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Perspectives on relapse prevention following intensive treatment of anorexia nervosa: A focus group study

Nikki Pagano, LCSW[1], **Deborah R. Glasofer, PhD**[1], **Evelyn Attia, MD**[1,2], **Julia Ruggiero, BA**[1], **Kelechi Eziri**[1], **Carly M. Goldstein, PhD**[3], **Joanna E. Steinglass, MD**[1]

[1]New York State Psychiatric Institute, Columbia University Irving Medical Center, New York, New York, USA

[2]Weill Cornell Medical College, New York, New York, USA

[3]Weight Control and Diabetes Research Center, The Miriam Hospital, Warren Alpert Medical School of Brown University, Providence, Rhode Island, USA

Abstract

Objective: Including the perspectives of individuals with lived experience of mental health issues is a critical step in research and treatment development. Focus groups with patients with a history of treatment for anorexia nervosa (AN) were conducted in anticipation of a clinical trial of Relapse Prevention and Changing Habits (REACH+).

Methods: Seven female adults (23–51 years) who had previously received inpatient treatment for AN, now in remission, participated in one of two semistructured focus groups. Rapid qualitative analysis was used to examine participants' contributions and identify common topics.

Results: Transcript analysis yielded three topics related to relapse prevention: (1) recovery aids, including a sense of agency in treatment decisions and finding new interests/passions, (2) recovery hindrances, such as lack of access to care, and (3) identification of members of support system. Aspects of REACH+ received positive feedback, such as continuity of care from the inpatient setting and the use of telehealth. Viewpoints differed with respect to the helpfulness of obtaining patient weights in treatment. The REACH+ online platform received positive comments regarding content and usability, as well as suggestions for additional content.

Correspondence Deborah R. Glasofer, New York State, Psychiatric Institute, Columbia University, Irving Medical Center, New York, NY, USA. deborah.glasofer@nyspi.columbia.edu.

Carly M. Goldstein and Joanna E. Steinglass contributed equally to this work.

AUTHOR CONTRIBUTIONS

Nicole Pagano: Formal analysis; visualization; writing – original draft; writing – review and editing. **Deborah R. Glasofer:** Formal analysis; supervision; visualization; writing – original draft; writing – review and editing. **Evelyn Attia:** Conceptualization; data curation; formal analysis; funding acquisition; investigation; project administration; resources; supervision; visualization; writing – original draft; writing – review and editing. **Julia Ruggiero:** Conceptualization; data curation; formal analysis; investigation; project administration; visualization; writing – review and editing. **Kelechi Eziri:** Data curation; formal analysis. **Carly M. Goldstein:** Conceptualization; data curation; formal analysis; investigation; methodology; project administration; resources; supervision; visualization; writing – review and editing. **Joanna E. Steinglass:** Conceptualization; data curation; formal analysis; funding acquisition; investigation; methodology; project administration; resources; supervision; visualization; writing – review and editing.

CONFLICT OF INTEREST STATEMENT

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Discussion: Qualitative feedback from patients with a history of AN highlighted the value of engaging patients in their own treatment decisions, as well as in treatment design and innovation. Within this small group, there were differences of opinion about treatment components, specifically weight assessment, that suggest the need for further data. User-centered design provides opportunities to improve the acceptability and, therefore, dissemination of novel treatments.

Public Significance: Relapse prevention is a critical treatment need for patients with anorexia nervosa, as this illness too often follows a protracted course. There are challenges in both obtaining specialized care and in retaining patients in treatment. Here, patient perspectives on these challenges offer input to allow for optimization of relapse prevention treatment. Shared decision-making may be particularly valuable to support an individual's sense of agency and engagement in care.

Keywords

anorexia nervosa; focus group; qualitative methods; relapse prevention; technology; telehealth

1 | INTRODUCTION

Anorexia nervosa (AN) is a life-threatening illness with a mortality rate among the highest of any psychiatric illness (Arcelus et al., 2011; Birmingham et al., 2005; Chesney et al., 2014). Behavioral inpatient treatment provides short-term weight restoration and improvement in psychological functioning (Attia & Walsh, 2009; Olmsted et al., 2010). However, post-hospitalization relapse rates are high. In studies completed in North America and Europe, with predominantly female samples ages 12 and older with a diagnosis of AN, post-hospitalization relapse rates have ranged from 35% to 57% (Carter et al., 2004; Kaplan et al., 2009; Khalsa et al., 2017). Aftercare may help prevent or slow relapse. However, there is a lack of data to support one particular relapse prevention treatment (Byrne et al., 2017; Herzog et al., 2022; Solmi et al., 2021).

Incorporating perspectives of individuals with lived experience of mental health issues in treatment development research may improve the quality of care (World Health Organization, 2013). Co-design methods, in which stakeholders are collaborators in the design process, can address persistent challenges in preventing relapse post-hospitalization for individuals with AN. In co-design methods, study participants and other patients who represent the intended treatment recipients are selected as collaborators who help identify the target audiences' needs and preferences (Morse et al., 2023). Participatory digital co-design is theoretically situated at the intersection of community-engaged research models and user-centered design (Cosco et al., 2021). Co-design methods are associated with benefits including improving user satisfaction or engagement (Elbers et al., 2021) and have been used with individuals with lived experience with substance use (Dietrich et al., 2021; Zhang et al., 2019) and anxiety disorders (Thabrew et al., 2021) to refine technology-based interventions.

