBS [215] behavioral activation tool provides a base set of activity recommendations but also allows users to input their own activities and to search for activities added by other users. Other depression support apps have begun to create self-management "personality" classifications (e.g., [116]), and are able to suggest activities in this type of language: 'other people who like similar self-management activities rate that they particularly enjoy running.' Suggesting reasonable activities for a user's current climate and weather (e.g., winter in Chicago, U.S.A.), activity preferences, and local geography are promising avenues. Personalized recommendations, combined with interaction ideas gathered through a crowdsourced method, could yield exciting opportunities.

### *7.1.2 Learn the productive ways that individuals provide support to each other*

While individuals managing depression are often positioned as the recipients of care [2,6], I found that participants actively supported other people also managing mental health needs. Those who understood how to be an effective supporter often had shared experience with what participants called the "irrationality" of depression. This shared experience allowed people to support each other, often through humor. Having to deal with depressive episodes over time meant that individuals often developed a set of strategies that worked for them, which they could then

suggest to others in need. However, participants discussed how it could be emotionally taxing to support others as well as manage their own moods and emotions. Given these observations of participants' developed expertise, we should seek to understand what makes effective collaborators and use this knowledge to support better education and interventions. We can learn from participants about the ways that they would like support to be delivered, for instance, by not trying to "solve" the issue if the participant instead wants to just "vent."

While some individuals managing depression participate in online forums [89,273] and social media [5,93] spaces, supporting others is often a taxing activity that places additional burden on these individuals. Therefore, an interesting design question in this area is – *how could we learn from the support provided by individuals managing mental illness, and leverage this to enable more effective support from people who do not have mental illness*? For instance, participants discussed having to "train" their friends to be able to say useful phrases when they were managing a negative mood [80]. Without the personal experience to understand how a depressive episode feels, people may say unhelpful and even harmful things to individuals managing depression.

To start to address this issue, recent HCI research has evaluated tools to build empathy regarding the experience of depression. A variety of empathetic games (e.g., [70,103,159]) include gameplay elements including growing vines or threatening clouds to simulate the challenges of depression self-management. In another empathy-building approach, Sas et al. [222] created a card-based kinesthetic design tool focused on statements and associated embodied postures indicative of depression. We can build on these initial efforts to create empathy and to teach others about positive ways to provide support. For example, we might consider helping people who do not have depression to learn processes to communicate in a more helpful manner. We can also

assist individuals managing depression with making their collaboration preferences known to friends and family. Understanding and developing education and resources in this area is a fruitful avenue for future design.

### *7.1.3 Support technology appropriation and adaptation work*

My final assets-based approach is to support current technology appropriation and adaptation routines. Some technologies specifically developed for mental health support, for instance, tools supported by the SilverCloud platform [76] combined with periodic human coach check-ins, have proved effective. However, many digital mental health technologies suffer from low uptake and even lower continued use over time [150]. Yet, my research shows that individuals are using many technologies not developed specifically for mental health support, as part of their depression self-management.

HCI researchers have observed individuals using platforms such as Instagram [11,93,94] and Facebook [35,66] to facilitate support for depression. Similarly, I found that the communication technologies used by individuals worldwide – apps for communicating through text (e.g., WhatsApp; Telegram; Facebook Messenger), voice, video, and pictures – play a major role in collaborative self-management of depression. Participants used these channels to mediate supportive interactions. They intentionally selected social technologies to ask for, receive, and share support with others. Participants showed remarkable ability to adapt their technologies to a variety of coordination and support tasks essential to support collaboration. Seeing how individuals are already creatively appropriating these tools, we could develop complementary technologies within individuals' ecosystems to augment current practices.

Solutions that enhance current practices by supporting needs within the 4-stage collaborative process are likely to be useful place to start. For example, there are opportunities to further support planning and reflection. Some participants struggled to remember the preferred communication channel of the person they wanted to reach for support. Therefore, a tool to suggest the best communication channel(s) to reach out to key contacts could be beneficial. Kornfield et al. [146] describe how it is useful to accomplish this kind of "setup" work when an individual is feeling well so that the tool is ready when a depressive episode occurs and an individual has lower cognitive and energy bandwidth to make decisions. Second, supporting reflection after collaborative interactions could be useful. After support interactions, participants often reflected on their next steps to resolve the issue that triggered their mood and considered whether they needed to talk to others for further support. A tool, for instance, an extension of note-taking applications on a smartphone, could help users to keep track of ongoing issues, advice, and next steps. Technology supporting reflection processes could also be integrated with self-tracking tools (e.g., [134,140,145,152,172]) to provide individuals with more insight over time about their mood and collaborative self-management activities.

