

Misfires, Missed Data, Misaligned Treatment: Disconnects in Collaborative Treatment of Eating Disorders

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Technology bears important relationships to our health and wellness and has been utilized over the past two decades as an aid to support both self-management goals as well as collaboration among treatment teams. However, when chronic illnesses such as eating disorders (ED) are managed outside of institutionalized care settings, designing effective technology to support collaboration in treatment necessitates that we understand the relationships between patients, clinicians, and support networks. We conducted in-depth, semi-structured, interviews with 9 ED patients and 10 clinicians to understand the ED journey through the lens of collaborative efforts, technology use, and potential detriments. Based on our analysis of these 19 interviews, we present novel findings on various underlying disconnects within the collaborative ED treatment process – disconnects among clinicians, between treatment foci, among preferences in tracking, within support networks, and in patients’ own identities. Our findings highlight how these various disconnects are concomitant with and gaps can stem from a lack of collaboration between different stakeholders in the ED journey. We also identify methods of facilitating collaboration in these disconnects through technological mediators.

CCS Concepts: • **Human-centered computing** → **Computer supported cooperative work**.

Additional Key Words and Phrases: Eating Disorder, Recovery, Treatment, Collaboration

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1 INTRODUCTION

Recovery from debilitating illnesses is not a solitary experience. Patient-centered care approaches [70] emphasize that “better care is provided *together*,” keeping the patient at the center of decision-making and by adopting a whole-person perspective. This approach considers the patient as an *active collaborator* within the treatment team, interacting with and facilitating communication among the various clinicians involved.

In the case of mental illnesses, in particular, a collaborative approach enhances communication of evaluative and ongoing therapeutic feedback, increases patients’ adherence to the treatment

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plan, helps reduce risk and frequency of crises, and facilitates navigating the varied and changing intentions and needs that may arise for a given patient [69]. For those with severe and persistent mental illness, such an approach can be critical in reducing the number of avoidable emergency room visits and in-patient stays [13]. Furthermore, by harnessing the social connections a patient may have with friends and family members, collaboration can also empower patients to fight the stigma around mental illnesses, and promote social reintegration and community inclusion [29].

Over the past two decades, technology has come to permeate these collaborative arrangements [42]. Within the Computer-Supported Cooperative Work and Social Computing (CSCW) area, a rich body of work has studied coordination of and communication among treatment teams in hospitals [10, 28, 95, 138], as well as how existing or new technology facilitates or hinders these practices [54, 64, 117]. As more individuals manage their chronic illnesses outside of in-patient settings [119], there is a critical need to engage with the patient in order to understand collaboration from their perspective and to unpack the interplay between their efforts and different stakeholders' in everyday illness management.

Eating disorders (EDs) present a prime case study in collaborative healthcare. These are complex conditions, with a variety of physical and psychological symptoms [65]. ED patients have the highest mortality rate of any mental illness [50], which makes identifying and implementing effective treatment crucial. EDs also have a long treatment trajectory, often referred to as a "journey" [100], due to the complex relationship between individuals' psychological and physical symptoms. It is not uncommon for those with EDs who have become underweight to reach weight restoration. Meaning, they are no longer underweight based on their body mass index, but the majority of patients never reaching full recovery, meaning the permanent removal of symptoms [118]. This journey is often highly individual as there are varying factors that contribute to the manifestation and maintenance of ED, (i.e., trauma, environment, body image, comorbidities, cognitive processes, and possible genetic factors). We aim to gain further insight into this treatment journey through the perspective of both patients and clinicians in order to further clarify the role of collaboration and technology in the ED recovery journey.

ED patients who live at an in-patient facility receive treatment from a team of clinicians that work in close coordination with one another [65]. However, the majority of an ED patient's recovery journey takes place outside of a clinical in-patient setting. For out-patient settings, the treatment team is most commonly made up of a therapist, dietitian, and primary care physician (PCP) [65, 91, 112, 114]. This team needs to coordinate a cohesive treatment plan for the ED patient in order to address the interwoven psychological and physical symptoms that an ED patient experiences. Collaboration also necessitates working with sometimes competing beliefs, values, and priorities between the ED patient and other stakeholders; power balancing between the patient and the clinician; navigating engagement strategies; maintaining consistency of care delivery; exercising relationship competencies; role blurring; and negotiating decision-making [69].

Technology-mediated self-disclosures [20, 36, 101], identity work [51, 133], support seeking [23], and recovery processes around EDs [24] have been explored in the CSCW literature. However, collaboration in ED treatment, involving heterogeneous teams of clinicians, patients, and support network members is less understood, especially in out-patient settings. This understanding is a critical and formative step that needs to precede the design of effective technological supports.

This paper addresses that gap by presenting a qualitative study, spanning eight months, on how collaboration already occurs in the treatment of ED. We draw on in-depth, semi-structured, interviews with a combination of both ED patients and clinicians about current practices, including what computing technologies they already utilize. In addition to replicating prior findings, inductive analysis of these interviews reveal novel results about underlying disconnects in this collaborative treatment process. Our analysis maps how these disconnects stem from an underlying tension

between the physical and the psychological symptoms of ED. This tension permeates numerous aspects of the collaborations in ED treatment, raising varied challenges in the process. Thus, we offer a two-fold contribution. First, it provides further insight into the unique challenges involved in a previously under-studied instance of healthcare collaboration. Second, it offers suggestions about designs that might better support, for all stakeholders, the collaborative nature of ED treatment.

2 RELATED WORK

2.1 Stakeholder Collaboration in Health Management

Over the years, a number of theories have been proposed to understand health behavior change and recovery journeys around illnesses, ranging from the Transtheoretical Model [109] to the Health Belief Model [121]. At the core of these theories is the notion of self-efficacy [9]—an individual’s impression of their own ability to perform a demanding or challenging task.

However, decision-making around one’s own health and wellness is *rarely* a strictly personal, solitary activity that happens in isolation in a patient’s life. More than four decades ago, George Engel advocated for a new paradigm of healthcare, noting that the “social” and the “psychological” should be given equal, if not more weight, than the biological domains in clinical practice [47]. In recent years, ecological perspectives on health management [88], as well as the growing patient-centered care movement [70], have both argued further that a patient’s decisions and intentions to manage their illness should be seen as a combination of mental work and embodied actions (or inaction) contingent on engagement with others. This is supported by empirical evidence that patients turn to others for help and support [46, 128]. These patients turn both to clinicians, who have the explicit role of offering information and advice, and to their support network [8].

However, despite the growing awareness, these collaborative aspects of managing illnesses are currently not well understood. It is critical to unpack the underpinnings of these collaborative relationships, when they support or hinder treatment, and how they influence health and wellness outcomes, especially in the case of chronic mental illnesses [69]. What makes this position more salient is that up to 70% of patients are diagnosed and treated for the most prevalent mental health conditions including anxiety, mood, and substance use disorders in out-patient settings [4]. Many of them, due to their underlying comorbidities, seek treatment from a panel of clinicians, rather than a single provider [13]. Mental disorders also require a long-term and systematic approach to foster access and continuity of care to achieve optimal management, beyond treating a patient’s acute symptoms. For instance, a patient with a DSM-5 diagnosis [7] of anorexia and a comorbid anxiety disorder may be consulting a psychiatrist for medication management, a therapist to receive cognitive behavioral therapy [96], and a social worker to help with reintegration and maintenance of overall functioning following a hospitalization episode. Further, the patient may be using any of the host of available mobile health apps for managing their symptoms on their own, outside of the treatment consultations. Finally, this patient may be drawing upon community resources, such as an online or offline peer support group, or reaching out to their family members and close friends to emotionally connect, given the prevailing stigma around mental illnesses.

In light of examples and experiences like those above, it has been identified in past work that collaborative care for debilitating mental illnesses such as eating disorder (ED) is important in continuing treatment and positive outcomes for ED patients [65, 91]. This notion of a necessity of collaborative and multidisciplinary care has been expanded by Gould and Hendrickson [62]. However, a primary emphasis in this research has been to study collaboration from the perspective of efficiency of healthcare delivery [72, 136], or to define policies to improve coordination of patient care through organizational leadership support, evidence-based provider decision-making, and clinical information systems as well as engaging patients in their care through self-management

support and linkages to community resources [60]. Less work has examined closely the manner in which this complex collaborative work is conducted.

