"I'm Still Here, But No One Hears You": A Qualitative Study of Young Women's Experiences of Persistent Distress Post Maudsley and Family-Based Therapy for Adolescent Anorexia Nervosa

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Research Article

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Abstract

Background: Maudsley and Family-Based Therapies (MFT/FBT) are the current treatment of choice for adolescent AN based on positive outcomes that include weight restoration in around two-thirds of adolescents. Nevertheless around a quarter drop-out from treatment, particularly in the earlier phases, and a notable proportion of treated adolescents are reported to experience ongoing psychological distress during and post-treatment. This study explores the under-researched experiences of these adolescents.

Method: Fourteen participants from Australia, New Zealand and the United Kingdom were interviewed about their experiences of MFT/FBT. An inductive thematic analysis of interview transcript data generated key themes related to their experiences, identity negotiations and the discursive materials these used to construct these.

Results: The participants identified working as a family unit as key to their recovery, highlighting the importance of family therapy interventions for adolescent AN. However, they perceived an almost exclusive focus on weight restoration in the first phase of MFT/FBT was associated with experiences that included a relative neglect of their psychological distress and a loss of voice. Key within these experiences were processes whereby the adolescent engaged in identity negotiation and (re)claiming of their voice and implicit in their family standing with them in the treatment was that their life was worth saving. What was noted as most helpful was when therapists advocated and took into consideration their unique needs and preferences and tailored treatment interventions to these.

Conclusions: There is a need to develop and research treatments that address, from the outset of treatment, the adolescents' psychological distress (including as experienced in the context of their weight restoration). This should be with priority accorded to the adolescent's voice and identity negotiations, as they and their families take steps to address the physical crisis of AN and in doing so, support more holistic and durable recovery.

Plain English Summary

Maudsley and Family-Based Therapies (MFT/FBT) are well-established, intensive approaches to the treatment of adolescent anorexia nervosa (AN). The first phase of treatment focuses on eating and weight restoration, where parents are given responsibility for the adolescent's home-based refeeding. This is followed by handing over of this responsibility to the adolescent with the final-phase a focusing on adolescent-specific psychological issues. While the majority of adolescents gain weight with this treatment, a substantive proportion experience ongoing psychological distress and around a quarter drop out in the first phase. Little is known about these adolescents' experiences.

In this project, we interviewed 14 individuals who had either dropped out of MFT/FBT or experienced ongoing psychological distress post-treatment. The participants noted that their parents' stance in supporting them was life-saving and contributed to a sense that their life was worth saving. However, they also noted a relative absence of focus on their psychological distress, particularly in the early stages of treatment. Most helpful for participants was when therapists took into consideration and tailored treatments to them. Future treatments need to consider ways to support an adolescent's psychological distress more comprehensively, prioritise their voice and support them in finding an identity outside of the AN identity.

Background

Anorexia Nervosa (AN) is characterised by significantly low weight and an obsessional fear of gaining weight (1), frequent onset in the adolescent years (2) and mortality of 6–15%, with half of all deaths resulting from suicide (3–6). Maudsley family therapy (MFT) (7) and its manualized version, Family Based therapy (FBT) (8) are reported to have positive treatment outcomes, particularly on ED symptomatology, in those adolescents assessed with higher ED symptomatology (9).

FBT has been proposed as the first line, 'gold-standard' evidence-based treatment for adolescent AN (10). Through a number of randomized controlled trials, FBT has been found to be associated with earlier weight restoration and reduced ED symptomatology and lower hospitalizations (and hence treatment cost), compared with individual adolescent therapy (self-psychology and cognitive individual therapy) (11) and family therapy that addressed systemic concerns rather than eating related behaviours (12).

