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Discovering a “sense of community”: patient experiences of connection in intentionally remote eating disorder care

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Abstract

Background While some findings indicate high levels of patient satisfaction with remote eating disorder treatment, others reflect feelings of disconnection due to unique telehealth treatment challenges. The COVID-19 pandemic presented circumstances that likely impacted the findings established thus far. As such, the present study sought to understand patient experiences of connection in an intentionally remote eating disorder treatment program, specifically in a context outside of pandemic transition.

Methods A secondary analysis of de-identified qualitative data previously obtained for quality improvement purposes via a client satisfaction survey was conducted. Adult patient responses ($N=38$) were analyzed via reflexive thematic analysis within a critical realist framework.

Results Four themes were generated from the data: (1) Embracing one’s humanity paves the way for connection, (2) Discovering a “sense of community” in remote care, (3) “They made me feel I was worth recovering”: connection as a vehicle for healing, and (4) Aligning expectations and reality: reconceptualizing the journey to connection in remote eating disorder care.

Conclusions Overall, findings suggest that it is possible for patients to form strong, impactful connections in remote treatment. Importantly, patient perspectives indicated that there were shifts in how these connections were experienced as a result of the remote care environment (e.g., how support could be provided and by whom). Considerations unique to remote care (e.g., offering training to improve clients’ comfort with technology) may be important to fostering connection, thereby contributing to improved patient experiences and treatment outcomes.

Plain English summary

This study investigated patient experiences of connection in remote eating disorder treatment using satisfaction survey data. Patients reported forming strong interpersonal connections that were deeply impactful to their recovery, emphasizing the importance of feeling understood, accepted, and cared for in building these connections. However, they noted some differences in how these connections were experienced as compared to in-person settings (e.g., how support could be provided and by whom), indicating a need for adaptations in

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remote care (e.g., training on how to use technology). These lived experience perspectives can help to inform the ongoing implementation of remote eating disorder treatment to improve patient care.

Keywords Adult, Connection, Eating disorder, Technology, Telehealth

Background

Eating disorders (EDs) are an urgent public health concern, causing considerable medical and psychosocial impairment as well as substantial cost to society [1–3]. Yet, numerous barriers to accessing ED treatment persist, including lack of time [4] or flexibility [5] and geographic location [6]. Although likely to be related to complex and inter-related reasons, only about 20% of individuals with EDs receive treatment [7], representing a concerning gap in care.

Technology-enabled, remote treatment, also often referred to as virtual treatment or treatment delivered via telehealth, demonstrates promise for reducing some of the aforementioned barriers (e.g., geographic location) and expanding access to care [8]. As a result of the COVID-19 pandemic, use of telehealth to provide ED treatment has surged. Preliminary research suggests comparable outcomes across remote and in-person settings [9–11] and indicates that remote treatment has improved access by increasing flexibility and convenience, reducing travel time and expenses, and minimizing time away from other responsibilities [12–14]. However, the abrupt shift to telehealth prompted by COVID-19 also created circumstances that likely affected patients' experiences in remote treatment, including a lack of healthcare provider experience and training, frequent technological challenges, and exacerbated loneliness due to social distancing [15–18].

Accordingly, current evidence is mixed regarding patient experiences in remote ED care. Some quantitative findings indicate high satisfaction and quality ratings while others demonstrate a patient preference for in-person treatment [14, 19–22]. Qualitative research provides a useful avenue to explore in a more nuanced manner what might account for these discrepancies. While qualitative findings cite advantages to remote treatment including increased availability of care team members (CTMs), new opportunities for involving loved ones in care, and enhanced translatability to life after treatment [12–14], they also reveal patient feelings of disconnection due to unique telehealth challenges, perhaps in part because of the aforementioned pandemic conditions. Specifically, these challenges include disruptions to the therapeutic relationship, feelings of isolation, barriers to traditional mechanisms of support, lack of physical presence, technology complications, and privacy concerns [12–14, 23]. Furthermore, participants in prior studies noted it felt strange when elements of face-to-face treatment were directly replicated for remote care (e.g.,

difficulty conducting written or drawing tasks, discomfort with seeing people's faces close-up) and identified a need for adaptation [14]. Indeed, participants reported feeling as though creative approaches may be needed to establish and solidify bonds in this environment [12, 14]. Thus, the increased accessibility offered by remote treatment may not inherently confer enhanced connection.

Connection with others, including relationships with providers, peers, and external support systems, may be important to patient experiences in ED treatment. For example, therapeutic relationships with providers have long been established as central to successful outcomes in mental health treatment [24–27]. Given evidence that interpersonal problems are associated with ED risk and predict poorer treatment outcomes, relational aspects of treatment may be particularly important for ED populations [28–30]. While quantitative studies of the therapeutic relationship in ED treatment present a complex picture, with some pointing to an association with outcomes [31, 32], qualitative studies consistently emphasize rapport as a significant factor in patients' treatment experiences [33]. Beyond relationships with providers, research has also supported the importance of other connections in ED treatment, including support and camaraderie among peers [33] as well as the influence of external support systems on the recovery process [34]. Since disconnection has emerged as a potential issue in prior studies of remote ED care, explicitly exploring connection in this environment is an essential step towards improving outcomes.