To that end, our research is situated in the rich interpersonal ecosystem that engenders eating disorder (ED) patients' recovery and illness management journeys. Through qualitative interviews with ED patients and clinicians, we provide formative insights to understand the collaborations in this ecosystem, as well as the disconnects that strain these collaborative relationships.

2.2 Collaborative Healthcare Research in CSCW

Significant efforts in the CSCW community have examined relationships between technology and health. This research has included studies that seek to understand healthcare practices, technology use in in- and out-patients settings, as well as the (social and organizational) consequences of implementing new technology in healthcare settings—for extensive reviews, see Fitzpatrick and Ellingsen [54], Gross [64], Schmidt and Bannon [117].

The personal informatics paradigm [48, 68] has dominated research on individuals' efforts to manage their illnesses. Researchers have analyzed the use of self-tracking technologies in the mental health field [75], starting with identifying people's self-monitoring practices, attitudes, and needs [93], the disparities that exist amongst users [33, 49], the benefits and possible challenges associated with the use of these technologies [73, 82, 85, 87], the social and emotional experiences of health "datafication" [74, 134], and the potential to augment these technologies with just-in-time interventions and passive sensing [86] as well as to support hybrid models of care [22, 127]. In particular, Eysenbach et al. [49] highlighted individual patient experiences with self-tracking technologies varied greatly. Honing on this direction, Murnane et al. [94] found that the gathering of personal health data through self-tracking technologies, nonetheless, could be useful in continuously assessing the mental health and well-being of its users in varied ways. Others, though, have argued that, for these benefits to be realized, a multitude of complex design considerations would need to be acknowledged when developing such technologies [75]. For example, tracking mental health is challenging, in part because "there are fewer clear data correlates for mental than physical wellness" [75, p. 636]. Thus, in one study, students "tracked behaviors that relate to their mood or mental wellness" [75, p. 636] rather than tracking mood per se. These prior findings emphasize the need to further understand patient and clinician experiences with, and use of, such technologies, as is one of the goals of this paper.

However, as noted above, illness management is a collaborative activity. As Chamberlain et al. argue: "Much of the rhetoric surrounding [self-tracking] technologies focuses on the individual [...]: an individual collecting [and] using data by and for themselves, with the underlying assumption that this data will lead to insight, and by extension improved health behaviors" [21]. Only recently, Murnane et al. reported on instances of "co-tracking," wherein "a social relation would take over the capture of personal data" [94, p. 13]. Thus, despite the contributions of the personal informatics approach, the interpersonal or collaborative underpinning of this activity is less explored in the CSCW literature.

Broadly speaking, much prior collaborative health research in CSCW has been conducted primarily in hospital settings to understand patient-clinician communication [10, 28, 95, 138], thereafter designing technologies to improve this communication [90]. As Fitzpatrick and Ellingsen's review indicated, a large focus has further been on electronic health records (EHRs), on planning and scheduling, and on issues around telemedicine, telehealth, teleconferencing, and telecare [54, 83, 115]. Along these lines, Graetz et al. [63] identified that sharing patient health information helped clinicians to communicate more easily and to implement a unified treatment plan to which they all contributed their clinical expertise. Since EDs are a chronic illness that require coordinated

treatment from several clinical experts [38, 65], they offer an important setting in which to examine and study such collaborations.

Furthermore, due in part to CSCW's historical emphasis on the "workplace," prior studies of collaboration have often unpacked only the clinical practitioner's perspective in supporting collaboration within the treatment team [77, 106]. Given the shifting landscape of healthcare delivery, where more and more individuals are managing their illnesses outside of institutionalized care settings [119], some research has dealt with the home, the broader family network, or the community as settings of concerns [2, 3, 34, 98, 105]. Still, limited research has directly engaged with the patient as a collaborator in their own treatment [111]. Some of these examples include understanding patient perspectives on clinician treatment approaches [43], as well as patient perceptions of ED treatment more broadly [104]. These past studies have contributed to the greater understanding of best practices for clinician treatment in eating disorders [38]. Yet, due to the collaboration of clinicians, patients, and other stakeholders in ED recovery, the way in which these interactions and stakeholders impact one another needs to be better understood. By examining both patients' and clinicians' experiences of ED treatment, we contribute to the existing body of CSCW research that provides implications for how to design collaborative systems for health.

Finally, our work builds on recent interest in the CSCW community to understand the role of diverse stakeholders in managing illnesses (e.g., see [30, 31, 75, 137]). Notably, Murnane et al. [94] recently offered a model of "personal informatics in interpersonal contexts," providing formative qualitative insights on the role of nested circles of support in illness management among bipolar disorder patients. We believe that augmenting these ecological understandings by also including insights about collaborations between clinician team and patients, as is the goal of this paper, is critical to advance the interpersonal dimension of personal informatics. Eating disorders, due to the interdisciplinary, team-based nature of their treatment [62, 65, 91], present a prime case study to unpack the characteristics of and complexities in these collaborations.

3 METHODS

To obtain a deeper understanding of interactions and collaborations during the eating disorder (ED) journey, we conducted a series of semi-structured interviews with ED patients and clinicians. We used semi-structured interviews due to the individualized nature of EDs and the complexity involved in their treatment [113]. This method allowed us to gain greater detail about participants' individual experiences surrounding illness history, treatment, and recovery. It also enabled the exploration of unique facets of how clinicians approach each individual patient differently. By interviewing both patients and clinicians, we could explore how these two groups collaborate, and what role technology played, if at all, in their collaboration.

Interview questions covered topics relating to patients' illness history; treatment plan, including interactions with or among various clinicians; tracking methods, either those prescribed by clinicians or those used by patients; interactions with members of a patient's support network; and social media use, with a focus on content related to ED. These questions were asked with the purpose of exploring collaboration, technology use, and individual approaches to the ED journey. These interviews were conducted via teleconferencing software such as Skype or Zoom, with the exception of 2 clinicians interviews which were done in person. Interviews lasted between 30 to 60 minutes.

3.1 Recruitment Methods

We recruited patients and clinicians using a variety of channels over eight months in 2019 and 2020. Given the sensitive nature of the topic and the illness, we encountered some challenges in recruitment, due to which our recruitment channels included both offline and online means. We first reached out to patients through social media postings on a variety of ED recovery webpages

and social media groups. The postings sought individuals to participate in an interview study about how individuals with an ED track their condition and reflect on it. Clinicians were recruited by emails with similar language through [anonymized institution's] health services and the local [anonymized ED group] chapter.

Prior to conducting the interviews, we gained informed consent from each participant. For patients, we also collected contact information for their clinician. It was made clear to the patient that this information was to be used for risk mitigation, in case of an emergency during the interview, as well as to be used after the interview to invite the clinician to participate in the study. No clinicians ended up being interviewed through patient participant contacts, due again to the sensitive nature of the study.

Participants were required to be United States residents in order to better control for mental health treatment standards, which may vary between countries. Clinician participants had to be actively treating a patient with an ED in order to participate. Patient participants had to have a DSM-5 [7] defined diagnosis of an ED, anorexia/bulimia, or an ED not otherwise specified, have been receiving treatment for at least 6 months, were at least 15 years of age or older, were active daily on one or more social media sites (e.g., Facebook, Twitter, Instagram, Reddit, etc.), and if under 18 years of age needed signed parental/guardian permission. Patients having 6 months or more of experience in treatment would better understand treatment methods and their positive or negative experiences in undergoing treatment.

Initially, we sought to recruit the clinicians who were treating the patients we interviewed, so we requested the patients to provide their clinicians' contact information. Once contacted, these clinicians either did not return our requests or indicated that they were not interested in participating in the study. In one case, a clinician stated that they would need to bill the patient for any time they spent participating in our study. Thus, we modified our recruitment methods to recruit patients and clinicians separately, as described above.