FBT is a three phase manualized treatment that begins with a focus on supporting parents to take responsibility for their child's eating and weight restoration, progressing to phase 2 where this responsibility is re-allocated to the adolescent once they have increased their food intake and sustained reliable weight gain. The final phase commences when the adolescent maintains at least 95% of their ideal body weight, and is focused on re-establishing autonomy and developing a healthy identity (13, 14); psychological processes and relational problems are not specifically addressed until this final phase of treatment (15, 16).

A Cochrane review of 25 published and unpublished randomised controlled trials that compared family therapy interventions, including FBT, with other AN treatments (17) has found some evidence of a small effect size of FBT related to weight gain post-treatment, however, little evidence of differences between outcomes for groups across all comparisons of treatments, including in ED symptomatology (weight, ED psychopathology), drop out, relapse or family functioning measures at post-intervention or at follow-up. This review concluded that there currently exists insufficient evidence that family therapy interventions were superior to educational interventions and other types of psychological interventions for adolescent anorexia nervosa at long term follow up. There was also insufficient evidence of (1) outcomes outside symptom remission with only two trials of 21 reporting outcomes based on a return to normal functioning; and (2) whether one type of family therapy was more effective than others. Furthermore, the lack of detailed information about individuals who drop out of adolescent AN treatments may have contributed to "the effect of artificially inflating the effectiveness of the interventions reviewed" (17). There is additional evidence to show that (1) up to 27 percent of families (18) drop out from MFT/FBT; (2) 40% of adolescents have been found to continue with ongoing psychological distress despite weight restoration (19); and (3) comorbid symptomology has a negative impact on treatment outcomes and increase rates of attrition (20–22).

A meta-synthesis of qualitative research into the experiences of family therapy for AN (23) has found three of 15 papers analysed adolescent and family experiences of family-based therapies with one consisting of data generated from open-ended survey questions (24). Two of these studies (24, 25) found that the most helpful aspect of MFT/FBT was parental support and understanding and the other study (26) found that the authoritative stance of therapists in watching their behavior to be helpful. Less helpful was the neglect of issues other than AN (24, 26) and the adolescents' unmet preferences for individual therapy (24). Furthermore, there is increasing evidence to support the need for ED treatment interventions to more comprehensively focus on questions of identity, including ways to address the person's ED identity investments and reclaiming identity outside the ED identity (27).

Overall there have been few studies that have focused on the experiences and identity struggles of those who either (1) drop out of MFT/FBT and/or (2) continue with substantive psychological distress post-treatment (19). This study sought to address this gap and give voice to those who experience persistent distress post MFT/FBT.

The Current Study

The current study utilised a qualitative framework to give voice to the person with a lived adolescent AN experience with a focus on participant:

1) Experiences of Maudsley and Family-Based Therapy for adolescent AN in those who were interested in participating in research to improve the intervention; and

2) Identity negotiations in the context of this treatment intervention for these participants.

The aim of this study is to explore how these experiences and identity negotiations might inform future augmentations and transformative treatments for adolescent AN.

Methods

Design

An inductive thematic analysis (28) with the understanding of themes as constructed within an interpersonal context. Analysis of data that comprised the themes/subthemes focused on some of the ways participants negotiated their identities through the discursive materials or language forms available to them at the time, the semantic and latent meanings they ascribed to the experiences of MFT/FBT and some of the dilemmas they faced (29) in the context of their recollection of experiences of MFT/FBT for adolescent AN. This study was also part of a larger study that explored the experiences and perspectives of parents who had experienced MFT/FBT (30) and clinicians who reported being trained and having practiced as MFT/FBT practitioners (31).

Participants

A purposive sampling technique was utilised to invite participants to talk about their experiences of MFT/FBT and generate a context through which they could voice aspects of the treatment that was both helpful and their ideas of ways the intervention could be improved. These participants responded to advertisements via Australian clinicians and after indicating their interest on completion of an eating disorders (ED) treatment experiences survey advertised through Facebook.