In sum, remote ED treatment presents an opportunity to reduce barriers to care. However, current findings are inconclusive regarding patient experiences in telehealth settings. Given the role of connections, broadly defined, in ED treatment experiences and outcomes, further investigation is necessary to understand experiences of connection in remote ED treatment, specifically in programs designed to be delivered remotely (i.e., intentionally remote) rather than those forced to shift online due to COVID-19. Thus, the aim of the present study was to qualitatively explore patient experiences of connection in a technology-enabled, intentionally remote ED treatment program within a context outside of pandemic transition. To address this aim, we sought to answer the following two research questions: (1) How do patients experience connection with others (i.e., providers, peers, external support systems)? (2) How does remote care delivery affect patients' experiences of connection?

Methods

Study context

The present study involved a secondary qualitative analysis of de-identified survey data obtained for quality improvement purposes at Within Health (also referred to as Within). Launched in June 2021, Within offers technology-enabled, intentionally remote intensive outpatient and partial hospitalization ED treatment programs for patients aged 13+ of all identities and ED diagnoses. Grounded in a milieu-based approach, Within's treatment emphasizes fostering a therapeutic environment, structured yet flexible programming, personalized support, and real-world growth opportunities [35] while prioritizing common therapeutic factors including building authentic relationships and instilling hope, which are crucial for healing and positive outcomes [27]. The program and its affiliated app include components developed to facilitate connection among patients and providers (e.g., a 'support button' and community 'living room' offering off-hours support).

All treatment services are delivered via telehealth by way of a HIPAA-compliant video conferencing platform embedded in a mobile application with weights and vital signs (e.g., blood pressure, heart rate) being remotely monitored by integrated devices provided to patients. The use of these technologies enables fully "in-home" care, with no in-person components requiring patients to travel to a physical treatment facility. However, given the medical complexity of many ED patients, Within staff collaborate closely with patients' local medical providers to obtain labs and medical tests, as is common practice

for in-person treatment at this level of care. Patients work with a multidisciplinary team of professionals, including a psychotherapist, registered dietitian, registered nurse, psychiatric provider, and clinical support staff (e.g., care partner, food specialist). Utilizing an integrative treatment model, these providers blend research-supported psychotherapies (e.g., Cognitive Behavioral Therapy, Dialectical Behavior Therapy, and Acceptance and Commitment Therapy) with experiential modalities (e.g., art therapy, movement), psychoeducational and supportive interventions, and other approaches to develop individualized, targeted treatment plans based on patients' unique preferences, characteristics, and circumstances. Treatment components include individual sessions with providers, couples and family work, group therapy, and meal support, as detailed in supplementary Table S1.

Responses to a client satisfaction survey administered upon discharge were utilized. The survey included 16 open-ended questions (see Table 1) eliciting free-text responses concerning patients' experiences in the program. Questions gathered feedback pertaining to patient experiences with the treatment program as a whole, their relationships with individual CTMs, and the remote care experience. A total of 59 adult patient survey responses were received from October 2022 (i.e., when the current version launched) through September 2023 (i.e., when the present study began). For reference, this timeframe occurred over one year into Within's program delivery and outside the peak pandemic period in the U.S. Of those 59 responses, only those collected from patients who agreed prior to completing the survey to have their responses used for external purposes (e.g., education, advertising; $N=38$) were included for analysis, representing 64% of respondents. Of note, patients who did not consent to their data being used for these purposes were excluded due to ethical concerns as this was considered an indicator of their potential discomfort with the publication of their individual written responses. While this could introduce bias, consenters and non-consenters did not significantly differ in their quantitative satisfaction ratings or likelihood of recommending the program, thus providing some reassurance regarding the potential skew of the data. In addition, principles of information power, including the study aim, sample specificity, theoretical background, quality of responses, and analytic strategy, were used to determine that the data held sufficient power to meet the study aim and address the research questions [36].

As this study contained retrospective data analysis only and survey responses were already de-identified, the study was deemed exempt by the Biomedical Research Alliance of New York (BRANY) Institutional Review Board, waiving requirements for research consent from participants. Due to the anonymous nature of the survey,

Table 1 Free-text response client satisfaction survey questions

Survey Questions

How has the Within Program impacted your eating disorder recovery journey?
How can Within Health better serve individuals receiving eating disorder treatment?
What do you consider to be the benefit of in-home care?
What do you see as the downside of in-home care?
How can we improve on in-home care?
How can the app work better for you?
Other feedback regarding your therapist at Within Health:
Other feedback regarding your dietitian at Within Health:
Other feedback regarding your food specialist and meal services at Within Health:
Other feedback regarding your nurse at Within Health:
Other feedback regarding your psychiatric provider at Within Health:
Other feedback regarding your care partner at Within Health:
Other feedback regarding group therapy at Within Health:
If you have received in-person meal support how does this compare to virtual meals at Within?
Other feedback regarding your meal support experience at Within Health:
Is there any other feedback you would like to give us?

demographic information and sample characteristics were not available for report.