3.2 Participants

In total, 21 patients and 17 clinicians responded that they were interested in the study. However, 11 of those patients were screened due to the study criteria above, resulting in 9 patient participants. For the patient sample, 8 identified their gender as female and 1 identified as male, with a mean age of 28 years. Similarly, 2 of the clinicians were screened and 5 could not follow up to schedule an interview, resulting in a total of 10 clinician participants. Of these, 4 were dietitians and 6 were therapists. All clinicians identified their gender as female. Table 1 summarizes statistics about our participant pool. The skew in terms of self-identified gender of the participants is consistent with the prevalence of ED among females and males – this condition manifests in females more frequently [122]. Similarly, the types of mental health clinicians represented in our clinician sample are more likely to be female [126].

Race and ethnicity data was not collected amongst our participants. Racial and ethnic minorities face greater mental health challenges due to existing systematic and structural disparities in healthcare access. However, ED is different; these disparities are less common among racially minoritized populations [55, 61]. Considering that race and ethnicity are likely to be less of a moderating or mediating variable, we did not collect this data. That said, demographic differences and collaboration in ED are an excellent direction for future research.

Table 1. Key demographics for each patient and clinician participant, including self-reported gender. Patient 2 declined to report their age (NR: not reported). Patients 3 and 4 were removed because they did not reside in the United States, and our IRB protocol did not allow for non-US residents. “Duration” indicates number of years since ED Diagnosis for a patient; “ED Pathology Started” indicates the age at which the particular patient was diagnosed with ED.

Patient #	Age	Gender	Duration	ED Pathology Started	Clinician #	Gender	Type	Experience
Patient 1	45 years	Female	17 years	Started at 28 years	Clinician 1	Female	Dietician	6 years
Patient 2	NR	Female	1 years	Started at >1 years	Clinician 2	Female	Dietician	11 years
Patient 5	33 years	Female	8 years	Started at 10 years	Clinician 3	Female	Dietician	6 years
Patient 6	23 years	Female	13 years	Started at >1 years	Clinician 4	Female	Therapist	12 years
Patient 7	25 years	Female	9 years	Started at 15 years	Clinician 5	Female	Therapist	11 years
Patient 8	18 years	Female	4 years	Started at 13 years	Clinician 6	Female	Therapist	18 years
Patient 9	30 years	Female	9 years	Started at 6 years	Clinician 7	Female	Therapist	9 years
Patient 10	21 years	Female	4 years	Started at 11 years	Clinician 8	Female	Dietician	5 years
Patient 11	29 years	Male	9 years	Started at 19 years	Clinician 9	Female	Therapist	15 years
					Clinician 10	Female	Therapist	9 years

We reached theoretical saturation [25, 59] after 5 to 7 patient interviews. That is, subsequent interviewees generally reiterated themes and patterns observed in the already collected data, and those interviews did not lead to drastic revisions of the themes or categories in the analysis¹.

3.3 Analysis

All interviews were audio recorded on a secure device and transcribed. Transcripts were initially generated using Temi’s² automated approach, then any transcription errors were corrected manually. Transcripts were then coded using an inductive analysis approach, drawing on constructivist grounded theory [25] and similar qualitative analysis methods [79]. The process began with reading the transcripts several times conducting line-by-line open coding. Then, through the implementation of comparative analyses of the open codes, axial codes were developed. This method of coding identified a wide range of trends in the data, and then determined meta themes in the more focused axial codes. While coding the interview transcripts, few direct contradictions arose in the data. It was more common for a participant to identify an individualized experience within their ED journey that was not shared by others than for participants’ experiences to contradict. To ensure an awareness and sensitivity to potentially relevant concepts, the research team reviewed the broad literature on EDs, ED treatment, and technology used in treatment in advance of the interviews. This prior literature was used to inform, but not to constrain, the coding process. The resulting codes, and the overarching themes that organize them, are discussed in the next section.

4 FINDINGS

The qualitative analysis described above resulted in five main themes related to the collaborative, team nature of ED recovery and treatment. For clarity, this section organizes these themes into two subsections. *Symptomatology and Treatment* discusses the patient’s psychological and physical experiences of ED, as well as various *treatment* approaches, including specialized treatment by a team of clinicians (i.e. therapist, dietitian, and primary care physician). This theme in the first subsection largely replicates findings from previous studies and demonstrates consistency in what

¹In some ways, this criterion more closely resembles what Dey [39] calls “theoretical sufficiency” and Nelson [97] calls “conceptual depth” (see also [116])

²<https://www.temi.com/>

we know about the ED experience [17] [35], especially those related to symptomatology and to treatment. Thus, this theme is described here briefly, with the purposes of setting the stage for the ensuing discussion of results.

The majority of this section then focuses on more novel findings about various underlying *Disconnects* that occurred throughout the collaborative treatment process. These disconnects pose serious challenges, but they also highlight important potential opportunities for design interventions. Although each of these themes occurred both in the patient interviews and in the clinician interviews, they sometimes did so to different degrees or in different ways. These differences and their implications are discussed following the first theme.

4.1 Symptomatology and Treatment

Though not the primary finding of our study, as it is confirmed by a multitude of past studies on ED, we identified a theme highlighting the symptomatology and treatment of EDs. EDs involve a complex array of symptoms, both psychological and physical *“Eating disorders look a lot of different ways and have a lot of different symptoms. Common ones for anorexia are going to be more of your restrictive eating and overexercise, which is a lot of what we see. But we do also see more [symptoms] related to bulimia, some bingeing and purging behaviors [...] and there’s lots of eating disorders that aren’t specifically specified”* (Clinician 1). Patients and clinicians also reported a high frequency of comorbid mental illnesses in patients [17]. For Patient 1, *“Most of the time my anxiety is tied to my eating disorder.”* That is, if a patient was struggling with their generalized anxiety, their ED symptomatology would also worsen, and vice versa.

Given these complexities in how symptoms can manifest, participants reported employing unique treatment plans that are *“tailored to [the patient] and what they’re presenting”* (Clinician 10). These treatment plans varied by the severity of the ED, by the patient’s current stage in their recovery journey, by the patient’s ability to adhere to the plan, and by the ability to see progress from them. One clinician described how they would respond to some of these variations.

“[I]f I’m seeing somebody for three months and the [ED] behavior is decreasing, then we’re on the right path, and the treatment plan will kind of change from there. Now, if I have somebody and I’ve been seeing them for a month and they just keep getting worse, again, the plan would change and I might either start seeing them more, or I might refer them to a high level of care to get stable and then they’d come back to me and we’ll start on coping skills. [...] [M]ost of my folks have trauma of some sort and that doesn’t really enter the treatment plan until all the medical and eating stuff is stable” (Clinician 9).

This example illustrates how one clinician may defer to other levels of treatment depending on the specific treatment needs of a given patient.

Patients’ treatment plans could also change on a more nuanced basis from session to session depending on variations in their symptoms, how well they were able to meet their goals in between sessions, or other factors. As the same clinician explained,

“wherever [the patient is] at, I meet them there. And you know, some days we would have planned on doing something like EMDR [Eye Movement Desensitization and Reprocessing] and they come in that day and I just say, well, are we doing EMDR today? And they’re like, ‘Nope, I had a whole lot of shit happen this weekend. I am not there. I can talk about other stuff.’ And I’m like, ‘okay.’ So you just kinda have to go with the flow and look where they’re at” (Clinician 9).

Such adaptations occur continually over long periods of time. Treatment for eating disorders is often a lengthy process, and it is uncommon for a patient to reach the stage of complete recovery.

In one clinical study, after 90 months (i.e., 7.5 years) of treatment, only 33% of participants with anorexia nervosa reached full recovery [35].

4.2 Disconnects

An optimal treatment plan and recovery journey requires significant coordination among all parties involved [65]. Clinicians with different specialties must coordinate their approaches to different aspects of an eating disorder³. Patients must acknowledge their condition and adhere to prescribed treatment plans. Patients' family members and friends must coordinate with clinicians to provide a broader environment and social connectedness conducive to recovery. The results above describe several instances of such coordination and collaboration among our participants.

