

ORIGINAL ARTICLE

Adolescent Patient Perspectives on Family-Based Treatment: A Pilot Study

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ABSTRACT

Objective: Family-based treatment (FBT) is the recommended first-line treatment for adolescent eating disorders (EDs), yet evidence suggests it is effective for only 50% of youth. Ambivalence about initiating treatment and/or recovery predicts treatment nonresponse for youth with other psychiatric disorders and may also contribute to poor FBT outcomes. Thus, understanding patient perspectives on FBT is essential to mitigating challenges to treatment acceptance, with great potential for improving treatment efficacy.

Methods: A qualitative, inductive approach was used to develop hypotheses about adolescents' perspectives on FBT and patient-perceived facilitators of ED recovery. Semi-structured interview data were analyzed using a grounded theory methodology.

Results: Interviewees ($N=10$) expressed ambivalence toward FBT—particularly its use of parental empowerment and pragmatic focus on weight recovery. Many participants stated that FBT was effective, necessary for recovery, and improved relationships with caregivers; however, some reported that a perceived lack of agency and sidelining of psychosocial distress and family conflict negatively impacted their treatment engagement. Regarding ED recovery, participants reported a preference for cognitive/emotional aspects of recovery and framed recovery as an ongoing or lifelong process. Peer support was identified as an important facilitator of behavior change.

Discussion: Findings support addressing adolescent concerns (e.g., psychosocial well-being, agency, connection with peers, and family relationships) within the FBT framework. Results may inform future FBT implementation and adaptation and suggest the need for continued investigation of the treatment experience from multiple perspectives (i.e., patients, family members, and clinicians).

1 | Introduction

Eating disorders (EDs) are serious mental health conditions associated with elevated mortality (Richards et al. 2018), high potential for relapse (Venturo-Conerly et al. 2020), and, for

many individuals, an enduring course of illness (Richards et al. 2018). As such, early detection and effective treatment in adolescence, the period of peak ED onset, are especially important for long-term prognosis (Richards et al. 2018; Uhlhaas et al. 2023).

Summary

- This pilot study is one of the first to interview youth directly about their experiences in family-based treatment (FBT) for eating disorders.
- We found that youth had mixed feelings about FBT. Some reported that it was effective and necessary, while others felt that their emotional well-being and agency were overlooked.
- Adaptations like additional one-on-one therapy time with youth or structured peer support may help youth feel more supported in treatment.

Family-based treatment (FBT) is the recommended treatment for adolescent anorexia nervosa (AN). Although FBT has demonstrated superior outcomes in achieving weight gain in adolescent patients with AN compared to other evidence-based approaches (Le Grange et al. 2022), roughly 50% of youth remain unremitted following a standard course of FBT when remission is defined as *both* weight restoration (to 95% of estimated body weight) and decreased ED psychopathology to within 1 SD of community norms (Le Grange et al. 2016; Lock et al. 2010). Improving rates of remission in this high-acuity clinical population is urgently needed, an effort that can be informed by evidence from the study of factors that impact treatment outcomes.

Although much work has been devoted to studying biological, psychological, and treatment-related predictors of outcome (Berends et al. 2016; Fassino et al. 2009; Le Grange et al. 2014; Schlegl et al. 2016), ED research rarely engages adolescent patient perspectives, perhaps due to the belief that their degree of malnutrition during early treatment or their young age compromises insight into their treatment experience. However, this omission excludes a valuable voice in how treatments are imagined and designed and in guiding what indices are used to evaluate and determine relative treatment outcomes. Specific to FBT, few studies have qualitatively examined adolescent perspectives on their FBT experience (Medway et al. 2019), and only a handful of studies about adolescent experiences with a range of family therapy modalities for EDs suggest potential patient-level critiques about these treatments (Conti et al. 2017; Halvorsen and Rø 2019; Le Grange and Gelman 1998; Nilsen et al. 2021; Singh et al. 2018).

1.1 | Adolescent Perspectives on Initiating ED Treatment

Family therapies for EDs (including FBT) consider caregivers as important allies in treatment (Gorrell et al. 2023; Loeb and Le Grange 2009) and center around empowering parents to intervene to support their child's recovery. Evidence across different adolescent treatment modalities suggests that reluctance to relinquish control of eating behavior to caretakers is a considerable barrier to initiating treatment (Griffiths et al. 2018; Nilsen et al. 2021; Venturo-Conerly et al. 2020). In qualitative and survey-based studies of inpatient-based family therapy, some participants also identified neglect of underlying issues, such as family conflict (Halvorsen and Rø 2019;

Nilsen et al. 2021) or the cause of the ED (Halvorsen and Rø 2019), as shortcomings of the treatment models they experienced. One FBT case study found that the adolescents experienced a sidelining of their internal emotional experience and a diminishing of their agency in the recovery process (Conti et al. 2017). These studies collectively raise questions about the extent to which adolescents receiving FBT may experience tension with its principles (e.g., parental empowerment and pragmatism) and how the experience of the FBT model among each of the participating family members may perhaps differ. Although some work has attributed patient ambivalence toward recovery and treatment (Casasnovas et al. 2007; Halvorsen and Rø 2019; Nilsen et al. 2021; Venturo-Conerly et al. 2020) to the ego-syntonic nature of restrictive EDs (Gregertsen et al. 2017), other factors (including aspects of the treatment itself) may contribute to adolescents' reluctance to engage in FBT. Adolescents may have valuable insight into which components of therapy are instrumental in aiding their recovery as well as those that might be modified, largely unexplored, that have the potential to improve adolescent engagement in treatment and overall treatment outcomes.