Fourteen participants aged 14-27 years (*M*= 18.58, *SD*= 3.20), who reported being diagnosed with AN and treated with MFT/FBT for adolescent AN on average 4 years earlier (range: 1-14 years) were interviewed (in person or online/telephone). See Table 1 for further demographics and MFT/FBT treatment details. Half of the participants reported weight restoration post-treatment (with one later relapsing); all the participants reporting ongoing ED symptoms and psychological distress post-MFT/FBT. Eleven participants reported additional treatments for co-morbid psychological problems prior to or post MFT/FBT with three of these participants reporting psychological counselling whilst also engaging in MFT/FBT (see Table 2 for details).

Procedure and Materials

This study was approved by the Western Sydney University Human Research Ethics Committee (approval number: H11303).

Semi-structured interviews were carried out by two researchers (JC, SC) (see Appendix A for interview format) that were audio recorded, transcribed verbatim and de-identified with participants' chosen pseudonyms. Transcripts were then given to participants to member check for accuracy and the removal of further identifying information for confidentiality.

Analysis

The analysis was data-driven and inductive with all themes generated from the dataset (28). Throughout the analytic process, themes were constructed through the explicit language used by participants, and an analysis of implicit meanings in their narratives, as language in this instance is assumed to construct a version of the participants' experiences and

meaning-making processes (32). Three authors (KS, SN, JC) familiarised themselves with the data by reading and re-reading transcripts, coding meaningful units of raw data into draft themes and subthemes. Two authors (CJ, JC) also coded raw data into 'nodes' using QSR NVivo-12 qualitative data analysis software, examined the nodes for similarities and differences and grouped data related to the research question into categories. These categories of data were then collated and contrasted with the earlier drafted themes/sub-themes before being analysed for any further relationships and grouped together to generate overarching themes and a thematic map that addressed the research questions through in-depth analysis of exemplar data within each theme/sub-theme (JC, CJ, PH). Analysis by the researchers (see Appendix C for researcher positioning statements) traced some of the discursive materials these participants used to piece together key experiences and dilemmas associated with components of MFT/FBT and including patterns of identity negotiation (29, 33, 34).

The draft analysis was given to participants to member check for the purposes of validity (see appendix B for member feedback provided by 4 participants) and to align analysis with participant feedback.

Results

Analysis traced these participants' experiences of key dimensions of the MFT/FBT interventions and ways they engaged in identity negotiations within these treatment contexts, including the reclaiming of identity and voice in matters related to their treatment (see thematic map, Figure 1).

Theme 1: Therapeutic focus

Participants recounted being both supported and distressed by the focus of Phase 1 of treatment on eating and weight restoration and handing control of these over to their parents. Of the 4 participants who reported completing the three phases of MFT/FBT, 3 concurrently had treatment with an individual therapist (Abbey, Amy & Maisy) and one participant retrospectively described being "taught" strategies by psychologists and dietitians during treatment to assist her with managing distress (Phoenix). Participant narratives highlighted that although MFT/FBT was preferred to inpatient treatment for most, when the therapeutic focus was predominantly on AN symptom reduction their emotional distress was obscured and further escalated.

Subtheme 1(a): Focus on the visible

Ten participants' narratives indicated that the early treatment focus of MFT/FBT, where their parents took responsibility for their eating, was experienced as a relief, albeit it was also a distressing experience

EXTRACTS 1:

Pheonix: […] As much as I hated it, and as much as I just wished for it to be over, it (MFT/FBT) did save me. The first few months were extremely distressing […] Knowing that I had no control whatsoever. [Later in interview] it was sort of down to business, let's do this as quick as possible to get your life back.

Kate: It was helpful…that saved my life. 100%. Going to that first appointment, they put me on eating plan. […] I'm glad that they got someone to be my eyes in that sense because I would not be here today.

Kaylee: The whole control aspect, it was, my parents had full control which made me feel real safe.