At the same time, various disconnects emerged throughout these collaborative interactions. Our analysis identified disconnects within the treatment team as a driving force. These disconnects stemmed from a broader distinction between physical treatment and psychological treatment, which manifested in different clinicians' orientations toward tracking technology. Such distinctions were also made by patients' support network members, ultimately leading their actions to be less supportive, sometimes even detrimental. At the same time, these disconnects also influenced patients, often at the explicit encouragement of their clinicians, to perceive a dissociation between their own identity as an individual and their identity as an ED patient. The remainder of this subsection describes in more detail each of these disconnects and the relationships among them.

4.2.1 Isolated Clinicians within Treatment Teams. Our interviews revealed that there can often be a lack of communication within a patient's treatment team. Once a patient has been successfully diagnosed with an ED, they generally pursued treatment with consultation from a therapist, dietitian, and PCP (primary care physician). However, these three specialists rarely communicated with one another regarding the patient's progress or recovery status *"It was obviously different when I was in [in-patient] treatment itself. There were team meetings where they [clinicians] would talk about us. But that's different [now] because they [clinicians] are all in different places and not connected. They only talk if they really, really need to"* (Patient 10). It was common for patients to express that their clinicians acknowledged the importance of this communication, but communications among clinicians were either sparse or non-existent. For example, when Patient 6, who has been seeing their team of clinicians for ED treatment consistently for eight months, was asked if, and how, their clinicians communicate they said, *"Even though they both said that they would, I don't think they ever made contact."* Other patients indicated that their clinicians would only speak if it was absolutely necessary, which included scenarios such as needing to alter medication, requesting more frequent visits, or discussing issues with the patient's insurance coverage:

"I know they email back and forth in order for me to get additional sessions, the doctor had to approve them for my therapist. So my therapist had to kind of send an update of how I was doing and she recommended, you know, continuing" (Patient 2).

Ultimately, the patients reported often serving as an intermediary for communication among clinicians. As Patient 10 described, *"[The nutritionist] will take my weight sometimes to make sure everything is staying the same and if there's stuff that she has concerns about, she will ask me to talk to my doctor [PCP] about it"*. Even in the case of concerns about the patient's health status, the clinicians will utilize the patient as a means of communicating with one another instead of communicating directly.

In addition, this disconnect within the treatment team was seen to go as far back as before the ED diagnosis. It was common for a patient's PCP to have limited knowledge about identifying

³<http://www.nyeatingdisorders.org/pdf/AED%20Medical%20Management%20Guide%203rd%20Edition.pdf>

eating disorder symptomatology, thus delaying that patient from seeking clinical treatment for their eating disorder. For instance, Patient 5 said of their PCP, *“He’s not super knowledgeable about eating disorders, but he is non-judgmental [...] and gives me resources.”* Also, one therapist described a patient for whom the ED diagnosis could have easily been missed:

“She’s very sick. She’s purging at least five times a week, and that’s on a good week. All you need for, believe me, a diagnosis is one time a week. And fortunately all of her lab work came back looking okay, for blood pressure and everything. But, you know, if I had sent her to somebody that was not well-informed, they probably would’ve been like, ‘What are you doing?’ That’s like a real concern. Especially cause their lab work can change within a couple of hours.” (Clinician 9).

This under-identification by medical doctors was not seen to be out of ill-intent, but out of a lack of knowledge about the symptomatology and treatment of an eating disorder. As Clinician 4 explained, *“almost one-hundred percent of the time a medical doctor is involved in that initial screening process. A lot of times [patients] feel more comfortable going to their primary care”*. For these reasons, patients may not seek specialized treatment for their ED unless their PCP expresses a need.

This disconnect within the treatment team proved to be crucial. ED is a unique mental illness as the patient’s psychological recovery is directly linked to their physical recovery [65]. Thus, administering a cohesive and effective treatment plan would likely require close communication between specialists responsible for fostering psychological recovery and those focused on physical recovery. Initial diagnosis would similarly likely require that PCPs have information at their disposal. As described above, though, patients instead experienced what they perceived as a patchwork of disjointed treatments. This disconnect both stemmed from and reinforced a distinction between the physical and the psychological aspects of ED, a distinction that had reverberating effects throughout numerous aspects of the experiences our participants described.

4.2.2 Separating Physical and Psychological Dimensions. Despite the deeply intertwined relationship between psychological and physical aspects noted above [65], ED patients reported these two aspects were treated almost entirely independently of one another. For example, Patient 9 described how, *“therapy is basically [discussing] how I’m feeling about my body and about the weight that I’m supposed to be gaining [...] dietitian appointments are strictly talking about my meal plan.”* Due to this divided treatment approach, patients often report that their physical and psychological recovery are at different stages. It was fairly common for a patient to have distinctly different, and mostly unrelated, treatment plans for their physical and psychological recovery.

Relatedly, some patients or support network members would not recognize the patient’s need for help until these physical symptoms arose:

“I’ve had some [patients] who didn’t realize they had a problem until their hair started falling out and they thought everything was normal. I’ve had other [patients] who mentioned their roommates noticed them like throwing up in the bathroom. I think that the spotlight on the behavior kind of shakes a little light onto it” (Clinician 2).

These physical symptoms were concomitant with less visible psychological symptoms the patient had been experiencing related to an untreated ED.

When asked what they need to do outside of clinical visits for their recovery, patients placed greater emphasis on psychological aspects than on physical aspects for managing their ED. For example, one patient answered:

“Uh, eating food. Um let me think. I guess just working on expressing my feelings or that type of stuff. That was really difficult for me when I was really sick. I guess just like trying

to have some balance in life and not get too stressed. Working through stress and stuff like that. Sit with emotions and that type of stuff" (Patient 7).

Although "eating food" was mentioned first, the patient spent much more time talking about their psychological state. Some patients even expressed that, despite being fully weight restored at the time of our interview, they still had so much work to do on the psychological treatment that they did not foresee being fully recovered in the near future.

This disconnect between psychological and physical treatments is also displayed in progress checks from different areas of the treatment team. When these clinicians do communicate, they can reveal discrepancies in a patient's condition:

"Like, you know, I have students tell me, Oh, I'm eating all the time, three meals a day, I'm not running at all, anything like that. But then we might see the labs from primary care and they're like, well, their labs and EKG aren't reflecting that so that then, you know, it's worth a deeper dive to kind of like, okay, what's happening here? You know, why aren't these stories lining up?" (Clinician 2).

Such communication about different dimensions of recovery is also important because those with ED commonly believe that they are not as sick as clinicians say they are:

"I just feel like I'm better than I am. My therapist says there is a little bit of a delusion there. She says 'You think you're a lot better than you are,' but I feel that I'm better than I am because I'm not as bad as I was [...] I was in a treatment facility. And now like I've, I haven't weight restored, but I'm eating" (Patient 9).

Such experiences reveal how physical symptoms, such as eating and weight, and psychological symptoms, such as self perception, are complexly interconnected in practice.

4.2.3 Divergent Orientations toward Tracking. One manifestation of the underlying disconnect within the treatment team occurred in a myriad of different ideas around tracking. Significant prior work has explored how tracking technologies can facilitate the treatment of numerous health conditions [75, 82, 94]. Along these lines, participants provided us detailed descriptions about methods for tracking an ED, both technological and otherwise. However, differences emerged, both among different clinicians' approaches to tracking, as well as between how patients and clinicians experienced these tracking methods.

Clinicians most commonly used Recovery Record [129] for tracking. Initially created as a self-reflection tool, this app allows ED patients to track the foods that they eat, their emotional response to eating that meal, and whether they engaged in any disordered eating behaviors. Clinicians saw many perceived benefits of using Recovery Record:

"I have [almost 100% of my patients who are in active stage of working towards recovery] using Recovery Record. [...] [T]hat's my primary go-to in that space, because it gives me a really solid indication about not only what the eating disorder is doing and how much the self is influencing the behavior, you know, like where the power dynamic lies between the self and the eating disorder, but also a lot of the feelings of behaviors that go along with the food intake. [...] [T]hat's part of my expectation is that they're logging in, interacting on a daily, multiple times a day basis with me and/or their team around their food and food behavior" (Clinician 4).

Many of the dietitians we interviewed reported similar uses of, and benefits from Recovery Record, even though it was not originally intended to be used by clinicians in a treatment setting [129].