1.2 | Adolescent Perspectives on Recovery

Through their lived experience, adolescents may also provide valuable perspectives on how progress in treatment should be evaluated and how recovery from an ED is defined. Historically, clinicians and researchers have often used physical criteria (e.g., percent median BMI, percent of expected body weight, resumption of menses) as indicators of remission and recovery when evaluating ED treatment outcomes (e.g., Eisler et al. 1997; Khalsa et al. 2017; Robin et al. 1999; Russell et al. 1987). However, more recent work suggests interest among clinicians and researchers in expanding the definition of ED recovery to include factors like cognitive improvement, emotional well-being, and quality of life (Bardone-Cone et al. 2010; Wade and Lock 2020). Moreover, a review of qualitative investigations of patients and caregivers who had engaged in a range of treatment types suggests that they also place high importance on psychological well-being and eating behaviors as treatment goals (Richmond et al. 2020). Some qualitative studies centering on the patient voice have even contested the use of weight as a valid measure of recovery altogether, citing the use of weight as a barrier to care for AN (Barko and Moorman 2023) and advocating for the usage of social, emotional, and psychological metrics of recovery instead (Bohrer et al. 2020; Kenny et al. 2020; Nilsen et al. 2020; Wetzler et al. 2020).

1.3 | The Current Study

Prior research has sought to examine patient perspectives on ED treatment protocols and interventions (e.g., Venturo-Conerly et al. 2020; Rienecke et al. 2023); however, few studies have assessed adolescents' experiences regarding FBT specifically (Le Grange and Gelman 1998). Additionally, as the field's definition of ED recovery and remission continues to evolve, it is important to engage with adolescent perspectives on the topic of their own recovery. Toward this goal, the present qualitative study ($N = 10$) conducted semi-structured interviews to examine the

perspectives of adolescent patients diagnosed with an ED on (1) their experience in FBT, (2) motivations driving any reluctance to engage in FBT, and (3) their definitions of ED recovery. This study was exploratory, with no *a priori* hypotheses to guide interviews or analysis.

2 | Methods

2.1 | Study Sample and Procedure

To capture a wide range of experiences with the FBT model, we recruited participants (aged 13–25 years old) who were either in Phase 2 or 3 of FBT ($n=7$), had completed FBT ($n=2$), or had discontinued prematurely ($n=1$). Patients in Phase 1 of FBT were excluded to minimize the potential impact of our study on factors that are a specific focus in this treatment phase (e.g., parental empowerment and the establishment of therapeutic alliance).

Participants were recruited (June–July 2023) from a comprehensive multidisciplinary ED program at an academic medical center in the United States. Patients were referred to this study by members of the ED program. We invited clinicians in the ED program to refer to us any current or recently completed patients who may be interested in the study. All clinicians were trained in and held a high degree of FBT experience. We received 11 referrals from team clinicians. All 11 accepted the invitation to participate; 10 completed the interview, and 1 was unable to complete the interview due to scheduling constraints. As this exploratory study aimed to generate initial hypotheses on adolescent experiences with FBT to inform future work, data saturation was not used as a criterion for determining sample size. Rather, with the support of referring clinicians who were asked to help identify patients who held identities underrepresented in ED research (i.e., queer and transgender patients, non-white patients, cisgender males), we used targeted recruitment (planned for up to 12) for diverse representation across diagnosis, stage of treatment, and gender identity. We aimed for a sample inclusive of the broad range of patients who undergo FBT, which includes patients with AN as well as BN diagnoses; thus, we did not restrict recruitment based on diagnosis.

Informed consent/assent was obtained from all participants and their caregiver(s) (for minors). All interviews were conducted by the lead author (CG) over a HIPAA-compliant video conferencing platform, recorded, and transcribed verbatim manually. Semi-structured qualitative interviews were conducted using an interview guide developed by CG and the research team (available in Supporting Information: Supplement A). Participants were compensated with a \$50 gift card. This study was approved by the supporting Institutional Review Board.

2.2 | Treatment Modality

FBT, a first-line outpatient treatment for AN, has three phases. In Phase 1, caregivers are encouraged to take responsibility for their child's eating and exercise decisions, with the goal of weight restoration and restoring a regular pattern of eating behaviors. Responsibility for eating is gradually transitioned back to the adolescent during Phase 2, and the focus shifts to

normal adolescent developmental concerns in Phase 3. FBT is undergirded by five fundamental tenets (Riencke and Le Grange 2022):

The therapist holds an agnostic view of the cause of the illness; The therapist takes a non-authoritarian stance in treatment; Parents are empowered to bring about the recovery of their child; The eating disorder is separated from the patient and externalized; and FBT utilizes a pragmatic approach to treatment, with the focus on the present.

All study participants worked with licensed clinicians with a high degree of FBT expertise.

2.3 | Data Analysis

Due to the exploratory nature of the study, we took a grounded theory approach to analysis, in which iterative coding (using NVivo software) was used to inductively identify themes from interview data. An initial codebook generated by CG using six interview transcripts (representing a range of ages, treatment stages, and gender identities) was reviewed and revised by four clinician-researchers (co-authors) with significant expertise in FBT and adolescent ED treatment. The updated codebook was then applied to all interviews.