Analysis

We analyzed patient responses via Braun and Clarke's reflexive thematic analysis (TA) [37, 38], a school of TA that conceptualizes meaning as contextual and partial, and emphasizes the researcher's active role in the analytic process [39]. This approach was well-suited for our aim of understanding patient experiences of connection in remote eating disorder treatment, as it allowed us to engage deeply with the individualized and context-specific ways participants understood these connections. The emphasis on reflexivity enabled us to critically reflect on how our positionality shaped our unique interpretations of these relational dynamics. Additionally, we chose to conduct our analysis within a critical realist framework, which presumes both the existence of a "reality" and acknowledges that our experience and understanding of this reality are shaped by our individual perspectives and social contexts [40]. By recognizing that our knowledge and experiences are constructed through

interpretation, critical realism allowed us to consider our participants' diverse perspectives, influenced by their cultural, social and individual contexts, as well as how our understandings of these perspectives were shaped by our own researcher interpretations.

The first and second authors (HW, CBS; Within employees) conducted the analysis, while the third author (RGB) provided feedback, offering a valuable external perspective. Following Braun and Clarke's [37, 38] iterative, six-phased approach, HW and CBS familiarized ourselves with the data, making note of initial observations and reactions. Utilizing an inductive, data-driven approach, we began coding using analytic software, *Atlas.ti* (version 24), initially coding semantically to remain close to participants' own descriptions and understandings of their experiences. We each independently coded half of the dataset, later swapping to review the other's codes, which allowed for reflexivity around our individual coding processes and created opportunities to begin discussing and evolving our initial set of codes. As coding progressed, we added latent codes to capture implicit meanings and collapsed, split, and relabeled codes as needed. Our codes and affiliated data excerpts were then collated into a directory, which we used to generate our candidate themes and ensure our analysis remained grounded in the data. Along with written and visual thematic mappings, this directory enabled collaboration across authors, particularly during consultations with RGB, as we further developed and finalized our analysis.

Positionality and reflexivity

HW, CBS, and RGB have diverse training in social work, counseling psychology, and clinical psychology, each bringing a unique lens to the data. All have experience working with EDs in clinical and research capacities, including in remote and higher-level-of-care treatment settings. Throughout our analysis, we incorporated reflexive practices to think critically about how our personal and professional positioning, lived experience, assumptions, and expectations about this topic were shaping our interpretations of the data. For example, we noted how our experience working in ED treatment settings, including at Within, could both provide us an insider perspective *and* limit our ways of seeing the data. Additionally, given the context of our study, we employed multiple coders, making an intentional modification to Braun and Clarke's original process to enhance reflexivity.

Results

We generated four themes from the data, described below and depicted in Figs. 1 and 2.