Adolescents and adults with AN have been consulted to understand the experience of inpatient treatment (Smith et al., 2016) and virtual family-based treatment (Couturier et al., 2022), the transition out of intensive treatment (Clark Bryan et al., 2022), the barriers to seeking treatment (Thomson et al., 2014), and the importance of familial and peer support (Coopey & Johnson, 2022; Nilsen et al., 2020) via qualitative research methods. These studies provide insight into patient and caregiver treatment experiences and emphasize the importance of continuity of care and supportive relationships during and following intensive treatment. Lack of access to care, ambivalence about recovery, self-criticism, difficulty tolerating negative emotions, and lack of supportive relationships have previously been identified as barriers to sustained recovery in qualitative eating disorders research (Clark Bryan et al., 2022; Federici & Kaplan, 2008; Venturo-Conerly et al., 2020).

Given the severity of AN and lack of relapse prevention treatments, this study aimed to gather information on the lived experiences of individuals with a history of AN, currently in remission from illness, specifically regarding what they found helpful in relapse prevention post-hospitalization. The study also obtained feedback to inform the development of a treatment currently being studied: Relapse Prevention and Changing Habits (REACH+) (Steinglass et al., 2022).

2 | METHODS

2.1 | Recruitment

Participants had received behaviorally based inpatient treatment at the Eating Disorder Research Unit (EDRU) including medical stabilization, resumption of regular eating, and weight restoration corresponding to a body mass index (BMI) of ~ 20 kg/m^2 at the New York State Psychiatric Institute (NYSPI) between 2009 and 2017 (Attia & Walsh, 2009). They were recruited from an ongoing, longitudinal follow-up study (Glasofer et al., 2020), and were selected to be contacted based on: diagnosis of AN at hospital admission, remission from AN for ≥3 months, age 18–60 years, access to an internet-connected device with videoconferencing capability, and being conversant in English. As definitions of remission vary (Steinglass et al., 2020), a combination of BMI status (≥18.5 kg/m^2), symptom remission (e.g., denial of dietary restriction, purging, or binge-eating behaviors), and lack of need for specialized treatment was used. Researchers obtained informed consent and compensated participants with a $25 debit card. All procedures were reviewed and approved by the NYSPI Institutional Review Board and participants signed informed consent.

2.2 | Measures/assessment

Depending on year of hospitalization, admission diagnosis was ascertained by *Structured Clinical Interview for DSM-IV-TR Axis I Disorders* (SCID-I) (First et al., 2002) or *Eating Disorder Assessment for DSM-5* (EDA-5) (Sysko et al., 2015). A member of the research staff confirmed AN remission via clinical interview by phone, obtained self-reported current weight, and verified participants were no longer in need of or receiving eating disorder treatment. A doctoral-level clinician reviewed this information with participants before obtaining consent.

2.3 | Co-design framework

Co-design phases 1 and 2, as described by Eyles and colleagues (assess background knowledge and evidence, assess user needs to inform intervention focus), were previously conducted by study principal investigators EA and JES (Eyles et al., 2016). In the preparation phase of the Multiphase Optimization Strategy (MOST) (MacPherson et al., 2022; Pfammatter et al., 2020; Whitesell et al., 2019), REACH+ was developed with experts in eating disorders and user-centered technology development (co-design phase 4, develop intervention). This study represents the team's late-stage MOST preparation phase and utilized co-design phases 3 (assess user needs to inform technology) and 5 (prototype testing) to inform intervention content tailoring and new content development (part of an iterative return to phase 4) before pilot testing (phase 6, ongoing now). Revisiting previous stages is a key feature of participatory design; the flexibility to make changes and revisions is a methodological strength (Spinuzzi, 2005). This study's approach was informed by the experience-based co-design model in which participants collaborate with researchers and provide their experiences as service consumers, which informs improving future patients' experiences receiving care (Bird et al., 2021; Kynoch & Ramis, 2019).

2.4 | Relapse prevention/REACH+ focus group interviews

Two 70–90-min semistructured focus groups were conducted (Focus Group 1, $n = 4$; Focus Group 2, $n = 3$). The same questions were presented across groups (see Appendix S1). Each meeting allowed 60–75 min for discussion and 15 min for post-interview processing. Focus groups occurred through Zoom Pro Video Communications, facilitated by two research clinicians (a psychiatrist, EA, and clinical psychologist, CG), with a research assistant (JR) joining to help with set up. Participants were asked to describe elements of treatment they believed were and were not helpful to them post-hospitalization.

The focus groups occurred concurrent with REACH+ online platform development, allowing an iterative development process. A research clinician described the proposed REACH+ treatment and demonstrated the platform. REACH+ is a 6-month telehealth study treatment for adults following hospitalization for AN (for details, see Steinglass et al., 2022). REACH+ consists of behavior, cognitive, and motivation components, as well as food monitoring and a skill consolidation phase. The intervention targets habitual control of maladaptive behavior in AN, aiming to help patients develop routines that promote weight maintenance, encourage behaviors in accordance with remission, and interrupt habits potentially hastening relapse. REACH+ components are "dosed" differentially, with the behavior component receiving the largest number of sessions. The treatment also includes common interventions considered essential to any AN relapse prevention approach, such as regular weight monitoring. In REACH+, weight is automatically transmitted to the therapist via cellular-connected scale with visible read-out. A specialized online platform, providing psychoeducational content and tools to practice REACH+ skills, extends therapy between sessions.

Participants asked questions about the intervention and platform under development and provided feedback. Data from this study came from this "process" conversation.

2.5 | Analysis

Focus groups were recorded and transcribed by an analytic team member (KE). A rapid qualitative analysis procedure (RQAP) was utilized (Gale et al., 2019; Hamilton, 2013). RQAP produces similar results and is significantly less resource intensive than deductive indepth qualitative analysis; this method for analyzing qualitative data was selected as it facilitated ongoing program development and implementation (Gale et al., 2019). RQAP may be appropriate for analyzing transcribed focus group data when priorities include reducing time and cost, increasing the amount of collected data, improving efficiency and accuracy, and obtaining a more accurate representation of participants' lived experiences (Hamilton, 2020; Vindrola-Padros & Johnson, 2020).