2.4 | Researcher Identity

The study lead (CG) has extensive training in qualitative research methods via a master's degree in community health research and is an expert by experience (participated in FBT for treatment of AN during adolescence). The remaining co-authors are practicing clinicians with a high degree of expertise in FBT and EDs.

3 | Results

Participant demographics are summarized in Table 1. The mean age was 16.00 years ($SD=2.4$, range: 13–21 years). All participants had initially received a DSM-5 AN diagnosis (restrictive subtype, $n=5$; binge-purge subtype, $n=1$; atypical, $n=4$) via clinical interview. Half of the interviewees ($n=5$, 50%) were White, and the majority were cisgender females ($n=7$, 70%).

Four main topic areas emerged from participant responses: perspectives on core principles of FBT, deterrents to treatment engagement, definitions of recovery, and recovery outside of treatment. Representative quotes are provided in Table 2.

3.1 | Patient Perspectives on Core Principles of FBT

Two participants reported predominantly positive experiences in FBT, two reported predominantly negative experiences, and six

TABLE 1 | Participant demographic and clinical characteristics.

	<i>M</i>	<i>SD</i>	<i>Range</i>
Age (years)	16	2.56	3.00–25.00
Duration of FBT (months) ^a	24	8.9	12–36
	<i>n</i>	%	
ED diagnosis ^b			
AN-R	5	50.0	
AN-BP	1	10.0	
Atypical AN	4	40.0	
AN-R, then BED	1	10.0	
FBT status			
Phase 2	5	50.0	
Phase 3	2	20.0	
Completed > 1 year ago	2	20.0	
Discontinued early	1	10.0	
Race/ethnicity ^{b,c}			
White	5	50.0	
Hispanic/Latino	1	10.0	
Asian	3	30.0	
Black/African American	1	10.0	
Not indicated	1	10.0	
Gender ^b			
Cisgender girl	7	70.0	
Cisgender boy	1	10.0	
Transgender boy	2	20.0	

Note: *N* = 10.

Abbreviations: AN-BP, anorexia nervosa, binge-purge type; AN-R, anorexia nervosa, restricting type; BED, binge eating disorder; ED, eating disorder; FBT, family-based treatment.

^aDuration of FBT refers to the duration in months that the participant was receiving FBT at the multidisciplinary ED program where this study was based.

^bED diagnosis and race/ethnicity percentages add up to > 100% due to some participants being counted in multiple categories.

^cRace/ethnicity and gender are reported based on data available in participants' electronic medical records.

reported ambivalent experiences. Participants' reflections were analyzed according to the five core principles of FBT (Rienecke and Le Grange 2022): parental empowerment, pragmatism, agnosticism, externalization, and non-authoritarian therapeutic stance, which emerged as themes during initial codebook creation.

3.1.1 | Agnosticism

FBT takes an agnostic approach to the cause of the ED. In contrast, all four participants who discussed this principle reported that addressing the cause of the ED, especially sociocultural contributors (e.g., weight stigma and gendered beauty standards),

was important to recovery; some expressed that they believed they were unable to do so in FBT.

3.1.2 | Non-Authoritarian Stance

FBT instructs clinicians to assume a collaborative, non-authoritarian stance when working with caregivers to nourish the patient. Participants commented on this principle least often. Three participants reported sometimes feeling a lack of agency for themselves and caregivers during treatment.

3.1.3 | Parental Empowerment

Parental empowerment refers to FBT's initial focus on empowering caregivers to assume control over eating and ED behaviors. All 10 participants reported negative perspectives on the principle, though 7 also reported positive perspectives. Per negative aspects, participants stated that conjoint therapy with caregivers deterred them from communicating honestly with their FBT clinician about sensitive topics (e.g., body image concerns, depression, anxiety, and gender dysphoria) (*n* = 5). Participants also reported that topics discussed during sessions would lead to conflict at home or be shared with caregivers without their consent (*n* = 5); that they felt mistrusted or misunderstood by caregivers during therapy (*n* = 4); that caregivers were unhelpful to their recovery (*n* = 4); or that they had difficulty transitioning away from caregiver supervision after FBT Phase 1 (*n* = 4). Of note, one participant experienced significant difficulty regaining agency after Phase 1 and reported that limited practice with making their own eating choices at the start of FBT contributed to a relapse and subsequent development of binge-eating disorder.

Per positive aspects, three participants reported that parental empowerment was necessary for their recovery, four reported that it built understanding with their caregivers, and four reported that it demonstrated caregivers' support and care.

3.1.4 | Externalization

FBT encourages families to see the ED as separate from the patient's own identity. One participant believed that externalization helped them accept treatment; three participants reported that this principle could feel disingenuous or could be used to undermine their agency and identity.

3.1.5 | Pragmatism

FBT focuses predominantly on weight restoration and symptom reduction, especially in the early stages of treatment. Four participants expressed that an early focus on weight gain and behavior change helped reduce their emotional/cognitive symptoms. Ten participants reported negative aspects of a pragmatic approach, such as neglect of emotional challenges or co-morbid psychiatric conditions, as well as stress associated with focusing on weight as a treatment goal. One transgender participant expressed that the focus on weight restoration above other concerns delayed access to gender-affirming care.