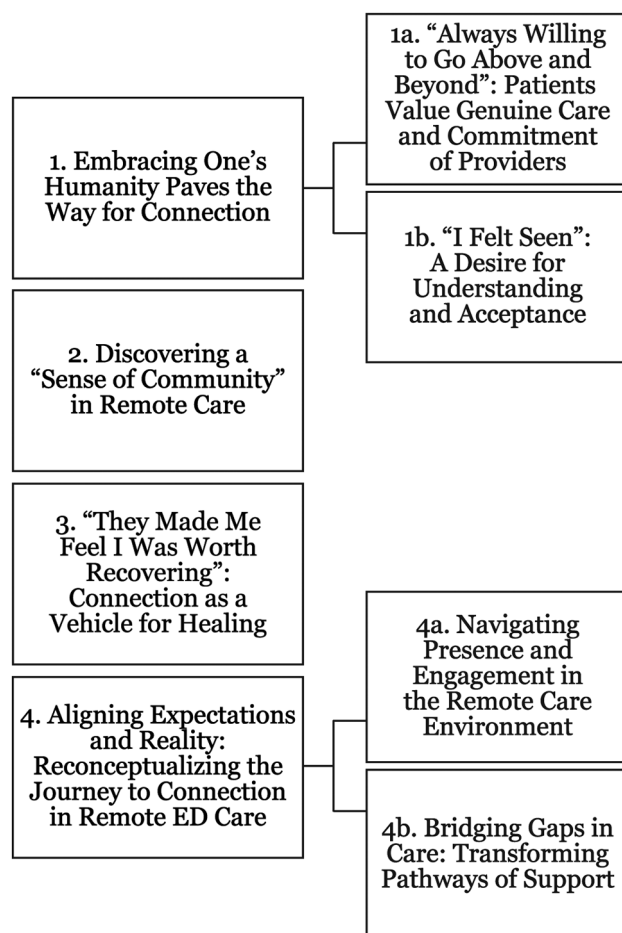


Fig. 1 Map of thematic structure

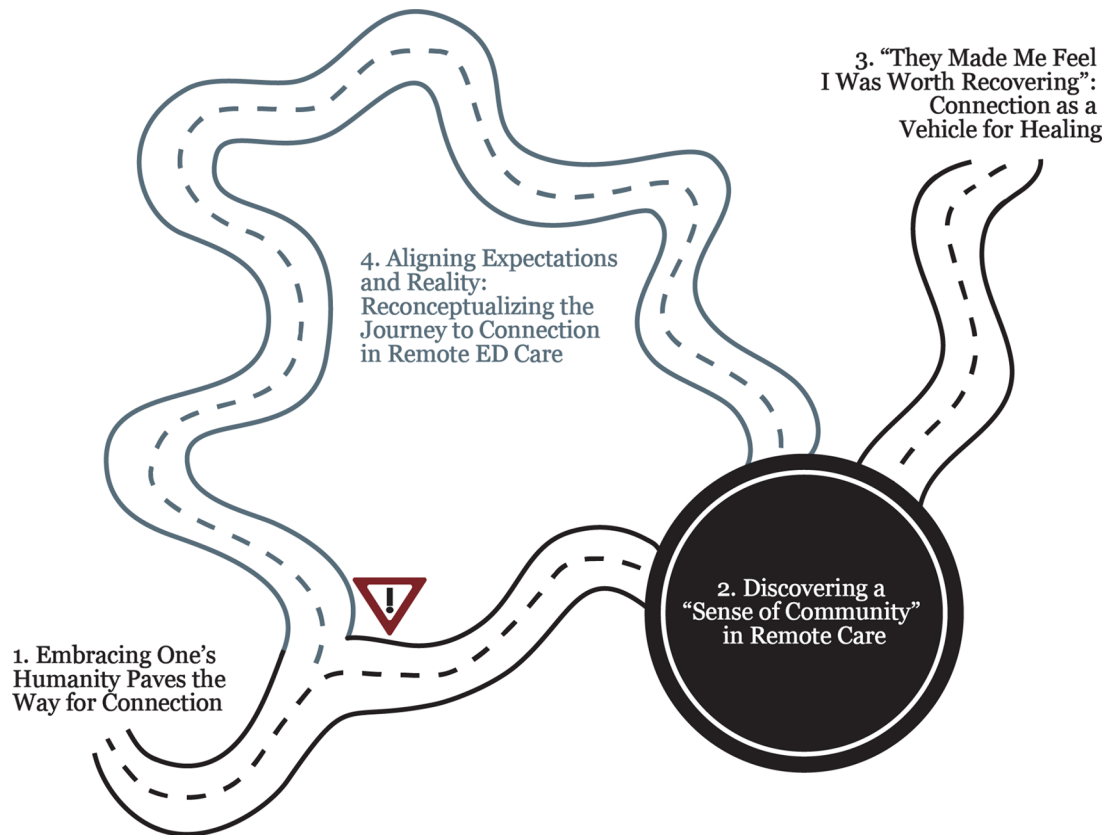


Fig. 2 Patient pathways to connection and healing. This figure depicts the associations between the four overarching themes. Feeling understood, accepted, and cared for as one's authentic self (Theme 1) contributed to patients' sense of connection and community in remote ED care (Theme 2). This connection ultimately facilitated patients toward healing and recovery (Theme 3). However, the yield sign denotes how, within the remote care environment, we may need to implement creative approaches and adaptations, thus following a different path in order for patients to reach connection and healing (Theme 4)

1. Embracing one's humanity paves the way for connection

Across the data, patients recognized specific experiences as being important for connection. In particular, they identified a sense of being understood, accepted, and cared for as their authentic selves as key components of fostering connection. Some patients reported successfully experiencing these, while others did not. Across these differing experiences of connection and disconnection, empathy, nonjudgmental acceptance, and ongoing investment from others throughout treatment were identified as significant factors in successful cultivation of meaningful relationships.

1a. "Always willing to go above and beyond": patients value genuine care and commitment of providers

Patients described the importance of feeling as though their providers genuinely cared about them and were invested in their recovery. Patients appreciated when providers offered compassion and sincerity, particularly valuing when they would take time to build rapport, understand their experiences, and demonstrate care. One patient stated their providers "demonstrated a level of

kindness, compassion, and understanding [they] haven't found anywhere else in [their] life." These sentiments reflect how critical core conditions [26] are for the therapeutic relationship.

Many remarked that providers went "above and beyond" expectations, emphasizing the importance of them being available, dependable, and responsive. One patient noted that their nurse "literally saved [their] life" and "addressed [their medical concerns] right away," while another described their dietitian as "much more than just that," explaining "she was one of [their] strongest supporters." Feeling as though a provider was "always there for [them]" reflected the compassion and commitment patients desired to form these bonds.

Additional ways patients wished for their providers to demonstrate their consideration included advocating for their needs, keeping their best interest in mind, and setting and holding loving boundaries. Knowing how to "press" or "challenge" a patient's ED in a compassionate and "appropriate way that didn't feel overwhelming" was a particularly important balance.