Finally, an important question to continue to explore is whether current technology tools and services appropriately support user's mental health and uphold privacy. For instance, when individuals appropriate these general tools for collaborative self-management, are there any harms or challenges that occur that would be absent from a specifically designed and guided mental health tool? Given the ways that individuals conduct collaborative support work within mainstream communication channels it is likely that as future communication platforms for general use (e.g.,

not specific to mental health) are developed, individuals managing depression will use them to for collaborative self-management purposes.

In sum, taking an assets-based lens to current collaborative self-management activities allows us to design and promote practices that individuals managing depression are already accomplishing. In the following section, I focus on how we can redesign features of current everyday technology solutions to better support current collaboration practices.

## 7.2 Redesigning Features of Everyday Technologies for Collaborative Self-Management

In Chapter 4 and 5 I described the variety of technologies that mediate collaborative self-management. Here, I discuss key features of these everyday technologies that individuals use for collaboration and how we can augment or redesign tools to better provide these useful features. I highlight implications of self-managing depression (e.g., challenges with memory, stigma) that require sensitivity when developing solutions in this space. Below, I discuss useful features for text messaging and social media, and then video call applications.

### *7.2.1 Useful Features for Text Messaging and Social Media Technologies*

In this section, I discuss 3 key features to consider for text messaging and social media technologies: multimodality, recording conversations, and content toggling. While each feature can be useful, I also discuss potential challenges to consider when integrating these features.

**Create Interactive Multimodal Platforms**. Participants used technology channels that enabled them to move fluidly between text, voice, video, and picture-based interactions. Thus, participants suggested that all texting applications should also include phone and video calling capabilities. Platforms which support a convergence of channels or "modes" are called interactive multimodal platforms [101]. For individuals managing depression, using these multimodal

platforms would enable connection at a variety of intensities and enable adaptation to in-the-moment emotional state, cognitive state, and physical location. As described in Chapter 4, enabling this adaptation through multimodality supports user privacy through being able to communicate regardless of who might be able to overhear the conversation, for instance, while at work or within shared living spaces.

However, diverse modes of communication *within* platforms did not necessarily mean that participants also wanted a diversity *of* media platforms, given challenges managing conversations across multiple applications. Several participants wished that people in their social network could all use the same communication platform. They then would not have to remember each person's idiosyncratic communication preferences or passwords across platforms. Participants were largely "maxed out" regarding their various communication tools, so adding a future collaborative self-management tool in addition to this selection would likely add to their current conversation tracking and sense-making burden. In lieu of a single unifying communication platform, "connective tissue" technologies that can aggregate and help individuals to keep track of conversations across multiple platforms are likely to be helpful. Some social media companies are already moving to make cross-platform interactions easier, for instance, the recent Facebook Messenger and Instagram connection [165]. Continued connections of this type can support current participant multi-platform communication activities, but also require further thinking about potential participant privacy concerns.

**Consider Privacy Challenges and Memory Benefits Related to Recording Communication**. Messaging technologies which record conversations (e.g., through a recorded text chat) could encroach on user privacy but could also be a helpful tool for managing memory

challenges. On one hand, several participants were concerned about whether social media sites were collecting data on them or "listening in" to what they were saying through collecting user metadata. For instance, Facebook's data policy [294] (as of February, 2021) notes that they collect user information about content, networks and connections, usage, user devices, and information other users provide about the user. Ellison et al. [82] describe a common process where people negotiate privacy concerns and social capital needs in social media environments. For example, P19 in the main study was working through some legal issues and preferred to discuss with friends on communication platforms that she was sure would be private with no record of their conversations. However, some of her friends only used certain platforms, so she was selective about what she shared when she wrote to them.

On the other hand, as discussed in Chapter 5, issues with memory made ephemeral communication technology like Snapchat difficult for some participants. Without a record of the previous conversation, participants could forget what they had been talking about. For these participants, being able to create records of "disappearing" communication for memory support purposes could be helpful. Overall, given the stigma [5,61] that individuals managing depression may experience, it is especially important for this population to easily understand the privacy and data policy implications of messaging platforms used to share sensitive information during collaborative self-management.