TABLE 2 | Example interview quotes about the five tenets of family-based treatment.

FBT tenet and subtheme	Example quote	n (%)
Parental empowerment		10 (100.0%)
Negative subthemes		10 (100.0%)
Decreased honesty with clinicians	"We would go in front of my parents, and they'd ask me like questions that I would want to answer truthfully, but I really just didn't feel comfortable doing it in front of other people ... I would honestly have told them the truth if I wasn't in front of my parents." (Age 13, Phase 3, atypical AN, White, cisgender girl)	5 (50.0%)
Heightened conflict with family	"It made a lot more arguments. I'd go to therapy and whatever we talk about would get me all riled up because I wouldn't be listened to, and it was all of this shit that I didn't want to talk about so I'd leave feeling like shit. And I'd cry on the car home." (Age 13, Phase 2, AN-R, White, cisgender girl)	5 (50.0%)
Misunderstandings and decreased trust with family	"I tell her [mother] that I'm full. And she'll ask me, 'Are you really full? Or do you just not want to eat it?' And tell her multiple times that I am. And then I'll ask her, 'Do you believe me?' and she'll say, 'I genuinely don't.' Sometimes it'll make me really upset. And then I won't eat kind of in protest, or I'll be so mad or upset that I just don't feel like eating." (Age 13, Phase 2, atypical AN, mixed-race [Black, Latinx, white], transgender boy)	4 (40.0%)
Parents as unhelpful	"I don't really let them in anymore. Like, when I'm struggling, I go to my friends. I don't go to my parents. And if I do mention something, they treat me like I'm about to explode. It's like they're walking on eggshells, because it kind of turns into, 'oh, there's something wrong, what did we do that made it', not like, 'this is happening, how can we approach it together.'" (Age 18, discontinued treatment, atypical AN/AN-BP, race/ethnicity unknown, transgender boy)	4 (40.0%)
Difficulty regaining agency	"It's not enough independence for the child. I didn't really have a choice in my snacks... a lot of the times I didn't get to make that relationship with food. I think that [developing BED] could have been prevented if I had like focused on more like, how to deal with like making food choices yourself, not like having it like served to me and like not having it based on like my family watching me." (Age 16, completed FBT > 1 year ago, AN and BED, Latinx, cisgender girl)	4 (40.0%)
Pressure on family	"I think it put a lot of stress on her [mother] too, because she would always have to, like, watch what I eat, she would have to plan my meals, snacks, and she had work and other kids. I feel like she felt really overwhelmed by like always having to hear like, 'Oh, this is what you should do.' Like, 'You should have to do this.'" (Age 16, completed FBT > 1 year ago, AN and BED, Latinx, cisgender girl)	1 (10.0%)
Positive subthemes		7 (70.0%)
Necessary to recover	"The unwavering support of my parents in that, like, kind of no matter what they were gonna feed me to the point to where I was physically healthier, and then my brain got healthier to the point I personally could start doing the work of recovery. Like, I definitely would not ever have been able to do that without someone else just like getting food in me for like, months." (Age 23, completed FBT > 1 year ago, atypical AN, White, cisgender girl)	3 (30.0%)
Family support and care	"It helped because it felt like we were doing it together. And they can help me when maybe I forget something, or if I'm not sure if I'm doing the right thing." (Age 16, Phase 3, AN-R, Asian [Burmese and Chinese], cisgender girl)	4 (40.0%)
Increased understanding between parents and adolescents	"I feel like Family-Based Treatment helps me to be able to educate my family. My mom is able to hear what I have to say about how I feel when it comes to my eating disorder. And then she's able to hear how to actually treat it or how to help." (Age 13, Phase 2, atypical AN, mixed-race [Black, Latinx, and White], transgender boy)	4 (40.0%)
Agnosticism		4 (40.0%)

(Continues)

TABLE 2 | (Continued)