In some cases, patients did not feel cared for by providers and struggled to form a connection. For instance, when patients “didn’t feel challenged” by their provider, spent a lot of time “advocating for [themselves] to get the help [they] deserved,” or felt their provider “seemed to lack compassion,” connection was less attainable. Similarly, patients noted frustration with inconsistent support and enforcement of boundaries. One shared, “I felt that some care partners did an amazing job, helping me ... tackle some of the more challenging parts of meals, while others seemed a little inattentive.” These comments provide further evidence that clear, consistent demonstration of a provider’s care for and commitment to the patient is fundamental to forging connection.

1b. “I felt seen”: a desire for understanding and acceptance

Patients also emphasized the significance of feeling seen, heard, and understood. One patient mentioned their dietitian “was able to hear [their] feedback and acknowledge [their] experiences,” and stated they were “able to advocate for [themselves] for the first time with a Health professional and feel truly heard.” Another expressed:

[My therapist] did a really good job of listening and validating some of the very real concerns that occur when tackling an eating disorder. ... he was a really great resource in acknowledging the additional burden that can occur when being a non-cis person seeking eating disorder treatment.

Patients stressed the importance of establishing a sense of safety to foster trust and vulnerability. For example, one patient articulated that their therapist “created a space safe enough for [them] to share [their] story and to heal.” Patients cited the importance of providers being compassionate, nonjudgmental, genuinely curious about their patients’ experiences, and willing to take time to listen and understand in order to achieve this sense of safety. In contrast, if patients “question[ed] the intentions” of their providers or felt they “did not care to get to know [them] as a person first,” they struggled to remain open to connection.

Notably, the importance of feeling seen and heard spanned across connections with providers and peers. For providers, using active listening skills to understand what patients were experiencing was essential. When they did so, providers were able to use this understanding to take patients’ needs and preferences into consideration, as well as advocate on their behalf and help their loved ones “understand what [they were] going through and how they could help and support.” One patient offered:

[my dietitian]...ALWAYS reflected back to me what she heard and clarified anything that might be confusing. This aided in me feeling valuable and important. She helped me to feel like I was part of the recovery process by letting me make many suggestions about what I needed to work on and challenged me to think differently about things.

For both peers and providers, collaboration and reciprocity were central to cultivating connection, such that each individual shared from their own perspective and also listened to and offered feedback or support to others. There was an emphasis on shared experiences, both those specific to the ED and outside of it (e.g., age, interests), which helped patients feel comfortable sharing with their peers and allowed them to better relate. In particular, there was a desire to connect with others aside from the ED (e.g., light-hearted conversation during meal support) to form friendships and community, as illustrated here: “Meal support...genuinely made the experience feel less alone, and getting to know the care partners and the other clients outside of groups was really special.”

Further highlighting the importance of feeling seen and heard, several patients reported holding identities they felt were less represented among the current milieu (e.g., transgender or gender nonconforming, “being in a fat body,” Avoidant/Restrictive Food Intake Disorder [ARFID] diagnosis) and thus sometimes felt uncomfortable or disregarded in treatment, leaving them struggling to connect.

2. Discovering a “sense of community” in remote care

Built upon these foundational components of connection, many patients reported successfully forming relationships in treatment. One patient shared there “is a genuine care and compassion that permeates the culture” while another expressed, “I feel like I had such a strong sense of community here, I really felt loved and supported. ... I really felt they cared about me.”

Across peers and providers, patients recounted feeling welcomed, accepted, and understood, fostering deep, “strong bonds.” Despite concern that certain aspects of remote care may be uncomfortable or awkward, they reported that the remote delivery of treatment had less impact on their experiences of connection than anticipated and ultimately offered both support and accountability. Counter to this initial hesitation, many even described it as “easy” to open up, trust, and connect in a remote setting, finding that others could be “calming” and help them “feel at ease.”

Patients felt strongly about these connections, expressing immense gratitude for working or interacting with certain individuals in the program. One patient shared that “ending treatment with [their therapist] was the

hardest part of [their] discharge,” noting “she’s someone you just want in your life, sitting beside you and holding you while you cry and then cheering you on once you’ve dried your tears” and expressing, “I’m so lucky to have worked with her.”

Because of the strong bonds they formed, patients spoke often of how much they would miss the people they met in treatment. Many reported that they hoped or planned to maintain these connections beyond their treatment stay (e.g., via virtual meet-ups or alumni programming):

I have no words to describe my gratitude. For the first time in 41 years I feel fully accepted, liked, understood, and worthy. ... I've created connections I hope to keep forever because I can't imagine my life without the Within family.

3. “They made me feel I was worth recovering”: connection as a vehicle for healing

Patients reported that when these connections were formed, the support received from them was deeply impactful to their healing. Peers, for example, provided validation through shared experiences and offered accountability through community. Additionally, patients identified providers as the “glue holding everything together” or their “rock throughout treatment,” illustrating the key influence of patient-provider relationships. Providers’ commitment to the patient’s treatment empowered them to invest in their own recovery and enabled “seemingly impossible changes” to oftentimes deeply ingrained, “longstanding ED behaviors”:

I have never felt as supported, empowered, and inspired to work so tirelessly toward recovery as I did while under the care of the staff at Within. My dedication to my own recovery was matched by the support and dedication of my team.