**Enable Content Toggling for Feed-Based Social Media**. Finally, participants discussed removing negativity from social media and pushing back against the way that social media can "*suck you in*" by improving feed filtering. The infamous Facebook "emotional contagion" study by Kramer et al. [148] provides evidence to the claim that on social media, emotional states can

be transferred to others without direct interaction between people. For participants in general and especially those who were particularly empathetic, seeing toxicity and negativity on social media along with news stories about negative events could easily impact their mental health if they spent too long using these platforms. Engaging with negative posts or arguments could also sap participant's limited mental energy and motivation [130]. Taking breaks from using social media sites and limiting daily social media use were common participant approaches to using social media in ways that remained positive. Given the reactions of participants to certain content, providing options to toggle one's feed to select only videos or pictures, or to remove content about politics, specific people, or events could be helpful avenues to explore in the future.

### *7.2.2 Useful Features for Video Calling Applications*

While I previously described individuals' technology ecosystems as including mainly user-facing tools (e.g., specific apps on their phone), the common use of video connection technology shows that technology ecosystems for collaborative self-management should also include cellular and Internet service, because apps alone do not enable connection with others without these underlying infrastructural connections. In this section I first describe the importance of improving connectivity, and then discuss conversational cues, and scheduling across time zones.

**Improve Internet and Cellular Connectivity**. Spotty Wi-Fi (and to a lesser extent, limited cellular coverage) was a major challenge that frequently impacted collaborative self-management experiences. While coverage and access to communication networks has been an ongoing issue across the United States, and participants described challenges with connection prior to the pandemic, the pandemic exacerbated many of these problems given the unprecedented utilization of these networks (e.g., [153,171,282]). Challenges with coverage led to frustrations

with not being able to respond quickly to others and issues of choppiness, lag, and echoes during support conversations. This was also the case beyond video calling applications. For example, when P09 in the main study sends memes to share humor, she sometimes experiences difficulties where messenger platforms "glitch up." While challenges with connectivity are often issues for individuals beyond those managing depression, these challenges take on new frustrations when connecting to others is an important element of managing one's health day-to-day. Frustrations are heightened for people who are already often dealing with a negative mood or issue where these challenges with connectivity layer on top of current challenges, making the overall experience even more frustrating. Therefore, focus on improving the service provision infrastructure for these tools is one important approach, as is creating communication technologies that can operate despite limited or spotty connectivity.

**Support Conversational Cues**. Many participants struggled to interact through video technologies in ways that they enjoyed in-person. A key complaint was the lack of ability for eye contact during conversation. Eye contact is possible currently by looking directly into a webcam [175], but means that a user cannot at the same time see the other person's face. Similarly, participants who were used to interacting in-person, for example for group therapy, found that it was difficult to interpret the whole group during multi-person calls when they had to "peer into" separate squares for each video stream. For multi-person video chats, enabling participants to see everyone else at the same time could assist this group-level conversation understanding. For instance, we might imagine a video call where individuals' images were overlayed on the same background, creating the illusion of a shared space. Alternatively, through VR experiences, a group's virtual avatars could all inhabit the same space.

**Enable Scheduling Across Time Zones**. Another challenge was dealing with time zones. Coordinating times to connect, especially for groups of people, could be problematic and exacerbate issues of negative mood and exhaustion. While coordinating across time zones may seem like a discrete task, for participants who had to do this frequently, especially across many relationships, this work became tiring. Current video connection technologies such as Zoom do this to help assist comprehension of what time a call is scheduled for (e.g., 11 am in Chicago, 5 pm in London), but most current video tools do not also help coordinate selecting a good time for the call within individuals' schedules. Thinking through the steps in the process to plan a support call (e.g., determining to reach out to a certain person, considering their general availability for connection, considering the current time where they are, etc.) might be a useful approach to developing future technology features that would reduce the planning burden.

Overall, participants clearly found tremendous value in technology-mediated collaborative self-management. However, as I described above, many technology channels could be further refined to support participant connection goals. Key support features within messaging and social media technologies include multimodality, recording conversations, and content toggling. Key support features for video call technologies include Internet and cellular connectivity, conversational cues, and scheduling across time zones. In the following section, I shift from discussing current technology features to discussing ideas for future technology-mediated interactions to support collaborative self-management.