An analytic team member (KE) iteratively created a codebook based on the interview guide and updated it during the coding process; the qualitative team reached coding structure consensus (KE and CG), coded transcripts, and organized coded transcripts into summary tables including: domains for interview questions, specific categories and descriptions, and relevant quotes from "process" conversation (KE). A research clinician (CG) modified the summary template after testing with a team member on 20 min of one transcript (KE). It was then tested on the next 20 min to confirm usability and relevance (KE and CG). This represented the first step of RQAP: summarizing focus group-level transcripts (Gale et al., 2019). Once the structure was finalized, another team member (JR) reviewed the table and reached consensus through consultation (with CG) for summary table categorization resolution. The qualitative expert (CG) conducted a secondary review of summaries and discussed with analytic team to ensure consistency in data capture across analysts and transcripts. Illustrative quotes were shortened for brevity without changing the quote's meaning, confirmed by additional authors with full consensus for every revision (DRG, NP, JES, and EA). Findings were organized into a summary matrix, broken into topics (also known as themes/domains), categories, descriptors, and illustrative quotes per the second step of RQAP (Gale et al., 2019). The research assistant (JR) prepared finalized tables with the lead author (NP) and qualitative expert (CG).

To mitigate bias, the co-authors were mindful of their identities (e.g., race, gender) and research agendas (e.g., technology in clinical care) per qualitative methods to enhance rigor (Barusch et al., 2011; Creswell & Poth, 2016; Houghton et al., 2013; Poduthase, 2015). Illustrative quote selection was decided unanimously; the qualitative process was pre-planned consistent with Creswell's (2007) audit trail recommendation.

3 | RESULTS

3.1 | Participants

Participants were recruited with the goal of filling two focus groups with four people each. A total of 46 individuals in remission from illness at their last assessment in the longitudinal follow-up study (Glasofer et al., 2020) were contacted by the research team; 23 individuals (50%) responded to the email expressing interest. Individuals were randomly selected to be contacted for a clinician screen until focus groups were full; eight were consented (four assigned to each focus group) and one did not show up to her assigned meeting ($N =$

7; see Table 1). Eight individuals were excluded for reasons ranging from ineligibility to participant discomfort with study procedures (e.g., confidentiality). Participant BMI at the time of participation was 19.4–22.9 kg/m^2; average admission BMI was 16.6 kg/m^2 and average BMI at last longitudinal study assessment was 20.9 kg/m^2. Average time since hospitalization was 8.6 years. All participants identified as female, and the majority of the sample identified as Caucasian (71%). Participants admitted to NYSPI after 2015 were asked to report their gender identity based on recognition of the distinction between sex assigned at birth and gender identity and the impact of eating disorders on all genders (Roberts et al., 2021; Simone et al., 2020; Watson et al., 2017); 100% of these individuals (n = 4) identified as cisgender women.

3.2 | Focus group topics

Focus group topics clustered into three broad areas: (1) recovery hindrances, (2) recovery aids, and (3) important members of the support system. Feedback about REACH+ addressed six elements: (1) continuity of care following hospitalization, (2) the online platform, (3) telehealth, (4) regular weighing, (5) in-session eating experiments, and (6) treatment foci. Tables 2 and 3 present illustrative comments within each topic; representative quotes are also included in the text below.

3.3 | Recovery hindrances

Over two-thirds (71%) spoke about interferences with recovery. Two individuals cited insufficient access to desired treatment resources post-hospitalization. One participant mentioned stigmatizing comments made by a provider that contributed to the fear of “becoming fat”:

> P5: “There was a resident that just looked at me multiple times and said, ‘You’ll never be fat.’ Okay, but what if I am? Then what? … That shouldn’t matter … and [the comment] is just reinforcing the fear. It was fatphobic, but I think it was just a lack of knowledge.”

In response to this statement, two focus group members nodded, suggesting agreement and that stigma may have also impacted them. Another described providers’ messages as overly simplistic (i.e., perceived as lacking a nuanced view of the recovery process). This participant is instead benefitted from messages of hope and harm reduction.

3.4 | Recovery aids

Over half (57%), across focus groups, mentioned finding a passion allowed for a new sense of purpose and motivation. Almost half (42%) agreed that selecting components of care they found helpful, rather than relying solely on others’ recommendations, was helpful in navigating outpatient treatment, which related to increased sense of agency.

> P1: “I have been dealing with this for several decades and so realizing these various treatment centers, this is what stuck …, this is what … fell flat. [I could see] … the trend of behavioral intervention or behavioral methods that really target some very autopilot habitual behaviors of mine tend to be more effective and long lasting for me.”

Two individuals discussed the utility of weighing; both were >6 years post-hospitalization.

Participants described helpful therapeutic elements: recovery podcasts (43%), behavior change strategies (29%), cognitive techniques (29%), psychoeducation (14%), and journaling (14%). The group endorsed wanting to see these elements in REACH+.

3.5 | Support system

Over half (57%) described the importance of a support system. For example:

> P6: “The one thing that I did have was my family – I had a very strong support system. But that was with me from the beginning of treatment, at [this program] through now. So that is kind of what I relied on the most …”

This topic emerged across focus groups, with variability in sources of support. Participants mentioned deriving support from family or significant others (43%), pets (14%), and other individuals with eating disorders (i.e., peer support) (14%).

3.6 | REACH+ elements

3.6.1 | Continuity of care—

Over two-thirds (71%) viewed working with a familiar group of providers as a beneficial element of REACH+.