FBT tenet and subtheme	Example quote	n (%)
Negative subthemes		4 (40.0%)
Addressing ED cause is important to recovery	"I mean, there was a reason I had an eating disorder. And the first time I got diagnosed with anorexia, all anybody was trying to do was put weight on me, which wasn't bad. But nobody was trying to fix the reason that I had an eating disorder. So I didn't get better, which was why I relapsed. Because weight didn't fix everything." (Age 13, Phase 2, AN-R, White, cisgender girl)	4 (40.0%)
Immersive culture of disordered eating	"One thing that maybe even started my eating disorder was I had this one good friends at lunch. I would be eating my food and she wouldn't have anything. And she'd be like, she'd point out stuff other people are eating. And she'd be like, 'Oh my god, like how could they eat that like, that's so bad,' or something like that. And then just make me feel really guilty for like, whatever I'm eating." (Age 13, Phase 2, atypical AN, mixed-race [Black, Latinx, and White], transgender boy)	4 (40.0%)
Pragmatism		10 (100.0%)
Negative subthemes		10 (100.0%)
Neglect of emotional difficulties	"It's almost made my parents prioritize my physical health over my mental health. When I was struggling the most mentally and emotionally, and I struggled a lot with that at the beginning, it was something that was really not talked about as much as I would have hoped or wished for." (Age 17, Phase 2, AN-R, White, cisgender girl)	9 (90.0%)
Stress from focusing on weight	"When I would get weighed in weekly, when I saw that I was gaining weight it felt like the world was ending ... that was so distressful to me that I started struggling with self-harm behaviors. And struggling with that makes me think, was all that worth me now being comfortable with knowing my weight? Or would it have been better if I just never knew." (Age 23, completed FBT > 1 year ago, atypical AN, White, cisgender girl)	4 (40.0%)
Positive subthemes		4 (40.0%)
Reduction of emotional/cognitive symptoms	"My parents pushed for me to gain a little bit more weight and then like, that extra weight just actually like, made my brain chill out. And then I was able to just have a little more motivation with like more fat on my myelin sheaths, basically." (Age 23, completed FBT > 1 year ago, atypical AN, White, cisgender girl)	4 (40.0%)
Externalization		4 (40.0%)
Negative aspects	"I remember my mom telling me several times that she didn't feel like she was actually talking to me or that I was actually me because my eating disorder was controlling me and taking over my brain and making me say things. And yeah, I felt very alone and hurt that she didn't even think of me as [participant name] anymore, she just saw a walking eating disorder." (Age 17, Phase 2, AN-R, White, cisgender girl)	3 (30.0%)
Positive aspects	"I think my mom read a book. And it was like, you have to differ the thought of anorexia versus your own voice. It's like important that even the patient themselves, they understand that not their voice and the real enemy is like anorexia, it's not the treatment or the people who are enforcing the treatment." (Age 16, completed FBT > 1 year ago, AN and BED, Latinx, cisgender girl)	1 (10.0%)
Non-authoritarianism		3 (30.0%)
Lack of adolescent agency	"I mean, they [doctors] make the standards. They tell me and then my parents don't really have any say in it, they just agree with whatever the doctor tells them." (Age 17, Phase 2, AN-R, Asian, cisgender boy)	3 (30.0%)

Note: N = 10.

Abbreviations: AN-BP, anorexia nervosa, binge-purge type; AN-R, anorexia nervosa, restricting type; BED, binge eating disorder; ED, eating disorder; FBT, family-based treatment.

3.2 | Engagement in Treatment

The most often mentioned factor interfering with treatment engagement was the influence of the ED “voice” ($n = 5$)—a term some participants used to describe ED cognitions. Other factors included feeling a lack of agency ($n = 4$), believing that treatment was ineffective ($n = 3$), experiencing sociocultural factors that encouraged disordered eating ($n = 2$), and frustration with the substantial time investment treatment required ($n = 2$).

The most frequently reported reason for remaining in treatment ($n = 6$) was pressure to continue from caregivers and treatment providers. However, participants also named factors that increased their motivation to continue treatment, such as seeing treatment as necessary for recovery ($n = 3$), increased awareness of negative health consequences of EDs ($n = 2$), and the desire to live a fuller life ($n = 1$).

While most participants reported positive or ambivalent viewpoints of FBT, two participants (one undergoing Phase 2 FBT, and one who had discontinued treatment during late Phase 2) were especially emphatic in their negative viewpoints of FBT. Commonalities between these two participants included a lack of agency regarding their healthcare decisions and significant conflict with family (conflict related to ED behaviors as well as

familial discord that preceded the ED) that they believed went unaddressed during treatment. Both participants expressed that they would have preferred an alternative to family therapy rather than residential treatment. See Supporting Information: Supplement B for representative quotes.

3.3 | Defining Recovery

When queried about definitions of recovery (see Table 3 for representative quotes), most participants emphasized cognitive/emotional ($n = 9$) and behavioral ($n = 6$) dimensions of recovery. Other named dimensions of recovery included physical recovery ($n = 5$) (e.g., hunger/fullness signals, weight restoration, increased physical strength), improved quality of life ($n = 4$), and gender affirmation ($n = 2$, for the two transgender participants). Five participants (including two who had completed FBT over a year ago) reported that they did not believe ED cognitions could fully remit and, instead, conceptualized recovery as resilience against lingering cognitions.

Five participants reported that their view of recovery was concordant with that of their FBT clinician and caregivers. One participant reported concordance with clinicians but not parents, and one reported concordance with parents but not clinicians.

TABLE 3 | Example quotes about participant definitions of recovery.

Subtheme	Example quote	<i>n</i> (%)
Cognitive and emotional recovery	“I’d say recovery is when you like, stop constantly thinking about food and aren’t overly conscious about what you’re eating. Like, you just eat what you want and aren’t thinking about, well, I gained weight. How do I look and all that kind of stuff?” (Age 17, Phase 2, AN-R, Asian, cisgender girl)	9 (90.0%)
Behavioral recovery	“I think recovery is being able to kind of shift back into eating in like, how life was before, like, developing an eating disorder. And like being aware that yes, it’s something that’s there, but not letting it control your own life.” (Age 18, discontinued treatment, atypical AN/AN-BP, unknown race/ethnicity, transgender boy)	6 (6.0%)
Physical recovery	“I would say I kind of remember feeling full, like all the time for a very long time. And it took, like, a really, really long time to actually feel physical sensations of like normal fullness and hunger. That took like, forever to get back.” (Age 23, completed FBT > 1 year ago, atypical AN, White, cisgender girl)	5 (5.0%)
Quality of life	“I felt that I’ve been at the point where I can live my life without eating disorder thoughts or behaviors being a part of it, and that my life is like, full and without an eating disorder ... Besides the fact that I’m just not using behaviors, but the parts of life that I enjoy and get to experience are the best parts of recovery.” (Age 23, completed FBT > 1 year ago, atypical AN, White, cisgender girl)	4 (4.0%)
Gender affirmation	“Once I did get gender affirming care, my disorder got a lot better. And I think that’s when I kind of did start to get better, and I had more hope that I could do it.” (Age 18, discontinued treatment, atypical AN/AN-BP, unknown race/ethnicity, transgender boy)	2 (2.0%)
Recovery as ongoing	“I still struggle with the eating disorder, it’s still there. I don’t think it’s ever really gonna disappear. But I don’t let it stop me from eating things. So I would say I’m recovered, because I’m still moving forward with life.” (Age 18, discontinued treatment, atypical AN/AN-BP, unknown race/ethnicity, transgender boy)	5 (5.0%)