In contrast, most therapists and counselors reported rarely using Recovery Record with patients, with some not using any form of tracking at all. While they occasionally coordinated with dietitians

on meal plans and tracking applications, therapists often had apprehensions about ED patients' ED habits of obsessive meal and calorie tracking:

"[O]ne thing that I think is really interesting about people with eating disorders is like tracking and preoccupation with data and like following what they've been doing or not doing. So I think like that's one reason I don't love Recovery Record because I think sometimes clients can ruminate on what they put in there and start to become obsessed with tracking in a different way. And then it also brings up this perfectionism, like, am I doing it right? Am I doing the recovery right? Am I doing this right? Am I, you know, and so on. So I think that, you know, there was a lot of issues with tracking" (Clinician 6).

These apprehensions are borne out in empirical work [cf. 49]. Thus, instead of tracking, therapist's tended to focus on methods such as cognitive behavioral therapy (CBT), talk therapy, and eye movement desensitization and reprocessing (EMDR) in order to manage the patient's ED.

In contrast, patients often reported tracking their ED treatment through unprescribed methods. These alternatives were commonly more qualitative in nature, such as journaling or using the 'notes' application on a patient's phone. Patients used these unprescribed methods to track what they perceived as personally valuable to their ED treatment and recovery. As Patient 1 expressed:

"I wish there was something out there that helped you do more than just, like I call it data collection, where it's like having you list the foods you eat and having you list your feelings. Like I wished there was something out there that gave you something deeper to think about, like more reflective to think about. [In residential treatment], they give you these assignments and they're really thought provoking. I even go back and I read the things that I wrote back in 2012 and 2017 and some of them are helpful to even write again. Like write a letter to your body or, um, let your body write back to you. But if there's nobody telling me to do those things, I forget to do them. [...] So I guess I wish that there was more open ended and thought provoking tracking kind of things. I guess it's not really tracking, but to me it is because it still shows growth, you know, more like in the anecdotal sense than in the number sense" (Patient 1, emphasis added).

This example articulates the desire of many patients for tools that that focused less on weight or eating and more on expressing their private thoughts and feelings.

Similarly, clinicians also noted that they preferred more in-depth emotional tracking to capture *in situ* feelings and experiences, especially around meal times, as they happen:

"[Asking later] might get a watered down like, 'Oh yeah, I've went through it, it wasn't that bad.' But if you'd ask them in the moment it would have been a lot more intense. [...] There's real time feelings and emotion going on. I think it would be helpful [to capture that]." – Clinician 2

At the same time, though, these qualitative tracking methods had a highly personal nature. Thus, patients did not readily share them, either with clinicians or with support network members. One patient spoke about why she has only ever disclosed her journaling to her sister:

"I guess the other members of my support network are more focused on like what I'm doing in my day, like eating wise and stuff. And I think my sister's a little bit more interested in the emotional types stuff. She wants to be a counselor and stuff" (Patient 7).

As another patient put it:

"I keep it very secretive so no one knows what I'm doing. It's not something I want people to ask me about or know about, so it's just easier to keep it quiet" (Patient 6).

A few participants noted that they went as far as to keep their journals under a password lock in their cell-phones to maintain privacy.

Patients also described how such qualitative tracking facilitated *moments of triumph* in their treatment journeys. In these moments, a patient consciously acknowledges their own progress. The length of the treatment trajectory, often many years, makes it important to recognize progress in recovery, even if that progress seems small. Some such moments were specifically related to food consumption.

*"I realized the other day it used to be really hard for me to eat like a piece of toast. So that's something like, wow, I used to be totally scared of this and now I'm not. I went and got a piece of toast, I didn't even think anything of it. When I realized **I was in a different place now**, I'm somewhere I didn't even think I would, if it would ever be possible for me" (Patient 7). (emphasis added)*

In other instances, moments of triumph were associated with general activities, for example:

*"Going to the movies used to be a trauma trigger. I can do that now and it doesn't bother me. But if I go back and look at that list [in her journal] and think, wow, that was actually something that was really hard for me and now I am able to do it and it is easy. It just **gives me more momentum to want to get better** and not fall into the thinking of I'm never going to get better" (Patient 1, emphasis added).*

These moments of triumph illustrate how tracking goes beyond things like meal recording and mood journaling, e.g., via Recovery Record. Instead, patients report that this kind of affective reflection, acknowledging those small recovery wins, helps to motivate them in their recovery.

While clinicians also appreciated the value of using tracking to celebrate progress, they conceived of it less in terms of moments of triumph and more in terms of accomplishing goals. Most clinicians lamented how many tracking apps do not do a good enough job of encouraging and supporting patients in their milestones. These milestones often involved reducing certain behaviors, such as time rigidity (e.g., not being able to eat anything before noon) or food aversions (e.g., refusing to eat pasta or dessert) [1] [110]:

"And so like I will have a treatment plan item to work with them on challenging some of that rigidity around like specific times or like precisely what can be included. I would love to be able to input that into Recovery Record. Like we are working on challenging timing rigidity or something cause that is so common" (Clinician 4).

Completing these challenging activities were envisioned as earning an in-app reward: charts showing an upward trend, a congratulatory splash screen, or even "give the person a medal [...] you did something hard today" (Clinician 4).

Thus, we see significant differences among patients' and clinicians' orientations toward tracking. Patients' preferred tracking methods emphasized reflecting on their personal recovery journal, whereas clinicians' visions of alternatives were still couched in the affordances of existing tools. Questions also emerge surrounding whether a tracking tool for ED patients should be utilized as an individual reflective tool to maintain desired privacy, or whether it should serve as a platform to enhance dialogue between the patient and clinician. These various motivations and uses are not necessarily mutually exclusive. However, they belie fundamentally different orientations to tracking, differences stemming, in part, from the underlying disconnect between the psychological and the physical aspects of ED described above.

4.2.4 Social Support and Social Detriments. This disconnect between psychological treatment and physical treatment extended to support network members, as well. Support networks and their influence play an important role during a patient's recovery journey [12, 37, 65]. The support networks described by our participants were fairly heterogeneous. Clinician 2 explained that

“friends and family can be the best cheerleaders ever.” Patient 1 described the value of a certain support network member:

“[My friend] is good at making me laugh all the time and just making me feel like I’m not [Patient 1] with an eating disorder. Like I’m [Patient 1] and I’m funny and I’m fun to be with and we can do things and laugh and be silly and I won’t be judged” (Patient 1).

This lack of judgement was a quality patients often praised in support network members.

Many patients, though, stated that the most important member of their support network was actually another ED patient. Patient 5 described the importance of one friend in particular:

“[My friend] has had a lot of treatment and knows a lot of the skills and things like that. Her approach is completely different and very helpful. My family’s approach, they all have really good intentions with the way they approach trying to be supportive, but it is often a misfire because it just does not help” (Patient 5).

Many patients similarly described receiving from each other a non-judgmental affirmation and validation that family members, no matter the strength of their connection, could not provide.

At the same time, patients also identified a variety of ways that social interactions negatively impacted their recovery journeys. For instance, Patient 1 explained how *“two months into the marriage comments started happening towards me from my ex husband. Such as, ‘you look like a pork chop,’ ‘you’re putting weight on,’ and he knew I had bad body image from when I was younger.”* Clinician 5 described other examples of similarly unhelpful comments:

“typically [the support network members] are critical. Like it’s not happening fast enough. It’s not moving fast enough. [...] [P]arents and spouses just don’t know how to speak. And so they often sound condescending and were like really fueling [the patient]. Um, and it’s sort of like ‘just eat’ or ‘just eat more’ or like, ‘why are you eating that? Like that’s junk food.’ Like, you know, there’s like so much criticism in the process” (Clinician 5).

As suggested in the above excerpts from the data, a patient’s support network sometimes focused far more on the patient’s physical recovery than on their psychological recovery. Support network members would ensure that the patient was eating throughout the day and adhering to the meal plan established by their dietitian, e.g., *“My mom often makes dinner or she might help me make my lunch”* (Patient 7). However, they would not check in on the patient’s psychological well-being. One patient described how her mother would not talk to her about her recovery, but her mother would check on her weight in other ways:

“My mom will buy me a pair of shorts or a shirt. She’ll be like, I just got you this. But I’ve learned that that’s her way of telling like where my weight’s at. Like when I try something on and she can tell, oh, she’s this size. That’s how she kind of checks in” (Patient 5).