> P6: “It’s so hard when you … start over with a new treatment program … it just kind of felt like nobody got me or my story … That’s also why I am very excited about this program, to hear about it. Just about having the same doctors, the same care once you get out and back to your normal routine …”

One participant who lived across the country noted, due to the geographic distance of this treatment program from her home, she had to establish a new care team upon discharge; she regarded this as a barrier to care.

3.6.2 | Online platform—

The majority (71%) provided positive feedback on the REACH+ online platform, commenting on design elements including content (43%), diversity of material format (43%), organization (43%), and usability/accessibility (29%). Almost half (43%) liked that the platform was designed for collaborative use during sessions and ongoing independent work between sessions, with one participant indicating that a review of the platform with the therapist was likely to help a user engage with it:

> P7: “There are a lot of great resources to access online and there are also just terrible resources … figuring out what is good and what is bad can be really triggering and upsetting for some people. So, having a library … and then having your therapist engaging in the same library sounds like a great way to fill the time between sessions with material that is going to be pro-recovery … in a way that feels safe.”

One participant appreciated that the materials on the platform were created or vetted by eating disorder professionals, noting the challenge of finding helpful material online while avoiding triggering content.

Over half (57%) offered suggestions for improvements, including more psychoeducational material (14%), a wider array of multimedia (14%), and recovery podcasts by prior NYSPI patients (14%). One of the youngest participants recommended including virtual peer support groups (14%).

3.6.3 | Telehealth—Over half (57%) indicated telehealth would be beneficial for recovery. Though telehealth delivery of REACH+ was not designed as an intermediate step between inpatient and outpatient care, one participant noted the helpfulness of twice weekly telehealth sessions as a stepdown from intensive treatment.

> P4: “I would have really enjoyed having a telehealth stepdown … I feel like telehealth after inpatient is not quite PHP, but it isn’t quite outpatient, it seems to be somewhere in the middle …”

One quarter (28%) expressed concerns about telehealth. One participant identified barriers to privacy in the home with telehealth and described attending in-person appointments to escape her home environment. The other expressed concern about the ability to be forthcoming while symptomatic and the possibility that telehealth may not facilitate maximum transparency for individuals with eating disorders:

> P3: “… in the depths of my eating disorder, that I would always lie … Because my habits were my thing, and my life revolved around it. So, I think the telehealth might make it hard for people to be accountable …”

This participant also endorsed telehealth as improving availability of specialized care.

3.6.4 | Regular weighing—There were marked differences of opinion about weekly weighing as part of REACH+. In the first group, there was consensus, with 100% (57% of the total sample) describing weighing as beneficial.

> P4: “So, at [this program] we were shown our weights … that … desensitized me to actual numbers. Because I saw those numbers so many times a week, so to this day I don’t really have a problem with seeing my weight … the number doesn’t mean anything …”

> P2: “I never weighed myself [prior to this treatment], which is why now I weigh myself to hold myself accountable, which is sort of a flip from what most people have said.”

One participant clarified that weekly weighing is a useful treatment element in the months following hospital discharge, but it has been important to her recovery to no longer track her weight frequently:

> P1: “… if I were to be discharged from an intensive inpatient unit, I think that it would be helpful and necessary for someone to monitor my weight, if not me, because if I were to just revert to my normal habits, being in my old environment, I would probably just end up losing weight honestly, because I think those triggers would still be there … right now where I am, being at a steady healthy place, if I weighed myself regularly it would reinforce that idea that this number actually matters …”

This individual also suggested adapting the intervention to individual preferences when discussing the online platform. The sentiment that patient preference could be considered was echoed by a participant in the second focus group (see Table 3).

In the second focus group, 100% (43% of the total sample) described regular weighing as not beneficial.

3.6.5 | In-session eating experiments—More than half of the participants (57%) did not offer any reaction to the inclusion of eating experiments as a part of REACH+ when queried. Almost half (43%) provided feedback, mentioned it might feel strange if the therapist was not eating, and suggested these feelings be pro-actively elicited and addressed. One participant considered the benefits of being challenged in this way while receiving therapeutic support.

> P7: "… part of the stuff with the meals that can be really great is just normalizing meals and making it kind of an engaging, fun activity, so if you can have a good conversation during it that's not just mental health therapy stuff, I think that would be challenging … if it's done in a way that's normalizing and engaging."

3.6.6 | Treatment foci—Approximately one-quarter of the sample (28%) expressed a desire for REACH+ to explicitly address emotions concurrently with behaviors, rather than focusing primarily on habit change.

> P5: "I'm all for behavioral sessions, but … maybe [including] … emotional exploration … I needed more to understand who I was and why I needed the things that I did … I needed more insight and clarity on any trauma or my biology, you know like … why is this my choice of maladaptive behavior?"

4 | DISCUSSION

Across two focus groups conducted with seven women with a history of AN, topics that promote and hinder relapse prevention were identified. There was agreement that finding a passion was valuable and access to care was challenging. Ideas from the group informed the development of a new study intervention for relapse prevention: the value of continuity of care and potential utility of telehealth were confirmed; additional content to enhance online platform was identified; mixed feelings about weighing and eating-in session that would warrant individual patient input were recognized—especially as the value of agency in treatment was consistently identified. Understanding the lived experience of those in remission from AN informed the iterative process of a treatment under development. The REACH+ online platform content was revised to enhance usability and likeability based on focus group feedback.

Participants reported several factors as helpful in preventing relapse. Developing a passion outside of the eating disorder and experiencing a sense of agency in treatment decision-making emerged as prominent elements, consistent with past qualitative research on AN (Conti et al., 2020). Notably, several participants viewed taking an active role in treatment decisions as aiding in recovery. Shared decision-making between patients and providers has become increasingly important in medical (Michaelis et al., 2017) and psychiatric (Samalin et al., 2018) care. In psychotherapeutic interventions, accommodating preferences has been associated with lower dropout rates (Swift et al., 2018) and the link between expectancies and treatment outcomes has been well established (Constantino et al., 2011; Greenberg et al., 2006; Price & Anderson, 2012; Webb et al., 2013). In family-based treatment for AN, belief in one's ability to participate in treatment predicts weight gain and outcome (Byrne et al., 2015). These contributions underscore the value of engaging weightrestored adults with AN in considering what interests they hope to pursue and to collaborate on treatment decisions that promote these goals.