Moreover, patients described how their relationships expanded their sense of self beyond the ED, for instance teaching them new things about themselves and challenging them to think differently. One patient explained, “I can’t begin to list off the things I’ve learned about myself ... Groups really gave me insights and perspectives that I may not have had language to express or even fully understand before.” In addition, patients shared that these connections allowed them to feel worthy and confident in their ability to recover:

This program, and the people I encountered at Within helped me achieve a level of self worth I never knew possible! They made me feel I was worth

recovering, and worth kindness. That self worth, led me to wanting to recover, not only for my family and care team, but for myself.

Some even characterized the guidance and support from providers and peers as “life changing,” again demonstrating the impact of these connections - not just for recovery, but for their broader lives as well.

4. Aligning expectations and reality: reconceptualizing the journey to connection in remote ED care

While forming connections in remote ED treatment appears feasible, there were notable shifts in the process of building and deepening these relationships. Patients’ expectations were grounded in perceptions of in-person treatment, which at times differed from the realities of remote care.

4a. Navigating presence and engagement in the remote care environment

The remote care environment, comprising the physical space and the technological platform through which treatment was accessed, required adjustments to how patients presented and engaged with others. Patients remarked that there was something *different* about not being physically present with others, noting that “simply the lack of physical connection” had the potential to impact their engagement, making it “harder to connect with people sometimes.” Accessing treatment remotely brought unique challenges in terms of the physical care environment, including privacy challenges and distractions (e.g., “Hard to find a private comfortable location when a bunch of family member[s] are around”), as well as the online care environment due to technological complications, including the app being “buggy (e.g., [the] video would sometimes show up sideways ...)” and difficulties “see[ing] everyone on such a small screen.” At times, these aspects of remote care affected the patient’s ability to be present and engage with others. Perhaps as a result, some felt there was less participation in remote care, though others noted a lack of participation is “common in treatment, virtual or in-person.”

Simultaneously, technology opened up new avenues for engagement in treatment, such as via break-out rooms during larger group sessions. These unique barriers coupled with the new methods for engagement generated by technology indicate that active participation and a communal sense of presence are attainable in this setting, but likely experienced differently than in in-person treatment.

4b. Bridging gaps in care: transforming pathways of support

Some patients felt it was difficult to receive the kinds of support they would expect from in-person care, noting

they missed physical connection (e.g., hugs) as well as the accountability from CTMs (e.g., identifying and disrupting ED behaviors). Without these kinds of support, patients felt they had to be more accountable to themselves and their recovery, commenting that in-person care “offers a different degree of accountability in terms of portioning” as it is “easy to adjust things to look like more on camera” and noting, “if you’re not really committed to recovering, [remote care] can be challenging.”

At the same time, accessing treatment remotely allowed patients to receive support in new ways and from alternative sources. For instance, patients were able to maintain connection with their support systems (e.g., family, friends, pets) that they may have otherwise been separated from if attending in-person treatment. One patient reported that having “the support of [their] parents in addition to the support from Within staff” was beneficial for both them and their family. Additionally, remote care enabled patients to practice recovery in their own, real-world environment while still retaining access to support, which they found to be helpful and translatable to life after treatment, as shown below:

It was so helpful to be able to do things in my natural environment. The challenges I faced are the same as they would be when discharged. It is incredibly helpful to be able to face those challenges with the support of caring and educated professionals alongside you.

Furthermore, technology itself opened up new avenues for support, for instance by offering easier access to communication with CTMs. One patient said, “I was worried about the effectiveness of virtual treatment but the ability to connect with my team and utilize the living room and the support button has been very useful in minimizing behaviors.” In addition, patients offered suggestions for ways to improve the existing technology (e.g., additional chat features, easier search functions) that would have allowed for easier access to support:

One thing we added towards the end of my time was a group chat with my team. ... Sometimes something would happen (good or bad) and it was really annoying to have to type it out to each member of my team. Having it all in one place was much more helpful.

Discussion

The aim of this study was to explore patient experiences of connection in intentionally remote ED treatment, specifically in a context outside of pandemic transition. Guided by reports of disrupted connection in the

literature, the present study focused explicitly on patients’ feelings of connection and the role of the remote care environment, given evidence that connection plays a significant role in ED treatment experiences and outcomes. Findings related to the first research question, regarding how patients experience connection with others, suggest that it is possible for patients to form strong relationships in remote treatment. Specifically, patient reports emphasized the importance of feeling understood, accepted, and cared for in order to build these connections. Patients identified how these relational aspects of treatment, particularly connection with providers, were deeply impactful to their treatment progression and recovery, reflecting prior work [31–34]. Importantly though, with respect to the second research question, patients indicated that while connections could be formed, there were shifts in how they were experienced as a result of the remote care environment.