## 7.3 Blue Sky Ideation for Collaborative Self-Management Support

Stretching our design space to consider future technologies beyond current scientific feasibility, I discuss participant ideations to showcase the creativity of individuals managing

depression, similar to O'Leary et al. [191]. This enables us to consider possibilities for design on different temporal horizons [204]. Many of these ideas were based on technologies portrayed in science fiction media like Star Trek [283,295] and Star Wars [281,296]. Below, I discuss sharing sensorial experiences, enabling shared space, and supporting freedom of movement, highlighting what we can learn from these ideas regarding considerations for collaborative self-management.

First, future tools could support sharing **sensorial experiences**. The ability to share sense-based experiences could increase the range of possibilities for connection. Participant ideas included sending smells, using telepathy, and connecting to pets while away from home. For example, sending smells through technology-mediated interactions could assist sharing in the same scent of tasty cooking or the humor of a bad whiff. Similarly, being able to share emotions (e.g., through the idea of "telepathic" communication) might enable better support from therapists or friends. Beyond human-human connections, several participants desired to better interact with pets via technology. While this dissertation focused largely on human-led support, many participants discussed the mental health support benefits of pets, especially dogs. Together, these sensorial ideas build upon current practices of sharing and connecting yet seek to heighten the experience through simulating in-person experiences. However, participants' interest in the ability to connect and share emotions, brain-to-brain, is not currently possible, and tells us that even with the ability to describe how one is feeling, another person might not understand how the mood feels to the individual who is experiencing it. Therefore, directly sharing emotions has the potential to transcend words and enable improved support.

Second, enabling **shared space with others** through technologies like holograms or virtual reality experiences would likely engender a more supportive experience. For example, hologram-

type communication might enable participants to look a person in the eye and see their whole body so that, "*it would be like we were sitting together*" (P18, main study). Technologies that support a shared presence at a group level could enable sharing in holiday traditions, for instance, through a hologram of the participant sitting at a table during a family meal. By sitting in a familiar place with familiar sights (and perhaps smells), participants thought that they would feel more supported, included, and safe than in current video call experiences. These ideas highlight how sharing space with others is often an important part of in-person collaborative self-management, replete with eye contact and co-presence. Many of the mediating technologies discussed in Chapter 4 and 5 are relatively low cue, for instance, text messages and phone calls enable only limited information about the other person. Thus, these shared space ideas move toward the richness of in-person experience through technological means.

Third, participants were interested in **speed and freedom of physical movement** to go places in their own towns as well as to and from friends and loved ones. One participant described the benefits of an eco-friendly car that could be folded up and put into a pocket to eliminate parking hassle. Other ideas included teleportation of supportive others. Important aspects here included teleporting others on an as-needed basis especially for those who appreciated physical touch and shared presence as well as group laughter. Other benefits of teleportation might include eliminating time spent traveling to visit people who live in far-away places. P20 in the main study thought that it would be scary to teleport people but would love to scan and share food or items to better interact with others in the moment, for instance, through sending bites of a tasty sandwich while at a café. The strong desire to see others in-person may relate to the challenges and desires driven by the COVID-19 pandemic when authorities recommended against in-person indoor interactions and

travel. Some participants also described a strong desire for human touch as a part of collaborative self-management (hugging, cuddling, etc.), and ideas around fast travel underscore that this need that is not met by current technology tools. Yarosh et al. [271] have begun to work on technologies that could transmit touch from afar, but these type of tools are still largely in their infancy and are removed from mainstream offerings.

In sum, thinking toward future tools, we can consider ways to support heightened connection experiences, share space (and place) [109] with others, and enable speed and freedom of physical movement.

## 7.4 Chapter Summary

In this second discussion chapter, I presented implications for designers working on future solutions for collaborative self-management. I detailed 3 high-level approaches to guide designers: integrating current self-management routines, learning the productive ways that individuals provide support to others, and supporting appropriation and adaptation of general technology tools. Then, I presented features of current technologies that play an important role in collaborative self-management. I concluded with future technology ideas derived from brainstorming with participants.

I the next chapter I discuss my research limitations.