Discrepant opinions emerged among participants on the usefulness of weighing. There is reason to assume that weighing is necessary in this medically fragile population (Fairburn, 2008; Lock & Le Grange, 2015; Waller & Mountford, 2015), though there is disagreement in how to best manage weight within treatment (Forbush et al., 2015). Findings from existing studies on open versus closed weighing (Shear et al., 2022) and frequency (Touyz et al., 1990) have been inconclusive; more research is underway (Murray et al., 2020). These perspectives highlight the need for empirical evaluation of the therapeutic value of monitoring weight among weight restored outpatient populations, to improve shared decision-making around this component of care.

Lack of access to care was mentioned as a significant impediment to recovery. Relatedly, continuity of care was one of the perceived benefits of REACH+, which in its current form is offered by providers familiar to participants from their inpatient treatment experience. The percentage of individuals with an eating disorder who receive specialized treatment remains low (Striegel Weissman & Rosselli, 2017), in part due to barriers such as cost, geography, and inequalities among ethnic and racial groups (Thompson & Park, 2016). Low familiarity with one's outpatient treatment team may contribute to treatment dissatisfaction and poor continuity. The importance of continuity of care has been well established for individuals with severe mental illness (Catty et al., 2013; Crawford et al., 2004). REACH+ aims to improve continuity of care through interactions with the outpatient team before discharge, which participants regarded positively. Future versions of a telehealth intervention such as REACH+ may begin with transitional sessions during the final phase of intensive treatment to improve the experience of continuity. A paucity of clinicians knowledgeable in and comfortable with treating eating disorders is another significant barrier. There has been a call to improve physician education in eating disorders and heightened awareness that many medical schools devote little to no time on the subject (Anderson et al., 2017; Ayton & Ibrahim, 2018), and exposure to cases in residency is limited (Mahr et al., 2015). The stories told by our focus groups should energize educational efforts already underway to improve knowledge among health care providers and trainee groups (Glasofer & Attia, 2021; Raffoul et al., 2022).

Ideally, clinician education should include raising awareness of implicit bias about body size. Here, focus group members coalesced around the impact of interactions with providers who made stigmatizing comments. Prior research has shown eating disorder specialists are not immune from biased attitudes and assumptions (Harrop, 2019; Puhl et al., 2014). Biases can create barriers to treatment for individuals in larger bodies through insurance coverage denials or losing coverage prematurely (Harrop, 2022). The intersection of implicit body size bias and marginalized groups' lack of treatment access is especially important in considering the inequities experienced by individuals with atypical AN, as some data suggest that non-White individuals comprise a slightly but significantly greater proportion of those with atypical AN compared with AN (Walsh et al., 2023). As the field works to improve care access and raise awareness of stigma, those in marginalized groups can help us better understand their experience of being weighed as part of treatment for a restrictive eating disorder. Future qualitative research capturing these perspectives will enhance this component of care, which is meant to ensure safety for a medically fragile population, with sensitivity.

Feedback on REACH+ highlighted the perceived pros and cons of telehealth. The convenience and availability of telehealth were viewed as positive, consistent with other reports of the increasing acceptability and feasibility of remote treatment delivery methods (Gorrell et al., 2022; Graell et al., 2020; Raykos et al., 2021). The transition from in-person to telehealth-based treatment warrants careful planning for successful implementation (Goode et al., 2023). One participant expressed concern about the ability to be transparent and remain accountable when receiving therapy virtually because of the ego-syntonic nature of the disorder. This concern is not among those previously mentioned in studies of the challenges of telehealth (Couturier et al., 2022; Waller et al., 2020) and warrants further consideration especially in recently discharged populations.

There was uniform positive regard for the use of a platform to deliver materials supporting the treatment. Participants liked the ability to interact on the platform with their therapist and to access materials between sessions. The focus groups liked the content and offered suggestions for improvement. Consistent with the iterative process of user-centered design (Graham et al., 2019), this stakeholder feedback has been integral in enhancing the platform. In response, creators of the REACH+ treatment (EA, DRG, and JES) added additional podcasts, videos, and handouts in various formats to improve variety and usability. Of note, one video was created by a focus group facilitator (EA) to summarize the power of recovery stories shared as part of this study. The resulting study will collect data on platform use, request feedback on materials and their formats, and make iterative modifications.

This study has several strengths, including representing the preferences of individuals with a history of AN, a population not typically provided with opportunities to co-design their life-saving care. The focus group format allowed facilitators to follow a semistructured interview guide to get input on the same topics across groups while also permitting flexibility to deviate in ways that produced previously unconsidered feedback. Such suggestions are already being implemented in an NIH-funded trial. Participants were selected from an expansive longitudinal study of individuals who received inpatient AN treatment regardless of socioeconomic status and health insurance coverage. REACH+ has been developed to treat AN, specifically. As there are many individuals experiencing eating disorders, additional work would be required to co-design an online treatment for other types of eating disorders. Given the relatively short timeframe in which AN can produce lifethreatening medical complications, more may be known about AN than other groups who face barriers to diagnosis and treatment.