The present findings provide support for several key components of connection described in prior literature and underscore how impactful connections can be for patients’ treatment and recovery. Most notably, the findings extend decades of research demonstrating the value of core conditions (i.e., empathy, congruence, and unconditional positive regard) for developing therapeutic relationships by illustrating their relevance in remote eating disorder treatment [26, 41–43]. Patient perspectives emphasized the importance of providers showing compassion, understanding, and empathy and highlighted the significance of feeling as though providers were willing to go above and beyond, for instance by individualizing their treatment approach, also reflecting prior qualitative findings [33]. Feeling understood, validated, and invested in by providers helped to foster a strong, trusting therapeutic relationship, laying the foundation for providers to effectively and appropriately challenge their patients’ EDs, indicating the impact connections can have for patients’ treatment trajectories. In addition, patients stressed the value of shared understanding and experiences among peers as this cultivated a sense of belonging, which prior research has noted is particularly important due to the isolating effects of the ED [33]. However, some patients who held identities that were not well represented in the milieu noted this could also compound the loneliness caused by the ED, as previously documented [33].

Consistent with prior research, the present findings also showed fundamental differences in how patients experience connection in remote versus in-person care, thus calling for a critical reconceptualization of connection in remote treatment. Specifically, patients reported that the lack of physical presence and contact, technology complications, and privacy concerns associated with the remote setting affected their engagement and the ways in

which they received support, mirroring prior work [12, 14, 23, 44]. Our findings further corroborate this existing research via patient reports indicating that, while remote care allows for greater availability of support from CTMs and loved ones and enhanced translatability to real life, it simultaneously requires increased agency, responsibility, and self-advocacy on behalf of the patient. These central differences in how patients experience connection in remote treatment reinforce the “need for creativity” in order to establish and maintain relationships in this care setting, as was previously identified [14]. Adapting expectations and taking considerations specific to the remote care environment, rather than directly replicating in-person care online, may prove essential to the ongoing and effective use of remote ED treatment.

Unlike prior work concluding that the aforementioned challenges resulted in relational disconnect and feelings of isolation in remote care [12–14, 23], the present findings depicted that it is possible for patients to form strong connections in *spite* of these differences from in-person treatment, thus (dis)connection is not an inherent limitation of remote care. Since prior studies examined overall treatment experiences, it is possible that patients formed connections that were not represented in the results because connection was not the topic of focus. Additionally, it is plausible that the patients included in the present study reported uniquely strong connections in part due to biases created by the study’s selection criteria. Alternatively, factors specific to the pandemic context may have contributed to this difference in findings. For instance, heightened loneliness due to social isolation may have contributed to feelings of disconnection in remote treatment during the height of the pandemic. Additionally, reports previously indicated a discomfort with online working [12, 14], which may have improved over time as we have adapted and become more accustomed to the use of technology, perhaps allowing patients to better form connections in a remote setting than at the start of the pandemic.

Lastly, programs examined in prior research were forced to rapidly shift to remote delivery to make “the best of a bad situation [p. 7]” amid the pandemic [12]. Given the relational disconnect reported by their participants, Brothwood et al. [12] concluded there was a “need to find new ways of building trusting relationships and a deeper connection online [p. 8]” in order for remote care to persist beyond the pandemic context. Herein lies another potential explanation for the difference in the present findings. Within Health was designed from inception to deliver ED treatment in a remote setting, and thus includes treatment components intentionally developed to facilitate connection online (e.g., a ‘support button’ and community ‘living room’ that provide off-hours support from both providers and peers).

Consequently, it is possible that these unique components of Within’s treatment program elicited more positive experiences with connection. These findings present preliminary evidence that, with considerations specific to the remote care environment, those trusting relationships and deeper connections can be formed.

Strengths and limitations

This work has several strengths, including its rigorous, reflexive implementation of qualitative methods and focus on ED patients’ lived experiences. Additionally, as this was a secondary analysis and patients completed the study survey without awareness that their responses would be utilized for research, there is low risk of demand characteristics, or cues that inadvertently reveal the study’s objectives causing participants to subconsciously change their responses, in turn biasing the study findings. However, multiple aspects of study design and methodology were predetermined, resulting in limitations to the sampling and data collection processes. Patients opted into survey participation and selection criteria required that patients consented to their data being used for education and advertising purposes. Thus, participants could hold non-representative perspectives, perhaps leading to selection and/or non-response bias [45]. Though review of quantitative satisfaction data revealed no significant differences between responses from patients who did and did not consent to their responses being used, there is some evidence to suggest that quantitative and qualitative feedback may not align [14], thus it remains possible that there were differences in the qualitative feedback patients provided. Furthermore, the survey’s anonymity precluded knowledge of patient demographics and survey items were designed for quality improvement purposes rather than being guided by the study research questions. Finally, while qualitative surveys can produce rich, complex data [46] and the present data were determined to hold sufficient power to meet the study aim, by nature of the method, there was no potential for further probing. Therefore, unlike interactive qualitative methods, there was no opportunity to ask participants follow-up questions or to request elaboration on their responses.