# 8. LIMITATIONS

My dissertation presents rich details about the collaborative self-management work of individuals managing depression. However, there are a few limitations to these studies and areas for future work. First, both studies present the perspectives of people living in the United States and within the U.S. healthcare system. While some participants described experiences living and having family in international locations, my findings do not necessarily relate to the experiences of individuals facing different cultural and healthcare system stressors [155,273]. However, a benefit of the remote interviewing procedure for the main study is that I was able to analyze across both urban and rural perspectives in the U.S. Further studies should investigate self-management activities in other national and cultural contexts as cultural norms may differ. Second, for the preliminary study, while interviews were conducted in the home for some participants, the recruiting strategy may have excluded those with symptoms of depression severe enough to prevent them from participating. Similarly, in the main study, participants largely fit within the "moderate" and "moderately severe" depression categories based on their PHQ-8 scores. One participant scored in the severe depression range, but beyond that participant, my work is unlikely to speak to the experiences of individuals suffering from severe depression, which would be an important population for future work.

Third, the preliminary study was more successful at recruiting minority population participants than the main study (57% white, 43% mixed race or POC vs. 75% white, 25% mixed race or POC). For the preliminary study, we recruited through flyers and word-of-mouth methods in racially diverse neighborhoods in Chicago. I also sought racial diversity in the main study sample (see Detailed Methodology section in Chapter 5) but was only able to recruit 25% of

participants from minority populations. In future studies, I will continue to partner with organizations to reach more racially diverse individuals managing mental health needs. Relatedly, regarding recruiting and study practices, for the main study, digital recruiting may have left out people we could have reached through in-person flyers (my plan prior to COVID-19) who did not have access to digital recruiting channels.

Additionally, while not a limitation in the traditional sense, I realized in the main study that managing depression can affect people's ability to quickly recall memories. All participants were able to discuss how they interacted with others for support, however, the practice of asking retrospective questions can be potentially challenging for some members of this population. Part of the issue for a few participants was that the pandemic had disrupted and lessened their day-to-day social interactions. Finally, I exclusively interviewed individuals managing depression because I wanted to understand the breadth of their support networks and wanted participants to feel comfortable describing any collaboration challenges they experienced. I recognize that collaborative self-management might look different for supportive others in the social network. Future work investigating the perspectives of collaborators who support individuals managing depression would build upon the findings discussed here and continue to deepen our understanding of collaborative self-management.

In the next and final chapter, I summarize my findings in relation to the research questions guiding this dissertation.

# 9. CONCLUSION

In this final chapter, I summarize the results of this dissertation in addressing my research questions. I then describe avenues for future work building on the contributions detailed below.

## 9.1 Contributions

This dissertation presented a rich picture of the collaborative self-management work of individuals managing depression. First, I summarize my contributions regarding conceptualization of collaborative self-management.

### *9.1.1 How do people conceptualize collaborative self-management of depression?*

In asking the question of conceptualization, I was interested in understanding both how individuals managing depression thought about their work, as well as how we as researchers could better understand the work conceptually. The first contribution of the dissertation is to underscore the importance and prevalence of collaborative work as a key aspect of self-management. I critique previous framing of self-management viewed as an individual set of practices by showing the crucial nature of supportive interactions with other people as part of day-to-day self-management of depression. In doing so, I highlight how mental health support solutions which focus solely on individual self-management are likely to neglect the rich collaborative work of these individuals.

Next, while collaborative self-management has been used in the chronic disease context to promote adherence to medical recommendations, I extended the term to the mental health domain. In introducing the term to the Human-Computer Interaction literature, I use it to analytically focus on the work of the individual as they plan, seek, receive, and reflect on support from others, viewing it as the intentional engagement in activities with others as a part of mental health and wellness self-management. In Chapter 6, I discussed 4 key characteristics of collaborative self-

management: agency, reciprocity, temporality, and interaction. I then shared the process of collaborative self-management, moving between awareness, planning, interaction, and reflection.