The primary limitation was sample size and homogeneity. Cohort differences might have been helped by a third focus group, which was not possible within the timeframe and scope of the treatment study. Fifty percent of individuals invited to participate in this study did not reply; their reasons for not responding are unknown but may have offered important perspectives. Though there are many advantages to using qualitative methodology, researcher bias and/or demand characteristics of those who choose to participate are notable potential limitations. Additionally, illustrative quotes were included in the paper's body; selection may have been influenced by researcher bias. Researcher biases may also have influenced the question selection. This is partially mitigated by the inclusion of a range of responses in the data tables, reporting of possible author biases, and co-author agreement on quote selections. In addition, RQAP by design may lack detail and nuance. The investigative team will request further feedback from participants who receive REACH+ as part of our commitment to iterative collaborative design.

The evolution of the collection of gender and sex information at this research institution demonstrates the importance of how researchers collect demographic information. Qualitative research in racially, ethnically, socio-economically diverse individuals of all sexes and genders could be used to improve treatment design and elicit stakeholder perspectives to answer questions related to the treatment of and recovery from eating disorders and to improve care for this vulnerable population. Future endeavors are needed to include perspectives from a range of stakeholders including those who face barriers to diagnosis and treatment, and those with intersectional identities who face systemic barriers to evidence-based intensive care.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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TABLE 1

Participant demographics

	Admission subtype	Race	Ethnicity	Admission education level	Admission age (years)	Years since hospitalization	Admission BMI	Current BMI	Location
P1	AN-R	Asian	Non-Hispanic	Bachelor’s degree	34	6.4	17.3	19.4	West Coast
P2	AN-R	Caucasian	Non-Hispanic	Bachelor’s degree	38	12.6	14.2	20.2	Southeast
P3	AN-R	Other	Hispanic	10th grade	16	6.7	16	22.9	Northeast
P4	AN-R	Caucasian	Non-Hispanic	High school diploma	22	12.0	17	21.3	West Coast
P5	AN-BP	Caucasian	Non-Hispanic	Bachelor’s degree	23	5.2	18.1	20.1	Northeast
P6	AN-R	Caucasian	Non-Hispanic	Master’s degree	33	5.0	17.4	19.9	Northeast
P7	AN-BP	Caucasian	Non-Hispanic	Bachelor’s degree	25	11.9	16.1	22.6	Southeast

Note: P# used to distinguish between participants. Participants P1–P4 attended the first focus group and participants P5–P7 attended the second focus group.

Abbreviations: BMI, body mass index; BP, binge/purge subtype; R, restricting subtype

TABLE 2

Themes about recovery following inpatient treatment for anorexia nervosa.

Domain	Category	Description	Illustrative quote(s)
Recovery aids	Finding a passion	Multiple participants reported that finding something separate from the eating disorder to dedicate themselves to has been beneficial in the recovery process. New interests allowed for a different sense of purpose and perspective, and new motivations.	P4:“*Something I did prior to [this program] and after* was *working with kids as a preschool teacher and I found that working with young children, like 3–4 years old, I was able to see life and food through their eyes, like them getting excited about a cupcake or getting excited about the little things in life. Being around that made me see things in a different light.*” P7: “*And then I went to grad school … leaving my town where I was ‘that’ sick person in and out of treatment … I think having this new identity and getting interested in the field I was studying and realizing that I have a lot more to offer in different ways and there was so much more about me [helped]. For me the engagement with life outside of [anorexia nervosa] was so much more of what switched for me.*”
	Choosing therapeutic components	Participants described that picking and choosing the components of treatment they found helpful, using their own sense of agency rather than relying solely on treatment recommendations, was helpful.	P1: *So, I kind of got a sense of what was helpful for me … because I have been dealing with this for several decades and so realizing these various treatment centers, this is what stuck…, this is what kind of fell flat. [I could see] … the trend of behavioral intervention or behavioral methods that really target some very autopilot habitual behaviors of mine tend to be more effective and long lasting for me …*” P1: “*One practical thing that’s been really actually surprisingly life-changing has been not weighing myself … before I would have a scale and be like ‘okay’ or even be blind weighed at the nutritionist or the doctor, but not being weighed at all actually teaches my brain that it just doesn’t flipping matter how much you weigh. Well, if you’re at a weight that’s dangerous then that is different … anyways I have problems with the BMI. But not doing that [weighing] has been helpful and on my annual physical, allowing my doctor to weigh me just as part of the protocol.*” P3: “*I stopped weighing myself and that made life so much easier. The nervousness around the whole part of my life at that time always revolved around that number. And even after I left [a private treatment center], I would do blind weights at the doctor - that was about 7 years ago. Ever since then I haven’t weighed myself, I didn’t care about the number, it did not matter to me anymore.*”
	Journaling	Participants found it useful to write down thoughts and feelings during and after recovery.	P4: “*…something that helped me from when my eating disorder developed all the way into [this program] and past that with general things in my life is journaling. I feel like that was a way for me to get my thoughts out and remove those eating disorder thoughts from me and make me able to look at checking the facts and the evidence (… or not) behind it.*”
	Recovery podcasts	Listening to others’ lived experiences (both ED-related and not) in podcasts was helpful.	P1: “*Also listening to recovery podcasts and stories about badass women has been really helpful. So, those things have kind of been pillars for me.*” P4: “*I thought what if we had podcasts about people who have been discharged from [this program], who have been previous participants and what their recovery stories were prior and after? So then not only are they [current patients] listening to someone’s story, but someone who had been at [the same program they are at].*”
	Cognitive strategies	Participants described coping strategies used to help them throughout the recovery process that specifically focused on tolerating cognitive processes.	P4: “*Also thinking of my brain as like a radio and imagining turning the volume down and not listening. And then…getting back in touch with the things I loved to do, getting back in nature and listening to the waves or wind and trees.*”
	Behavior change strategies	Interrupting routines associated with the ED was useful, whether it was reminders to break habits associated with restrictive eating or making bigger life changes.	P5: “*… using [a food diary contained in smartphone application] … was helpful for… remembering [to eat] … like mechanical eating… I set up reminders for 6 times a day for meals. And that lived on my phone for up until last year or the year before, and it just formed inside your brain, ‘you got to go eat something, you got to go eat something’. Even if you don’t do it that moment, just seeing it on my phone was like ‘right’. So, that was shockingly helpful.*” P7: “*I think that part of moving [cities] for me and having to change my life was really helpful and changed my habits.*”
	Psychoeducation	Psychoeducation helped participants combat ED thoughts	P2: “*Actual information telling me my body needs this in terms of nutrition in order to run a marathon and things like that. So, it* was *formulating a place within my own head and having that information readily available.*”