Future research

Future research should utilize prospective study designs and/or interactive qualitative methods and prioritize the collection of demographic data to allow for a deeper, more contextualized investigation into patient experiences of connection in remote ED treatment. Though given the design of the present study, we were unable to examine how specific aspects of the treatment program related to patient responses, future studies might further explore if and how such aspects of the remote care environment can facilitate connection. Researchers could

also examine how patient experiences and satisfaction with remote care relate to ED treatment outcomes [47, 48]. Lastly, more research is needed to understand the relationship between satisfaction rating scale and free-text response questions [49, 50], given a trend in which quantitative data suggests more positive treatment experiences than qualitative [14].

Clinical implications

Findings from this study suggest that relational aspects of care from in-person settings, including connections with providers, peers, and external support systems, are also valued by patients in remote care and play a significant role in their treatment and recovery. Thus, fostering these connections by cultivating an environment in which patients feel understood, accepted, and invested in by others is critical. Specifically, prioritizing the development of therapeutic relationships by engaging in behaviors that promote the core conditions remains foundational to connection in remote care. Of note, while patients expressed their appreciation for feeling as though their providers were always there for them and went above and beyond, it is important to clarify that this should not be interpreted as a recommendation for providers to disregard their professional boundaries or overextend themselves, as such behaviors have been associated with clinician burnout [51, 52].

In order to build community and foster patients' sense of belonging among the milieu, it may be helpful to attend to group composition and offer specialized groups (e.g., gender-specific [53], diagnosis-specific [54]), particularly for patients who hold identities historically underrepresented in ED treatment (e.g., gender diverse/transgender individuals, patients with ARFID), in addition to providing opportunities for peers to connect outside of the ED. Furthermore, given the potential for greater reliance on support systems in remote treatment, involving patients' caregivers and loved ones more deliberately via skills-based and support groups as well as coaching can help ensure they are equipped with the necessary tools and resilience to support their loved ones.

Lastly, given shifts in connection across care settings, adaptations in remote treatment may also be important for ongoing viability. For instance, attention to the user experience is essential based on numerous reports that technical difficulties can act as barriers to connection. Furthermore, existing telehealth guidelines [55, 56] should continue to inform remote care implementation, including recommendations to discuss ways to ensure patient privacy (e.g., headphones), offer training to improve patient comfort with technology (e.g., how-to guides), and leverage technology to offer alternative avenues for engagement and support (e.g., using breakout rooms to facilitate peer dialogue). Such considerations

will be important to fostering connection in remote care, thereby contributing to improved patient experiences and treatment outcomes.

Conclusions

This study features lived experience perspectives regarding connection in a technology-enabled, intentionally-remote ED treatment program. Patients conveyed that relational aspects of care, including connections with providers, peers, and external support systems, played a significant role in their treatment and recovery. Overall, the study illustrates that it is possible for strong, impactful connections to be forged in the remote care environment, therefore (dis)connection is not a necessary weakness of this care model. However, patients expressed that the connections they formed in remote treatment were experienced differently than those they have formed in in-person settings, suggesting that adaptations in remote care may be important to consider. Moving forward, attending to such considerations, such as by placing heightened attention on the user experience, patient privacy, and opportunities to leverage technology, will support the development of these valuable interpersonal connections.

Abbreviations

ED	Eating disorder
CTM	Care team member
HIPAA	Health Insurance Portability and Accountability Act
TA	Thematic analysis
ARFID	Avoidant/Restrictive Food Intake Disorder

Supplementary Information

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Supplementary Material 1

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Author contributions

All authors were involved in the conceptualization of the study. HW led the project. HW and CBS devised the methodology and conducted the data analysis with consultation from RGB. HW led the preparation of the manuscript with support from CBS. RGB, JG, and WOP reviewed and edited the manuscript before submission. WOP was responsible for funding and resource acquisition and provided general supervision. All authors read and approved the final manuscript.

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Data availability

The datasets generated and/or analyzed during the current study are not publicly available due to privacy and ethical concerns but are available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate

This study was deemed exempt by the Biomedical Research Alliance of New York (BRANY) Institutional Review Board. Participants had previously provided consent for their survey responses to be used for external purposes (e.g., education, advertising).

Consent for publication

Not applicable.

Competing interests

HW is an employee of Within Health Provider Services FL PLLC. CBS is an employee of Within Health Provider Services FL PLLC and is a consultant to and holds stock options issued by Within Health Group, Inc. RGB receives consulting fees from Within Health Provider Services FL PLLC. JG is a consultant to Within Health Provider Services FL PLLC and Within Health Group, Inc., an affiliate of Within Health Provider Services FL PLLC, and is an investor and holds equity in Within Health Group, Inc. WOP is the sole owner and President of Within Health Provider Services FL PLLC. She is a co-founder, co-owner, and the Chief Executive Officer of Within Health Group, Inc.

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