My findings regarding *who* individuals collaborated with to accomplish this work include family, significant others, friends, peers managing depression, and healthcare professionals, as well as roles less frequently discussed in the literature – coworkers and strangers. As described in Chapter 5, participants selected others to turn to for support based on criteria including how well the individual(s) understood them as a person, whether they were in physical proximity, whether the individual(s) had experience or knowledge of managing mental illness, and how frequently they communicated. I described *how* individuals carried out collaborative self-management across two different categories of support practices: mood-focused and preventative. Mood-focused practices included: checking-in; sharing stories, venting and empathetic listening; making sense of situations collaboratively; sharing advice; and affirming, encouraging, and calming. Preventative support practices included: engaging in shared, group and community activities; sharing humor; and setting boundaries. Together, this diverse selection of practices shows us the breadth of day-to-day collaborative support activities and provides a foundation for future targeted support solutions. Finally, regarding *where* these activities occurred, I showed the tight coupling between technology-mediated channel selection and emotion state, cognitive state, and physical location. Participants moved fluidly between text, phone, video, and picture-based channels.

Next, I summarize my contributions regarding technology ecosystems for collaborative self-management support.

### *9.1.2 How does an individual's technology ecosystem enable or constrain collaborative self-management of depression?*

My dissertation showcased mainstream communication technologies as critical avenues to enable and augment the work of collaborative self-management. Specifically, these tools, including texting apps, social media platforms, and native phone calling applications, were not specifically developed for mental health support yet were used frequently for that purpose. While previous HCI literature has shown the benefits of mental health support provided through online communities and social media, my studies have widened our knowledge of the variety of collaborative support tools utilized by individuals managing depression. Everyday technologies for mental health supported communication, entertainment and distraction, and mobile health and tracking.

Participants preferred opportunities for multi-modal communication (e.g., moving between text, phone, and video). However, channel selection was not only based on static individual preference, but also on the dynamic needs of participants in the moment. Technology channels were critical to support collaborative self-management by enabling flexible connection with others and in-the-moment support. Participants' ability to interact and feel safe and secure related to how well their channel and location matched the intent of their interactions. Technologies to communicate with others as part of mental health self-management primarily included text-based, voice, video, and picture-sharing applications. Individuals selected technology-mediated channels to connect with others based on a collection of considerations such as location (e.g., work or home), emotion state, cognitive state, and the communication preferences, availability, and location of the person with whom they were connecting.

Technologies also presented challenges to participating in collaborative self-management. Some participants struggled to manage conversations across multiple social media and messaging applications. Participants also had to consider the privacy of different channels, both in terms of who could see the digital text within the channel as well as who might physically overhear their conversations. For participants in general and especially those who were particularly empathetic, seeing toxicity and negativity on social media along with news stories about negative events could easily impact their mental health if they spent too long using these platforms. Others wanted to avoid wasting their mental energy engaging with negative posts or arguments. Finally, challenges with Wi-Fi and cellular coverage led to frustrations with not being able to respond quickly to others and issues of choppiness, lag, and echoes during support conversations.

In the following section, I summarize my discussion of how to redesign technology-mediated supportive experiences.

### *9.1.3 How might we redesign technology-mediated supportive experiences to better fit the needs of individuals managing depression and those they collaborate with for self-management?*

Digital mental health support technologies for individuals managing depression often focus on treatment targets to improve or reduce symptoms of the condition. However, based on the findings of this dissertation, I suggested that we also identify the strengths of these individuals – an assets-based approach. I presented three ideas to guide designers in future work to support collaborative self-management: integrate an individual's previous work developing self-management routines, learn the productive ways that individuals provide support to each other, and support technology appropriation and adaptation work.

We should consider incorporation into existing management routines and communication structures where people are already sharing support. Understanding how users are appropriating technology can provide insight regarding what users want or need. Key support features within messaging and social media technologies include multimodality, recording conversations, and content toggling. Key features for video call technologies include Internet and cellular connectivity, conversational cues, and scheduling across time zones.

Finally, future tools for collaborative self-management support could focus on sharing sensorial experiences through simulating in-person experiences or more deeply sharing participants' emotions. Tools could also support sharing space with others (e.g., through holograms or virtual reality experiences). In addition, participants were interested in speed and freedom of physical movement to go places in their own towns as well as to and from friends and loved ones.