Domain	Category	Description	Illustrative quote(s)
Recovery hindrances	“Traditional” psychotherapy approaches	Conventional methods for treating recovery sometimes viewed as not helpful by some participants who had a long duration of illness	P7: “*I think it was the messaging that I had to do in a certain way [that did not help], and that if I didn’t then I wasn’t ever going to get recovered. I really did well with providers that were willing to engage with me where I was at and work with me on harm reduction, and planting seeds, and hope. I think sometimes it’s really black and white - ‘if you don’t do this, your life is going to be terrible and awful’ - how I phrase it with people is that I think it will be a lot harder, I think having an eating disorder sort of makes it harder to do these things but it’s not that black and white. And I think that really helped me keep hope to move forward.*”
	Insensitive or stigmatizing comments by providers	Some comments made by providers created more fear or anxiety around weight or eating, instead of helping	P5: “*There was a resident that just looked at me multiple times and said, ‘You’ll never be fat.’ Okay, but what if I am? Then what? … That shouldn’t matter … and [the comment] is just reinforcing the fear. It was fatphobic, but I think it was just a lack of knowledge.*”
	Lack of access to resources	Some patients had a difficult time accessing resources after inpatient treatment	P2: *I had to go back into getting a job and was thrust back into situations lacking a support system in terms of counseling or therapy or anything like that.*” P5: “*So I did not have insurance that was accepted by basically anything. So, I went straight from inpatient to outpatient, there were no other steps.*”
Important members of support system	Family	The presence of family members was expressed as a useful network of support during recovery	P6: “*The one thing that I did have was my family - I had a very strong support system. But that was with me from the beginning of treatment, at [this program] through now. So that is kind of what I relied on the most, I would say.*”
	Significant other	The presence of a partner was expressed as a useful network of support during recovery	P3: “*And during that time, I also met my fiancé and everything. So, just also having that extra support with me and opening up to someone else other than my parents, my siblings, my therapist and everything always felt so much more relieving …*”
	Animals/pets	The presence of pets was helpful and calming during telehealth sessions	P4: “*Well, I bring my cats to sessions, and they bring their lizards and guinea pigs and stuff. So, I find that those are the beneficial things about telehealth. Being in your own home and having your comforts with you, like pets.*”
	Peer-led support activities	Taking part in discussions with other people with eating disorders aided in recovery	P1: “*What I found to be helpful for me were support groups…I think it depends on the composition of the group, but it tends to be, if you’re in a strong group, very solutions-oriented or recovery-minded with a focus on behavioral change.*”

Note: P# used to distinguish between participants. Participants P1–P4 attended the first focus group and participants P5–P7 attended the second focus group. Quotes were edited slightly for brevity and clarity.

Abbreviation: ED, eating disorder

TABLE 3

Feedback on specific elements of REACH+.

Element	Description	Illustrative quote(s)--beneficial for recovery	Illustrative quote(s)--not beneficial for recovery
Continuity of care	Continuing to work with familiar professionals, as opposed to switching programs.	P6: "*So, after [this program] I went to [a private treatment program], I did the whole step-down process. So, I was a partial inpatient … and then did the outpatient [program]. Then, I went to full outpatient and then saw a nutritionist and therapist on my own … it's so hard when you have to start over with a new treatment program …it just kind of felt like nobody got me or my story or whatever, so I had to start all over. That's also why I am very excited about this program, to hear about it. Just about having the same doctors, the same care once you get out and back to your normal routine …*" P4: "*So, I wish that when I got discharged from [this program] there had been access to that so I wouldn't have had to find an outside provider here. It would have felt like there were more of a continuity of care … I think it would have been really nice. There were outpatient options available at [this program] but I couldn't go to it.*"	–
Telehealth	Interacting with a provider online.	P4: "*I would have really enjoyed having a telehealth step-down … I've noticed that if you have step downs that are more gradual, I feel like telehealth after inpatient is not quite PHP, but it isn't quite outpatient, it seems to be somewhere in the middle. You have multiple sessions a week and then it varies out. I feel like that would have been very helpful.*" P3: "*Yes, I agree with P4 that the availability of telehealth after discharge would have been helpful for a large majority of people.*" P6: "*I think it's [telehealth] also super convenient. I've been fortunate enough to have private space, and it also works out well with lifestyle challenges like having kids or even commuting, all that stuff. So, I think it's great.*"	P3: "*I think that in-person it is kind of hard to lie or have your habits come in. I know that when I was in the depths of my eating disorder, that I would always lie. I was a master manipulator and liar. I knew how to play people–you know what I mean. Because my habits were my thing, and my life revolved around it. So, I think the telehealth might make it hard for people to be accountable for their own behaviors …*"
Regular weighing	Consistent weighing as part of a telehealth treatment.	P2: "*I never weighed myself, which is why now I weigh myself to hold myself accountable, which is sort of a flip from what most people have said.*" P4: "*So, at [this program] we were shown our weights. And that kind of desensitized me to actual numbers. Because I saw those numbers so many times a week, so to this day I don't really have a problem with seeing my weight at the doctor's … Even the size on my clothes, when I saw the number, it was just like, 'Welp, got to get over it.' … it's a number, the number doesn't mean anything. So, I think I kind of had a different experience where to this day, numbers don't mean anything to me.*" P3: "*I think that being weighed and having to acknowledge the number, which I understand is part of being therapeutic and everything, I think it's okay only because patients would have a support after seeing it. There is a big difference when you do it on your own. I remember when I would weigh myself on my own, I would feel a lot of shame, anxiety, nervousness and feeling like that sense of failure or something. But I feel like if it is done and my therapist or somebody is there to help me, then … that is a better environment and situation to be in, rather than when I don't want to weigh myself and don't want to see the number … there is someone to help me if I am feeling very anxious of my weight going up.*" P1: "*… knowing my weight at different times in my recovery has had different significance or power. But I think, being discharged, [weighing yourself] actually does matter for a period of time. And I think that if I were to be discharged from an intensive inpatient unit, I think that it would be helpful and necessary for someone to monitor my weight, if not me, because if I were to just revert to my normal habits, being in my old environment, I would probably just end up losing weight honestly, because I think those triggers would still be there.*"	P1: "*I think just right now where I am, being at a steady healthy place, if I weighed myself regularly it would reinforce that idea that this number actually matters. And before I would have a scale and be like 'okay' or even be blind weighed at the nutritionist or the doctor but not being weighed at all actually teaches my brain that it just doesn't flipping matter how much you weigh.*" P7: "*Maybe giving the person the option, I think would be my only feedback. I think if they want the exposure piece and can handle that, then that's great but if they feel they need to be self-protected and not see that, then I think that maybe we should give them that option.*"
Online platform	Online platform organization,	P4: "*I liked the habit tracker that was on there, especially after you talked a little bit about the brain circuits, how that's a part of it and included that … I think what you*	P1: "*I am not huge on wanting to be on screens, but I think that the different themes were attractive, you know my curiosity had me*