Clinicians described how, in such situations, *“support network members such as parents may be too ‘overbearing and controlling’ over the patient’s recovery to be truly supportive”* (Clinician 2). Although it shows support network members’ desire to help, clinicians said, this form of support is not effective as it does not facilitate the patient in recovering.

Patients perceived that this imbalance – that their support network focused more on physical dimensions and less on psychological ones – occurred in part because support network members felt they had more knowledge about the physical aspects of ED. This lack of communication surrounding the patient’s psychological recovery was also exacerbated by the sense of confidentiality surrounding what is discussed during a patient’s therapy session. Patients themselves seemed far less inclined to share details of their psychological recovery than their physical recovery.

Patients also described how different members of their support network were often disconnected from one another. For Patient 8, *“most of the members of my support network are kind of like split*

up. So it's like a little bit of my friends and then a little bit of my family and they don't really talk about it with each other." Support network members reportedly only communicated with one another if the patient was in a critical state where in-patient treatment was necessary. This lack of communication seemed to result in disjointed, uncoordinated support for the patient. More open communication and collaboration within the support network, patients suggested, could help alleviate this inconsistency.

This lack of open communication among support network members also extended to communication with clinicians. The clinicians we interviewed reported rarely communicating with members of a patient's support network. The most contact that the patients' support network members had with the patients' clinicians came either from a parent contacting a therapist or dietitian to discuss scheduling, or from the family all attending the same PCP. For example, *"Me, my mom, my sister and my stepdad, all go to the same doctor and have for the past 15 years"* (Patient 5). For young adult patients, clinicians did collaborate with parents on elements of the treatment:

"My mom sometimes interacts with them. Um, that's mostly like if I ask her like, can you talk to them to make sure I'm understanding something correctly or like I might just want her to come to an appointment cause I wanna like, make sure that they're understanding each other" (Patient 7).

However, there was rarely any discussion reported between the clinicians and support network members as to an adult patient's treatment plan, progress, or how to effectively support the patient. Furthermore, when support network members did obtain knowledge of current recovery steps and treatment plans by the treatment team, it was generally plans only dealing with physical symptoms.

4.2.5 Illness Versus Personal Identity. Finally, patients described experiencing a disconnect between their personal identity as an individual and illness identity as an ED patient⁴. This distinction is hinted at in the the above quote from Patient 1 describing a support network member *"making me feel like I'm not [Patient 1] with an eating disorder"* (Patient 1). It was made more explicit by another patient: *"I don't want to be profiled as someone with an eating disorder"* (Patient 7). Such desires often led patients to gravitate towards recovery affirmation quotes stating that one should not be defined by their ED, and patients expressed gaining comfort from those messages.

"I find quotes that have quick little statements, you know, whether it says I am enough or everybody's body deserves fuel, those kinds of things that appear on eating disorders sites. I feel those are really helpful and a lot of times I'll share them on my page or repost them from Instagram onto my Facebook page or even just save them into my photos on my phone so I have them" (Patient 1).

For our participants, this desire to be defined in terms other than their ED diagnosis stemmed largely from the stigma associated with ED, especially anorexia nervosa. For example, non-patients often believe that an individual with AN is choosing to experience the disorder and can change their behavior on their own [120]. The detachment of one's personal identity from one's identity as an ED patient can be seen as a strategy to mitigate experiencing such stigmas. Such detachment even occurred around certain orientations toward recovery. For example, *"I just don't feel like I'm like one of those obnoxious recovery girls. Yeah, my therapist tells me I need to be more like them, but I'm not like them"* (Patient 9). By not seeing herself as a *"recovery girl"*, Patient 9 could distance herself from the stigmas associated with such identities.

⁴This illness identity bears some similarities with disability identity [18, 40, 71], such as emphasizing self-worth or carrying social stigmas. However, for our participants, it lacked the affirmation of and pride in one's condition that is more common with disability identity, nor did participants highlight the role of their illness identity in political activism.

Such identity dissociation could also arise from the denial of illness that is experienced by many ED patients. It is common for those with anorexia (AN) to deny the existence of their disorder [131, 132], to actively work to conceal their condition from others' detection [131], and to remain in denial even after pursuing treatment (e.g., "At first I really didn't want to get help. I really didn't want to talk to anyone about this. I needed my husband to push me" – Patient 2). As a further example, Patient 7 described her experience of denying her illness and resisting against her mother's insistence on treatment to the point that they entered a battle for her medical guardianship.

"As part of the medical guardianship proceedings, I had to get assessed by [medical doctor] and [psychiatrist] at [ED treatment center]. I got assessed by them last August. They wrote some like 50 or 60 pages about my eating disorder. It was this massive document. When it came back to me, I was way too scared to read it. [...] I was way too scared to read that huge document for a long time. In early November, I just finally got the guts to read it and it was really weird. I read it, I'm like, oh my gosh, if this document were about someone else, I would think they should go to treatment. It was really weird how easy it was for me to think that after all that resistance" (Patient 7).

Such denial can provide patients a way to preserve one's identity. Denials can also enable patients to avoid confronting the underlying emotional and psychological issues that have caused their ED, effectively shutting them off from potential the assistance of clinicians or of their support network.

In many cases, patients took this distinction a step beyond identity. Patients commonly described their ED as a separate entity from themselves, with its own traits and thought processes. As one patient said, "Eating disorders tend to be sneaky and cheat and lie. When I think of myself through my eating disorder, I'm not a sneak or a liar or a cheat" (Patient 1). Many patients used similar language to differentiate their condition from themselves.

Clinicians noted how this disconnect in a patient's psychological state can also result in part from a tendency to overestimate their ability to achieve certain treatment goals. Clinician 6 explained this concept through one of her patients:

"[S]he had this goal that she thought she was going to be way beyond where she was. I mean she wouldn't even finish a full snack during the first session. It took like 45 minutes for her to eat like half of the yogurt. And so there was really a mismatch between what she believed she was able to do goal-wise and the reality of actually living with the disorder and the amount of distressing thoughts and things that were getting in the way. So I would say [that is one thing I] kind of encountered the most is like a not understanding about the severity and then sort of an unrealistic sense about, you know, where they are and how long it's going to take to really recover from an eating disorder" (Clinician 6).

This example shows how identity disconnects can raise issues during treatment, particularly with respect to expectations.

At the same time, clinicians seemed to support this disconnected identity model. Patients spoke about how their therapists would acknowledge and label disordered thought processes as part of the patient's "eating disorder brain" separate from the individual. Similarly, clinicians spoke about how they would encourage patients through sessions to "boss back" at their ED through activities such as monitored collaborative eating (Clinician 4):

"I often talk in terms of like an externalized disorder. So it's almost the eating disorder as a separate person in the room, if that makes sense. And so like, if I'm sitting with somebody and they're having breakfast and they haven't had breakfast because they've been like adhering to these restrictive food rules that they can't eat until noon. Um, so what is it like to boss back to the eating disorder right now? You know, and so like, we can talk about

that and encouraging an empowerment sort of oriented way, but also, um, I can help them challenge some of those distortions that are, um, limiting their behavior” (Clinician 4).

Dietitians and therapists used this kind of disconnection from the distinct ED entity to discourage patients from giving into these “eating disorder thoughts.” Such thoughts, patients were told, do not reflect what is truly best for the patient physically and psychologically, nor do they reflect who the patient truly is.

These disconnects, between a patient’s personal identity and a separate ED identity, both align with and build on prior findings. ED patients, especially those with AN, often strongly identify with their illness as an integral part of their identity [123, 132]. ED patients, particularly with AN, often abandon their pre-ED identities and become consumed by their new ED identity [52]. Our findings help elucidate how patients and clinicians collaboratively work to dissociate the patient’s illness identity from their personal identity. At the same time, these findings also highlight some of the complex challenges that emerge in fostering and maintaining these disconnected identities.