Abbey: […] cause there was part of me that was, obviously I was fighting it but there was part of me that was like, "Oh thank god" like "I can't get away with it. I just have to like sit and eat this"

The allocation of responsibility for their eating to their parents was experienced as life-saving for these participants. The marking out of a boundary by which they were no longer responsible for their eating cultivated for some, a sense of relief and safety (e.g. Kaylee) and the possibility of getting "your life back" from AN, despite also being "extremely distressing" (Phoenix). Furthermore, the sense that others could "be my eyes" (Kate) indicated that these participants valued not only the support but also the alternative perspectives of others in assisting them to take steps to diminish the influence of AN on their lives. This included parents being supported by treatment teams to engage in nutritional nourishment despite a divided sense of self ("part of me … fighting it"; Abbey). Identified as helpful was when their parents were experienced as a steady support, informed yet understanding, cultivating safety whilst taking control over their eating that contributed to a containment of their distress in the context of the challenging time of nutritional restoration.

Alongside MFT/FBT being a life-saving treatment that addressed the medical crisis of AN, the participants also recounted parallel experiences of distress during and post MFT/FBT irrespective of extent of their eating and weight restoration and all of them acknowledged the significance of support by others for this distress, including family members.

Theme 1(b): Focus on the invisible

Thirteen of the 14 participants argued that there was a lack of treatment focus on their experiences of psychological distress during MFT/FBT, including co-morbid psychological problems (see table 2). One participant (Maisy) reported MFT/FBT was experienced as "extremely pivotal to me getting better" and tailored to her preferences where her siblings attended only the first session. Individual therapy in addition to MFT/FBT was experienced for her as both an opportunity to "challenge my thoughts", "learn how to self-soothe" through mindfulness techniques and a motivational intervention that worked "to convince me that recovery was a good thing". She also highlighted the significance of seeing an individual therapist in addition to MFT/FBT who was "an outside person […] different from my parents".

For ten of the participants who reported dropping out prematurely from MFT/FBT, an absence of focus on addressing emotional distress and interpersonal struggles was cited as a major contributor to this decision. For example;

EXTRACTS 2:

Harley: Because they never really addressed the underlying problems, it was all so much harder than it probably should have been, because I was still battling with the thoughts and battling with the guilt and all that.

Charlotte: My mum does have issues with her eating […] just made me feel like I was doing the wrong thing as a woman and as a female.[…] my sadness and how much I was hurting would also be expressed as anger[…] a lot of the times I would find it so difficult that I would ask to sit outside [of MFT/FBT sessions]. […] They[parents] hated seeing me so sad and I hated seeing them so sad, and it was just very confronting to have to bring that all up in family therapy and then not really take it further […] Like we opened old wounds and then they never really got closed and healed.

Beth: […] […] I never really got a chance to properly, like talk out, like my anger, like with people. Like I never got to just express how I was really feeling, which is probably why I was so angry, because it was all, like building up inside, because I never got to express how I was feeling.

The inadvertent effect of prioritizing of physical safety in phase 1 of MFT/FBT meant that these participants' psychological safety was obscured with the implicit meaning taken from what was "going on inside" (Hayley) did not matter. For Charlotte, the structure of MFT/FBT meant the "old wounds" were opened and not healed, including the parallel process of eating difficulties of women in her family being left unaddressed contributing to an identity conflict where she was left questioning herself and to feelings of "sadness". Implicit in these participants' experiences of anger, was their valued stance and desire for openness within their family systems. They recollected their anger being responded to by

being positioned as outsiders to their own therapy, losing their voice with systemic family issues left substantively unaddressed.

Within this context, a different sort of safety issue arose with six of the 14 adolescents reporting suicidal ideation during and/or post MFT/FBT treatment.

EXTRACTS 3:

Kate: […] I never got to the point where I could really end my life but there were feelings of just wanted to end it because it's easier than the voices that are in your head (crying, quite upset) and then you go into these sessions and they're supposed to be sessions where you can let yourself speak your mind and you get time with the psychologist and it's almost like, you just need to sit there and be quiet while everyone talks around you. They're talking about you too (emotional).