Note: $N = 10$.

Abbreviations: AN-BP, anorexia nervosa, binge-purge type; AN-R, anorexia nervosa, restricting type; FBT, family-based treatment.

Six participants reported that parents and clinicians placed disproportionate emphasis on weight restoration (see Supporting Information: Supplement B for representative quotes).

3.4 | Facilitators of Change Outside of FBT

When queried about factors outside of treatment that may have aided recovery (see Table 4), the most frequently mentioned theme was peer support ($n = 7$) (e.g., connecting with peers over the shared lived experience of ED recovery; emotional support from trusted friends). Five participants also mentioned the importance of internal self-reflection, and three participants reported that hospitalization served as a “wake up call,” while also acknowledging its challenges.

4 | Discussion

The current study aimed to explore patient experiences with FBT and their definitions of recovery. Participants were generally ambivalent about FBT. Many noted FBT’s effectiveness as a behavioral intervention that helped them to gain weight and reduce ED behaviors—in line with FBT’s specific goals within a time-limited intervention. However, participants also expressed that emotional challenges, family conflict, the cause of the ED, or building personal skills and agency were not adequately addressed during treatment.

Specifically, participants expressed ambivalence toward FBT’s pragmatic focus on weight restoration, particularly

during early treatment. Although this could reflect fear of weight gain associated with AN, it may also reflect adolescents’ reported desire to emphasize their emotional and cognitive symptoms even during early treatment. Qualitative work on processes of change in family therapies for AN found that a holistic focus on the adolescent’s psychosocial well-being facilitated positive change and recovery, whereas a narrow focus on weight and food intake and an inflexible treatment approach hindered positive change (Cripps et al. 2024). These findings and participants’ narratives raise questions about whether weight restoration should be the primary focus of early treatment. They also challenge the notion that for a majority, psychological ED symptoms will necessarily improve with long-term weight restoration (Accurso et al. 2014). One participant in the current study who was surveyed more than a year post-discharge from FBT continued to report persistent ED cognitions, despite being weight restored (returned to patient’s premorbid growth curve at the 67th percentile for age, per medical chart), and five participants defined recovery as a state of resilience against *ongoing* ED cognitions. These findings echo prior studies suggesting that, although early weight gain is one of the most consistent predictors of full recovery (Le Grange et al. 2014), ED cognitions and comorbidities can persist after weight restoration and may be equally important treatment targets (Egbert et al. 2023; Haynos et al. 2014). This points to a need for continued research efforts to determine why weight restoration promotes psychological recovery for some adolescents better than for others (Loeb and Le Grange 2009; Murray et al. 2019). It also illustrates the importance of efficiently addressing psychosocial distress, perhaps even during early treatment, to increase therapeutic

TABLE 4 | Example quotes about facilitators of change outside of family-based treatment (FBT).

Subtheme	Example quote	<i>n</i> (%)
Lived experience peers	“I remember the few times I heard someone recovered share their story, or saw something about recovery in the beginning, that it instilled the little tiniest bit of hope in me. So I think having more of that, and a relationship with someone who’s recovered would have been pretty cool.” (Age 23, completed FBT > 1 year ago, atypical AN, White, cisgender girl)	2 (20.0%)
ED support groups	“Since there are a lot of other girls there who are in the same situation as me, and it doesn’t seem to involve family members, it feels a lot easier to be able to talk about things and not have to hide or conceal how I feel or how I think, because I know that the people there are thinking the same thing as me or have at some point.” (Age 17, Phase 2, AN-R, White, cisgender girl)	2 (20.0%)
Friends	“They were just there to comfort me or make sure I ate ... It was more of a personal connection, since I already knew these people. They knew me as a person. And the therapist kind of knew me as an eating disorder. She kind of made me into a split personality of like, a person and an eating disorder. But my friends just thought me as a person that was struggling with something.” (Age 18, discontinued treatment, atypical AN/AN-BP, unknown race/ethnicity, transgender boy)	6 (60.0%)
Internal self-reflection	“It comes from your own self, kind of, more than what somebody else tells you ... in the end, nobody can really force you into recovery unless you’re willing to do it yourself.” (Age 16, completed FBT > 1 year ago, AN and BED, Latinx, cisgender girl)	5 (50.0%)
Hospitalization	“I think when I went to the hospital, it felt more real. And it felt like something a lot more serious that I had to do to get better.” (Age 16, Phase 3, AN-R, Asian [Burmese and Chinese], cisgender girl)	3 (30.0%)

Note: $N = 10$.