5 DISCUSSION

Through our qualitative interview-based study we identified a complex array of disconnects within an ED patient’s treatment journey. These disconnects spanned a variety of aspects of the patient’s treatment such as disconnects in tracking preferences (with clinicians having variations in their utilization of tracking tools as well as patients and clinicians having different preferences in type of data collected), clinicians (with clinicians not consistently interacting with one another and using the patient to interact), physical and psychology treatment (stemming and fostered by the disconnects in the treatment team), identity (between illness and personal identity), and support network (with disconnects within the support network as well as the support network from the patients’ clinicians). We also uncovered many correlations in these disconnects as none of them happened in isolation from another.

This discussion first compares and contrasts our findings about these disconnects with results from prior work. It then offers some suggestions of how these findings could be applied to inform designing technology supports for improved collaboration.

5.1 Comparing Disconnects in ED Recovery with Prior Work

In line with prior advice [62, 65, 91], treatment teams in our study were comprised of clinicians with heterogeneous specialties. At the same time, we also found limited communication and coordination among these diverse clinicians. Dejesse and Zelman [38] found that a similar lack of communication between nutritionists and other mental health providers led to different clinicians adopting clashing treatment strategies. In our study, though, despite limited apparent communication, the only evidence of such conflicts was in missed diagnoses, e.g., where a PCP might not be familiar enough with ED symptoms to identify the condition in a patient.

Our findings on tracking also expand upon prior work. For example, both Eysenbach et al. [49] and Cordeiro et al. [33] found that some ED patients reported that technologies such as Recovery Record were helpful. In contrast, none of the patients among our participants were particularly enthusiastic about tracking apps. We also build on this prior work by finding that clinicians have mixed preferences about tracking, with dietitians finding it more useful than therapists.

Among our participants, we found little evidence of the disordered tracking Kelley et al. [75] described, in which users obsessively track weight or calorie intake. This difference was somewhat surprising, since Eikey and Reddy [41] similarly found that use of weight loss apps tended to exacerbate EDs. This difference may arise from the fact that all patients in our study were undergoing active treatment, and clinicians explicitly told patients not to use such tracking apps.

In terms of what to track, our findings build on prior work in two ways. First, similar to prior studies focused on patients [75], we find that therapists also perceive limited utility in such mood tracking applications. Thus, tracking mood directly is likely less useful, both for patients and for clinicians. Second, our findings also provide insights into the kinds of tracking that ED patients, and possibly some clinicians, might find more valuable. As described, patients thrived on tracking approaches that facilitated “moments of triumph,” opportunities to reflect on and appreciate the magnitude of their own progress in their recovery journey. While prior technologies for supporting reflection often hinge on personal diaries [15, 57, 84, 92, 107], such approaches are less common in technologies designed for tracking ED treatment and recovery. Furthermore, reflective diaries are rarely collaborative [see 19, for an exception]. Indeed, our findings suggested that patients were hesitant to share their reflective self-tracking with anyone, neither with their clinicians nor with close members of their support network. Thus, while potentially beneficial for an individual patient, technologies designed around reflective diary keeping may have limited utility in assisting collaboration.

Our results also reinforce prior findings about support networks, such as the importance of a non-judgement support network, mixed quality of support from family members, and finding support from other patients with a similar diagnosis [94]. Also, our findings similarly indicate that support network members focused solely on weight gain, rather than the patient’s overall health, as a measure of progress [37], and that dysfunction among family members led to differing perspectives on ED that hindered progress [67]. Although our participants did not explicitly mention clashes between different family members, they did acknowledge that support networks were not always entirely supportive.

We did not, however, find evidence of “co-tracking” [94]. This difference may arise from differences between bipolar disorder, on which Murnane et al. [94] focused, and ED. For example, bipolar patients often rely heavily on accurate and complete records, the symptoms of bipolar disorder in particular interfered with a patient’s self-tracking, and tracking can actually provide valuable stability for bipolar patients [94]. In contrast, self-tracking can exacerbate ED symptoms, as noted by clinicians in our study and in prior work [41, 75]. This lack of co-tracking may also stem from support network members’ focus on the physical dimensions of ED (eating, weight, etc.). Again, our patient participants found tracking these aspects less useful in supporting their recovery. Future work would benefit from exploring the ways that specific mental health conditions or symptomatology may relate with orientations toward, and implications of, (self-)tracking.

Finally, identity reconstruction was an important but fraught component of treatment for our participants. Our findings provide further evidence about how tracking that emphasizes data collection can alter perceptions of one’s self and one’s identity [74, 81, 134]. Furthermore, ED patients often do this identity reconstruction work through interaction with other ED patients [51, 89]. Indeed, the most important support network members for many of our participants were other ED patients. Thus, there may be an untapped potential to design systems that focus on such patient-patient collaboration, in particular to support the identity work so crucial to ED recovery. This line of reasoning highlights some of this paper’s implications for designing to facilitate collaboration in ED treatment, a point we turn to next.

5.2 Designing for Communication and Collaboration in the Midst of Disconnects

Our primary findings around the importance of communication and collaboration in supporting the ED journey both resonate with and build upon significant prior work studying collaboration in medical settings [54]. This subsection considers how prior design recommendations and interventions might apply to technologies for supporting communication within different stakeholder groups: among clinicians, between clinicians and patients, and among heterogeneous support

networks. For each, this subsection also offers suggestions on how prior technology designs might be adapted or extended to meet the disconnects that this study identified within ED treatment.

5.2.1 Supporting Collaboration Between Clinicians. As noted above, significant proportions of prior work studying medical collaboration have focused on clinical, especially hospital, settings [54]. However, approaches from those settings may not transfer to ED treatment. For example, combining digital records with other, sometimes paper-based records [26, 53, 125] may be less effective when each clinicians work at different practices in entirely different physical locations from one another. Similarly, strategies for supporting information sharing among nurses during a shift change [124] or between elders and care workers in assisted living [99] often rely on situated aspects of the physical environment and temporal routines. Even prior studies of ad hoc, loosely formed teams [e.g., 78] have found significant use of a shared physical space to be crucial. Thus, design strategies and recommendations from such work are unlikely to facilitate information sharing among various clinicians treating a given ED patient.

Instead, it may be more advantageous to draw on studies of sharing medical information across organizations. For example, Winthereik and Vikkelsø [135] found that hospital discharge letters were often supplemented with multi-color annotations to help guide a patient's primary care physician. However, our results indicated no such coordination when an ED patient moved from an in-patient facility to out-patient treatment. Coordination among ED clinicians could also be seen as similar to the sharing and standardization of records across multiple organizations [44, 45]. Implementing such centralized systems could be helpful in coordinating the work of diverse clinicians treating the same ED patient. Furthermore, differences we identified in clinicians' preferences around tracking would suggest that such processes of standardization would be quite important.

At the same time, patients' accounts notwithstanding, the importance of a team approach to treating ED [65] makes it likely that these clinicians do indeed communicate to some extent. Beyond simply sharing information, future work should explore designing such communication technologies to facilitate developing a consistent narrative for a patient. Doing so would mean coordinating not only on the patient's current status and treatment plan, but also on where each patient currently sees herself or himself in their own recovery journey. This latter point emphasizes the importance of facilitating collaboration between clinicians and patients, to which we turn next.

5.2.2 Supporting Collaboration Between Patients and Clinicians. In terms of supporting collaboration between clinicians and patients, the most salient possibilities pertain to addressing differences in preferences about tracking. Our results suggest that tracking technologies would benefit from including different types of health data, both quantitative (e.g., food recording) and qualitative (e.g., moments of triumph). While these qualitative, affective dimensions are present for patients with primarily physical conditions, e.g., irritable bowel syndrome [31], they were more prominent for our ED patients. Furthermore, our results highlight how providing patients nuanced control over sharing such information with various clinicians could aid in providing a more holistic view on the multifaceted nature of a patient's recovery progress.