Beth: I think I didn't, like make it clear how, like depressed I was, and like the feelings of, like wanting to just end it all really. And I would never dare to say that in front of my mum, so I never did. And that's, like kind of one of the things I was struggling with and struggled with it for a long time. And I thought I just never spoke up about it.

Harley (further quote from member checking): […] Still to this day because of Maudsley if there's a situation where I feel like there are links or similarities with control related or people talking at or about me like they did in Maudsley, my suicidal ideations are triggered. The focus on the impact of my family – which was a big aspect of Maudsley - as a result of the anorexia contributed to feelings of being a burden and secondarily, at times I wanted to kill myself because the FBT highlighted the damage I was doing to everyone around me.

These participants argued that nutritional and weight restoration alone did not reduce their psychological distress; distress that continued largely unaddressed for them during the MFT/FBT intervention. Kate recollected experiences of a loss of voice where she was recruited into need(ing) "to sit there and be quiet"; Beth actively hid her distress, particularly from her mother; and Harley (when member checking the analysis) emphasized the lasting impression of treatment where being talked "at" or "about" continued to trigger "suicidal ideations" with continued identity associations of herself as a "burden" on others. These participants were active in their arguments that AN treatments need a greater focus on enabling the voicing, holding and processing of their and their family members' emotional distress.

Parallel to the adolescent's distress was family distress and conflict that was also experienced in the context of parents taking responsibility for their eating and weight restoration.

EXTRACTS 4:

Rachel:. It [meals] just ended up being hard, plates smashed, tables turned, me punching, kicking and screaming, […] and then at the end of the time and it'd be like four hours later and we'd both be exhausted; no food would've been eaten.

Kaylee: […] I didn't know who to listen to or who to follow (my parents or my urges) and so those were the destructive ways I dealt with them. For my parents, they wouldn't have known why I was acting out either, as I couldn't verbalise what was happening internally. So they responded to my outburst with screaming and anger and physical restraint towards me because I assume in their eyes, I was just being difficult about eating. Their reaction made the stress in my head even worse and made me even more suicidal, but I don't blame them for how they responded.

Increased conflict in the family was evident in the participant narratives, with examples cited including angry outbursts with four participants disclosing anger that was physically expressed through parental restraint such as being held down or against a wall. Kaylee clarified that she was not blaming her parents for their responses at the time, that included physical restraint, however, she also recounted how these responses contributed to further distress, including suicidal ideation. These participant experiences highlighted a question asked in earlier research – do "the ends justify the means? […] Is there

a way to facilitate weight restoration without causing psychological damage to the adolescent and their family members?" (16).

On the other hand, the participants talked about the importance of MFT/FBT in ameliorating a sense of being alone and when therapists were experienced as advocating for them, with four participants talking specifically about the importance of the treatment contributing to the sense of feeling less "alone" in addressing AN.

EXTRACTS 5

Amy: […] in comparison to me going alone to therapy, my parents are actually getting an insight of where I'm at, […] the therapist, just to bounce off what I've said, from her conclusion, and what she feels is okay and what's not okay, and um just I guess, in my best interests, what I should be doing, for her then to talk to my parents about it. Like that was – that was good.

Beth: […] it definitely did teach my family them some things, and it definitely educated them on what would be helpful for me and what wouldn't be helpful. And I think it was nice not to feel alone; it was nice to have my family there. So, it wasn't just, like by myself.

Charlotte: […] it taught them a lot about the tricks and the way that I was managing my eating disorder and keeping up with hiding food and water loading and making sure that I'd gained such and such amount of weight before the next appointment, […] and how it manifested itself in different ways, and different habits, and so then they were then able to become a lot more on top of it.

These extracts exemplify key components the therapeutic relationship that included advocacy, scaffolding insight into self and by others (Amy) and ameliorating a sense of being alone in treatment through engagement with families in the intervention (Beth), including in standing against AN together (Charlotte).