Abbreviations: AN-BP, anorexia nervosa, binge-purge type; AN-R, anorexia nervosa, restricting type; BED, binge eating disorder; ED, eating disorder; FBT, family-based treatment.

alliance and effectively equip adolescents to face ongoing ED cognitions. There is opportunity within FBT or via adjunctive interventions to improve psychosocial treatment outcomes—aspects of recovery that patients tend to emphasize (Singh et al. 2018) and that predict relapse (Carter et al. 2004; Channon and deSilva 1985; Federici and Kaplan 2008), remission, treatment dropout (Lock et al. 2006), positive behavior change (Cripps et al. 2024), and long-term improvements in psychosocial functioning (Bardone-Cone et al. 2019).

Some participants also reported that FBT's focus on parental empowerment felt at odds with their own agency and autonomy. FBT navigates the often ego-syntonic nature of restrictive EDs by empowering parents to support renourishment during early treatment. As part of this intervention, an FBT clinician may help some families with parenting shifts; for example, stepping in to ensure necessary nutrition intake and setting firmer boundaries around ED-related behaviors may require more assertive parenting than had been needed before ED onset. Although this shift is generally well-intended by both the clinician and caregivers, not all adolescent interviewees viewed their parents as effective supporters of their recovery. Notably, the two participants with particularly negative experiences of FBT attributed part of their treatment difficulties to significant conflict with parents that preceded the ED. This echoes prior findings suggesting that high levels of expressed emotion or criticism from parents predict worse FBT outcomes and treatment dropout (Bohon et al. 2023; Hedlund et al. 2003; Le Grange et al. 1992; Rienecke et al. 2016; Szumukler et al. 1985). Treatment for an ED places considerable strain not only on the adolescent but also on the caregivers who support them (Zabala et al. 2009), which has the potential to reveal and exacerbate existing family discord. More recent work has begun to focus on how best to support families and specifically caregivers, who may benefit from more support while implementing FBT (Thibault et al. 2023; Treasure and Nazar 2016; Wilksch 2023) particularly during early treatment. Qualitative studies have indicated that both caregivers and patients often find caregiver-focused adjunctive interventions helpful in improving caregiver–patient communication and relationship-building, increasing caregiver understanding of EDs, decreasing expressed emotion, and even improving treatment outcomes (Aarnio-Peterson et al. 2024; Macdonald et al. 2015).

Additionally, even participants who felt ambivalent or positive about parental empowerment expressed a desire for more individual therapy, confidentiality, and a sense of agency earlier in treatment. As lack of agency was the second most frequently mentioned factor that contributed to discontent with FBT, these data raise questions about whether family-focused therapies can do more earlier in treatment to center patient desires and perspectives, and/or to cultivate their internal motivation to recover. Prospective cohort studies among adolescents and adults suggest that self-efficacy can predict ED treatment duration and outcomes (Keshen et al. 2017; Pinto et al. 2008) and some work specifically in adolescent samples found that feeling validated and respected was associated with treatment acceptance and determination for recovery (Conti et al. 2021; Gledhill et al. 2023; Nilsen et al. 2020). Furthermore, prior work using interviews with patients who had undergone FBT found that a sense of increased independence and access to developmentally

typical experiences associated with FBT Phases 2 and 3 was experienced as intrinsically motivating toward recovery, whereas Phase 1 of treatment was experienced as a period of developmental regression (Medway et al. 2019). This echoes sentiments participants in our current study expressed: that a desire for a fuller life was a motivator for treatment engagement. During FBT, individual therapeutic interactions with patients earlier in treatment to address patients' emotional and developmental concerns could increase their sense of self-efficacy and intrinsic motivation to recover. The integration of individual therapy approaches (e.g., Dialectical Behavioral Therapy) within an FBT model has shown benefits in decreasing ED cognitions and improving emotional regulation strategies among adolescents (Reilly et al. 2020; Johnston et al. 2015; Murray et al. 2015; Pennell et al. 2019; Peterson et al. 2020), and adaptations to FBT for transition-age youth (FBT-TAY) that take a more collaborative stance with the patient are well-accepted (Dimitropoulos et al. 2018). Such approaches that integrate individual therapy and collaboration with patients might be useful to consider, even for younger adolescents or for patients struggling with earlier stages of treatment.

Many participants reported that peers played an instrumental role in recovery and that their ideal treatment would include connection with a recovered peer. Within FBT, the social reintegration of youth with their peers is a focus of later phases of treatment but is not typically specific to peers who share their illness history. Prior work found that connection with recovered peers—via peer relationships formed within intensive ED treatment or a structured peer mentorship program—was also perceived as helpful to recovery (Gledhill et al. 2023; LaMarre et al. 2024) and that the value placed on relationships/obligations to others was an important source of motivation for recovery among adults who had experienced a range of treatment modalities in adolescence (Venturo-Conerly et al. 2020). Although there are acknowledged risks to building a community based on shared lived experience, such as potential exposure to new behaviors (Colton and Pistrang 2004; Offord et al. 2006), providing peer-led adjunctive interventions may be able to address participants' desire for more emotional support even during early treatment and bolster their intrinsic motivation for treatment through connection with peers who have already recovered.