## 9.2 Future Research Avenues

The contributions of this dissertation provide fertile ground to investigate future topics. First, there is more to understand within the temporal aspects of collaborative self-management. O'Leary et al. [191] and I noted the importance of technology-mediated channels in connecting individuals quickly for emergent support needs. However, I would like to know more about how the episodic nature of depressive episodes (for instance, depressive episodes coming and going at unexpected times) influences when people reach out for support. From a clinical perspective, how important is speed in reaching out to others to act on a negative mood that is just beginning to grow? On a larger survey-scale level, I am curious to know how frequently people engage in collaborative self-management activities. Some of my participants collaborated to manage their

mental health multiple times a day, and others did so every few weeks or months. I am curious to know if patterns of collaboration can tell us anything about how well individuals are managing and times when they might need extra support. Similarly, time plays a role in illness trajectories and uptake and abandonment of technologies over time. Future research could investigate whether individuals who have been more recently diagnosed use or desire to use technology support tools in different ways than individuals who have been managing depression for extended periods.

Similarly, there is opportunity for further conceptualization of "everyday mental health support tools" which are sometimes but not always used for mental health support. Indeed, it is interesting to think about social media from this perspective. Clearly, social media channels mediated the work of individuals managing depression and provided key lifelines to needed support. However, social media was also perceived to exacerbate negative moods, particularly when used for long periods of time [130]. This distinction contrasts against tools that are developed for mental health support (e.g., meditation applications, tele-therapy tools), where an individual may not use them for as long, but they are developed often an eye to the needs of individuals managing mental illness(es). An ongoing question here is whether current mainstream communication tools appropriately support the needs of individuals managing depression, especially around privacy and confidentiality concerns, as well as the type of content and interactions that users are exposed to on these platforms.

Finally, collaborative self-management is relevant to conditions beyond depression. I believe it is important to explore this concept for other mental health needs and chronic illnesses. I advocate for deeply understanding collaboration not as separate from self-management, but as an integral aspect of the work of managing one's health. In my dissertation I built on the

observations of previous researchers regarding collaborative support activities and advanced a conceptualization of collaborative self-management that I plan to explore further in my own research, and I hope as well by others in the research community.

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# VITA

## Eleanor R. Burgess

### EDUCATION

Doctor of Philosophy in Media, Technology & Society at Northwestern University, September 2016 – present. Dissertation title: Collaborative Self-Management of Depression.

Master of Science in Technology Entrepreneurship (Distinction) at University College London, September 2015 – September 2016. Thesis title: Effectuation and Network Effect: Building Company Identity and Community. US-UK Fulbright Technology Award.

Bachelor of Arts in Communication Studies, Minor in Global Health Studies, Certificate in Integrated Marketing Communications at Northwestern University, September 2012 – June 2015.

### PUBLICATIONS

**Peer-reviewed publications**

1. Emily G. Lattie, **Eleanor R. Burgess**, David C. Mohr, Madhu C. Reddy. 2020. *Care Managers and Role Ambiguity: The Challenges of Supporting the Mental Health Needs of Patients with Chronic Conditions*. Computer Supported Cooperative Work (CSCW).
2. Jordan Eschler, **Eleanor R. Burgess**, Madhu C. Reddy, David C. Mohr. *Emergent Self-Regulation Practices in Technology and Social Media Use of Individuals Living with Depression*. In 2020 CHI Conference on Human Factors in Computing Systems Proceedings (CHI 2020). April 25–30, 2020, Honolulu, HI, USA. ACM Press.
3. **Eleanor R. Burgess**, Nathan Walter, Sandra J. Ball-Rokeach, Sheila T. Murphy. 2019. *Communication hotspots: How infrastructure shapes people's health*. Health Communication.
4. **Eleanor R. Burgess**, Kathryn E. Ringland, Jennifer Nicholas, Ashley Knapp, Jordan Eschler, David C. Mohr, Madhu C. Reddy. 2019. *"I think people are powerful": The sociality of individuals managing depression*. In Proceedings of the 2019 ACM Conference on Computer Supported Cooperative Work and Social Computing (CSCW '19). ACM Press.
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6. Renwen Zhang, **Eleanor R. Burgess**, Madhu C. Reddy, Nan E. Rothrock, Surabhi Bhatt, Luke V. Rasmussen, Zeeshan A. Butt, Justin B. Starren. 2019. *Provider perspectives on the integration of patient-reported outcomes in an electronic health record.* Journal of American Medical Informatics Association (JAMIA) Open.
7. **Eleanor R. Burgess** and Aaron Shaw. 2016. *Evaluating Open Collaboration Opportunities in the Fire Service with FireCrowd*. In Proceedings of the 12th International Symposium on Open Collaboration (OpenSym '16). ACM Press.