Element	Description	Illustrative quote(s)--beneficial for recovery	Illustrative quote(s)--not beneficial for recovery
	content, and viability as a treatment extender.	*set up which is essentially telehealth, like you and your therapist screenshare and go over how things are going, I think that's important. Because I feel like when you do an individual session in-person, it is hard to have all of that, I don't feel like it's put on paper or into words. I mean like I've gotten worksheets like that, but to be able to see it and summarize it and be able to access what we are doing here … it seems more comprehensive in treatment, that it's all there and you're able to access each part of it.*” P3: “*I think what you showed us, I really like that each thing has its own section and that it was easy to read, easy to access. Also, I really liked that, well personally since the pandemic happened, I have been online for school, and the setting kind of reminded me of some of the classes I had, but not in a bad way. … and it's structured similar to that, but yours was much easier to understand and get to.*” P7: “*The other piece you talked about that I thought sounded really nice was the kind of library of media to access, because I think there are a lot of great resources to access online and there are also just terrible resources. And figuring out what is good and what is bad can be really triggering and upsetting for some people. So, having a library that you can engage in when you need it and then having your therapist engaging in the same library sounds like a great way to fill the time between sessions with material that is going to be pro-recovery and encouragement and motivation and behavioral in a way that feels safe.*”	*wondering what was behind this tile or what kind of options are here. Also, I'd say that I am an auditory learner … so I tend not to gravitate towards worksheets … or reading things on my own. So, maybe just think about different types of people and how they learn … and prefer to receive information. I would definitely go straight to a podcast, or anything audio I would do.”* P2: “*I think having, and I don't think they should be super specific or super varied, but just having the option, I think that's something the podcast should provide, or the level of specificity in the fact sheets. Some people will need more of the facts, some people need more guides. So that would be my sense.*”
In-session eating experiments	Collaboratively working through eating experiences during sessions.	P5: “*[In-session eating experiments] sound like a more organized version of a process meal … I also think it can be framed as a great challenge, like I feel comfortable eating even when someone else isn't eating, hmm let me see if I can work through this … I do think it's maybe a good way to face that challenge.*”	P7: “*… I can appreciate the therapist can't eat every single session, all day long. But I think that part of the stuff with the meals that can be really great is just normalizing meals and making it kind of an engaging, fun activity, so if you can have a good conversation during it that's not just mental health therapy stuff, I think that would be challenging, in talking about challenging things, or just silence. So, if it's done in a way that's normalizing and engaging.*” P6: “*I think it would be a little odd to just be eating by myself and having someone watch me … I guess I haven't really experienced that, but just off the top of my head, it sounds a little awkward, being on camera and eating. But maybe, I don't know if there is some way to ease the transition of that or I don't know.*”
Treatment foci	Some patients expressed interest in having therapy sessions focus on emotions, rather than solely on behavior change, thinking, and motivation.	–	P5: “*I'm all for behavioral sessions, but … maybe trying to take a few steps back and, you know … more mental … or emotional exploration. That was a big thing that I was a missing with my counselor, I kind of felt like I needed more to understand who I was and why I needed the things that I did in order to stop the behaviors. I needed more insight and clarity on any trauma or my biology, you know like why I chose that and not substance use, you know what I mean, like why is this my choice of maladaptive behavior?*” P7: “*Well, I think it depends on how structured it is, right? … I get frustrated sometimes in the recovery process when they just go to the behavioral portion and then later, we can deal with the emotions, but for me those are the same thing. As eating happens, the emotions come up … and if you say, ‘hey don't talk about that yet’ when you're in a safe secure environment, that can be really challenging.*”

Note: P# used to distinguish between participants. Participants P1–P4 attended the first focus group and participants P5–P7 attended the second focus group. Quotes were edited slightly for brevity and clarity