For some adolescents with greater family discord, an adapted form of FBT may be indicated. Although individual formats of therapy, such as Cognitive Behavioral Therapy-Enhanced for EDs or Adolescent Focused Therapy, have shown some benefit for adolescents with restrictive EDs (Dalle Grave et al. 2013; Lock et al. 2010; Robin et al. 1999; Stewart and Baumann 2024), treatments that stem from FBT (such as parent-focused therapy [PFT], in which parents and adolescents are seen separately) are still recommended interventions. Thus, intentionally working to improve family communication and function may hold particular promise in ensuring sustained and longer-term recovery for some youth. Prior work has suggested that emotional coaching sessions for caregivers involved in FBT improved parental warmth and rates of full remission for adolescents by the end of treatment (Aarnio-Peterson et al. 2024). Furthermore, some FBT practitioners have noted the importance of family formulation in the family therapy for adolescent AN (FT-AN) model, the basis for the FBT model (Gorrell et al. 2023). In FT-AN,

an initial treatment phase is focused on engaging the family around shared treatment goals; this practice improves treatment engagement and therapeutic alliance (Baudinet et al. 2021). Incorporating such elements of family formulation early on in FBT may be a way to both increase adolescent willingness to engage and manage family conflict within treatment. Rather than being a departure from the FBT model, this approach may help align FBT with its roots in family therapy (Gorrell et al. 2023).

4.1 | Strengths and Limitations

Strengths of the current study include its contribution to emerging literature supporting patient preference and feedback as integral to improving treatment response for young people with EDs (Halvorsen and Rø 2019; Nilsen et al. 2021; Conti et al. 2017). Due to the use of targeted recruitment, this work also reflects patient perspectives from those with identities that have historically been less well represented in ED research (Egbert et al. 2022; Goel et al. 2022; Burke et al. 2020). Along with these strengths, limitations of our sample include a lack of representation of publicly insured and uninsured patient populations, limited collection of socioeconomic status indicators, and exclusion of Phase 1 participants due to concerns about treatment interference. Regarding participant demographics, unfortunately, data from the current study do not include the duration of illness before initiating FBT, a factor that will be important to examine in future research of this nature. As this study focused on hypothesis generation rather than data saturation, our findings have limited generalizability due to intentional recruitment—based on individual clinician judgment—of a small but heterogeneous sample (with regard to age, gender, and stage of treatment). Although our findings are not a comprehensive qualitative assessment of the FBT experience, they may guide future qualitative inquiries into experiences with FBT. Furthermore, the inclusion of multiple participants currently undergoing FBT Phase 2 is both a strength and a limitation. As participants have not yet experienced the full arc of treatment, they may be skewed to view treatment more negatively without having experienced the portions of treatment focused on restoring autonomy and addressing developmental concerns; however, they may also have a clearer memory and account of the challenges experienced during early and mid-treatment. The study lead's (CG) disclosure to interviewees of their expert-by-experience positionality is similarly both a strength and a limitation; although disclosure of interviewer identity could be seen as reducing the objectivity of data collection, some scholars of qualitative methodology encourage disclosure of interviewer positionality (Bukamal 2022; Carter et al. 2014; Cohen et al. 2007) as interviewing is an inherently relational process in which interviewer–interviewee shared identity could be beneficial to establishing trust and promoting authenticity in communication.

5 | Conclusions

Overall, findings suggest that, for some adolescents, FBT may not adequately address interpersonal challenges within a family system or support adolescents in their emotional and cognitive recovery. Adolescents' responses also suggest the potential

desire to incorporate peer support and augmentations to FBT that promote agency and/or reduce familial conflict. Regarding adolescents' views on ED recovery following FBT, results underscore the importance of prioritizing cognitions/emotions alongside weight status and including overall quality of life in measuring and evaluating treatment outcomes. Important future directions in this line of inquiry include studies that simultaneously integrate caregiver, clinician, and patient perspectives on FBT, as well as studies that verify the generalizability of our participants' concerns across larger sample sizes and different subpopulations of FBT patients. Further, as research efforts aimed at improving FBT's efficacy among different ED diagnoses and diverse patient populations continue (Richards et al. 2018), future work should strive to integrate adolescent patient perspectives and allow these perspectives to inform and guide the implementation and adaptation of ED interventions.

Author Contributions

Catherine Gao: conceptualization, data curation, formal analysis, investigation, methodology, project administration, writing – original draft, writing – review and editing. **Catherine R. Drury:** data curation, validation, visualization, writing – review and editing. **Simar Singh:** data curation, validation, visualization, writing – review and editing. **Daniel Le Grange:** writing – review and editing. **Sasha Gorrell:** conceptualization, methodology, project administration, supervision, validation, visualization, writing – review and editing.

Ethics Statement

All participants gave their informed consent for participation in the study. The study was conducted in accordance with the Declaration of Helsinki, and the protocol was approved by the University's institutional review board (IRB # 22-38265).

Conflicts of Interest

Daniel Le Grange receives royalties from Guilford Press and Routledge and is co-director of the Training Institute for Child and Adolescent Eating Disorders LLC. The other authors declare no conflicts of interest.

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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Supporting Information

Additional supporting information can be found online in the Supporting Information section.