For example, the negative side effects of self-tracking for ED patients [41, 75] could be avoided by emphasizing emotional state, especially moments of triumph. The details of such moments could be retained only for the patient, while sharing only the timing of these moments with clinicians. Since such identifiable moments of triumph in a patient's recovery were important, both as indicators of a patient's treatment progress and in motivating the patient to continue with recovery efforts. Sharing only the timing of these moments would provide clinicians a more holistic view simultaneously providing patients gain more immediate, tangible feedback and recognition of their progress. Indeed, combining such moments of triumph with more quantitative data can facilitate observational learning, which can lead to more motivation towards treatment [32]. Such

designs so may also introduce the possibility for collaborative reflection [108] between the patients and their clinicians.

The disconnect we found in the patient's personal and illness identity indicates that it is important for patients starting out in their treatment process to feel accepted and not stigmatized for seeking treatment. One strategy for addressing such issues involves patient journaling. The utility of such journaling can be noted in the psychology literature on expressive writing, which suggests that venting out negative emotions and confronting inhibited thoughts as self-disclosures, beyond the dyadic clinician-patient setting, can have therapeutic benefits [103]. Moreover, giving an experience structure and meaning is known to make it more manageable and facilitate a sense of resolution [102]. Our results suggest opportunities for making journaling a collaborative activity between patients and clinicians. In its simplest form, patients could share and socially interact with the clinician from time to time. However, the power dynamics of the patient-clinician relationship differ from other explorations of collaborative diary keeping [19]. Thus, the design should focus on empowering patients to be in control both of the logging and the sharing.

Taken together, supporting collaboration between ED patients and clinicians through technology means brings up the question of how technology mediates and impacts their therapeutic relationship [80]. Prior work notes that technology in mental health is more effective when prescribed by the clinician to the patient [130]. However, a variety of tensions around use and applicability of mental health technologies in clinical context have surfaced in recent years [6]. Often times, psychiatrists realize the potential for mental health tools to offer novel adjunctive monitoring and support services for some patients, but they also wonder about the legal ramifications of using or recommending them in clinical care, especially when the tools collect personal health data [5]. Therefore, the design implications we stated above will need to be complemented with examinations of what could be appropriate legal and regulatory frameworks with which their use at the point of care might be legitimized.

5.2.3 Supporting Collaboration Between Support Networks and Other Heterogeneous Groups. Finally, the most challenging disconnects occurred around interactions with support network members. In contrast to prior studies of informal caregivers [27, 90], the support network members in our study rarely communicated with one another or with the patient about the patient's ED recovery. As noted above, this lack of communication resulted in less cohesive support, with support network members engaging in a variety of checking behaviors to assess the patient's progress without actually talking to either the patient or other support network members. One could envision designing various communication technologies to support collaboration and coordination among these support network members, as suggested in prior work [27, 90]. Such designs would need to help support network members move beyond their emphasis on physical recovery, as noted in the results above, to engage equally with the patient's mental and emotional recovery. Put differently, support network technologies for ED treatment need to support equally the emotions of patients and the emotional labor those support network members perform [27, 76, 90].

In order for such designs to be beneficial, attention should also be paid to facilitating increased communication between support network members and the ED patient's clinician. Doing so could help increase support network knowledge about EDs and how to play their role in the patient's recovery effectively, a point our participants noted was lacking among their support networks. However, the benefits of such communication go beyond only developing skills or information exchange. We suggest that, in the case of ED, technologies supporting communication among support networks and clinicians be designed to reflect the multi-dimensional nature of the condition. That is, just as ED recovery is a journey for the patient, it may also be conceived of, and designed for, as a journey for support network members, too.

Indeed, our findings above highlighted that the single most important member of a patient's support network was often another ED patient. In this way, ED support networks may be less like caregiver groups [27, 90] and more like support groups among patients [16, 56, 66]. Such a perspective challenges stereotypes about support networks, suggesting that technologies to support ED treatment may need to be designed flexibly with respect to the specific roles and relationships that any given user enacts at a particular time [11, 14]. It also reemphasizes the central importance of such technologies being designed with consideration around the emotional labor involved in these activities [27, 76, 90].

Finally, similar to the legal complexities around supporting patient-clinician collaborations, noted in Section 5.2.2, legal aspects will need to be considered here as well. From the perspective of the Health Insurance Portability and Accountability Act (HIPAA), support network members constitute a third party in a patient's treatment. HIPAA applies if a provider (clinician) were to share data and treatment information with a patient's support network member. This sharing is allowed under HIPAA only if the patient does not oppose this sharing, or tells the provider that it can do so. However, HIPAA does not prevent a patient from sharing their own information at their own will. Given the complex, sometimes tense relationships our study identified between ED patients and members of their support network, technologies that involve support network members will need to be designed with thoughtful care, both toward legal considerations such as HIPAA and the interpersonal relationships governed by those legal considerations.

6 LIMITATIONS AND FUTURE RESEARCH

We acknowledge some limitations of our study, their potential effects on our results, and opportunities for future research to alleviate these concerns. Due to the sensitive nature of discussing ED treatment and recovery, we had a low number of patient and clinician (total $N = 19$) participants for our interviews. Even though this was a smaller sample size than we initially anticipated recruiting, we still managed to reach the point of theoretical saturation from our interviews. Moreover, ideally, the clinician and patient participants would be connected: that is, we would interview an ED patient and that same patient's clinician. Interviewing these individuals in connected pairs would allow us to fill in different pieces of the process that may not have been expressed by one sole participant. However, given the sensitivity of the illness across target groups, there was apprehension to provide information to close this gap. Despite this, we still understood the different pieces from patient and clinician perspectives without the connection.

Additionally, we recognize the limitation of only interviewing clinicians who were therapists, counselors, or dietitians. Not including certain clinicians, such as psychiatrists or PCPs, in our interviews may have limited our results, as these stakeholders' perceptions were not included in our findings. Future research could include investigating the disconnects unravelled in this paper within these clinical populations our study did not address (e.g., PCPs and psychiatrists).

Next, though we planned to recruit support network members of the patients we interviewed, we found that it was common for the support network member that patients identified as most important to their recovery to also be other ED patients. We concluded that utilizing other ED patients as our support network sample presented a multitude of complications to our study that we did not initially anticipate when designing the study. The added intricacy of primary support network members also being ED patients adds a layer of complexity that should be addressed, as ED patient support network members may have differing insights into these disconnects compared to a non-patient support network member. This trend of support network members also being ED patients would need to be addressed in future research. Furthermore, it would be beneficial for future work on this topic to gather more information from other support network members involved in the treatment process. Support network members would be able to provide additional

insights and perspectives into the ED journey and any relevant disconnects not apparent in the collaborations we explored in this paper.

We finally note that mental illnesses, including ED, are heterogeneous experiences [58], with different individuals requiring different types of treatment and intervention. Future research can examine how the disconnects relate to patients' socio-demographic attributes such as race, ethnicity, gender identity, or living situation, including identifying those disconnects that may be amplified more in certain subgroups than in others.

7 CONCLUSION

Eating disorders (ED) require complex collaborative treatment that incorporates both clinicians and members of patients' support networks. However, prior research provides little understanding of the challenges of ED differ from other settings of medical collaboration. Through a series of interviews with eating disorder (ED) patients and clinicians spread over eight months, this paper provides insights into the multitude of disconnects that exist within the eating disorder journey. These disconnects occur among clinicians, between the physical and psychological symptoms of ED, between clinicians' and patients' orientations toward tracking technologies, between clinical treatment strategies and actions of close friends or family members, and finally within the ED patients themselves between their identity as an ED patient and their own personal identity. The paper also considers how prior design recommendations or interventions from prior work may, or in some cases may not, apply well to the case of ED treatment.

On the one hand, we hope that these findings can further influence investigations and solutions to help address these disconnects, improve collaboration between stakeholders, and promote a stronger, more efficient ED treatment process. At the same time, it is unlikely that the kinds of disconnects identified in this study can be resolved entirely, either by technology alone or by technology in concert with other interventions. Thus, we also suggest that designers consider ways to help patients, their clinicians, and their support networks collaborate despite the presence of these disconnects. Finally, we suggest it will be crucial that potential technological designs be shared with and iteratively co-designed with the patients, clinicians, and other stakeholders. Such a strategy is most likely to improve patients' experiences and the experiences of others throughout a patient's ED journey.

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