Theme 2: Identity Negotiations

Alongside the participants' treatment experiences were their parallel identity negotiations that were shaped by their experiences of personal agency and voice throughout treatment and their engagement in the MFT/FBT practice of externalisation of the illness (theme 2a). Furthermore, the implicit meanings ascribed to their parents' support was that their life was worth living (theme 2b)

Theme 2(a): Negotiating personal agency and voice

All the participants at some point in their narratives talked about struggles to negotiate personal agency and voice in their treatment, particularly in the first phase of MFT/FBT where their parents were allocated responsibility for their eating restoration.

EXTRACTS 6

Phoenix: Because at stage one I definitely felt like a monkey in a cage and I had no control. My parents were doing everything for me.

Kate: […] I felt tiny. I felt like everyone was overpowering to me and it was, I would just shut up and shut down. […] I just didn't feel like a person. […] You feel like you're getting treated like just someone who's sick…it's not the way you want to be seen.

These extracts exemplify the identity negotiations of participants as they ascribed meaning to their parents being asked to take responsibility for their eating in the first phase of MFT/FBT. Phoenix's use of the metaphor of a "monkey in a cage" depicted her experiences of a loss of personal agency, being monitored and unable to escape. The participants ascribed a number of negative identity conclusions in the context of their parents taking responsibility for their eating – for example for Kate this reinforced the identity of herself as a "sick" person that did not fit with who she understood herself to be.

Furthermore, parent's taking responsibility for their eating had real effects on some of the participant's relationships with their parents that had unintended impacts on their sense of themselves as a daughter.

EXTRACTS 7:

Lydia: […] it [treatment] really fractured our relationship […] at that point, there was such a high level of conflict all the time, mutual distrust. […] , I think I lost my sense of that [self as person and daughter] and it's almost as though I regressed and I was um, I was acting how I was being treated.

Harley (member checking): Maudsley and FBT ruined a previously strong relationship and caused my parents and siblings their own psychological unease and detriment. This contributed to a loss of myself and my identity and resulted in further destructive behaviours.

A loss of voice was recounted by eight participants in the context of externalisation of the illness where they too experienced themselves as externalised with the AN.

EXTRACTS 8

Nora: […] just the fact that you had an eating disorder meant they were dismissive of anything you say, they believed anything you say was completely motivated by the eating disorder […] I was very distressed by that because I thought I'm still me, I'm still here, I can recognise that I have anxiety and unhelpful thoughts but I can still communicate as a person. […] I'm still me.

Lydia: I think to a certain degree, the treatment team had drilled into them [parents] that um I was not a person, I was an eating disorder and giving the reins to an eating disorder.

Charlotte: I was just infuriated that, you know, I'm trying to say something or have a conversation with my mum, and she's referring to like anorexia and not Charlotte, telling Charlotte to come back whenever. Um, and I was like, "No, listen, like listen to me. I'm trying to tell you something" - that was very difficult - I've never really used that separation terminology until probably now, […] my eating disorder was me, […] That was my talent, that was what I was good at, that's what I excelled in because I'd lost a lot of my identity, so I felt that that was my identity. So when - when people would refer to not say that they were talking to Charlotte I'd be like, "Are you kidding me?" But now I can see that that's different and I can see the difference.

These extracts exemplify the potential effects of the MFT/FBT practice of externalisation of the illness that led to the person's voice being assumed by others to be the AN/ED. This misappropriation of the person's sense of self ("I'm still me"; Nora) to the disorder by others ("I was an eating disorder"; Lydia) contributed further to a loss of voice and exacerbation of distress. Charlotte highlighted the problem of externalization when built on the assumption that it is possible to achieve "separation" of the person from the ED when their identity is invested in the egosyntonic dimensions of the experience ("I felt that was my identity"). These extracts highlight the unintended consequences and struggles when the practice of externalization of the illness aimed to completely separate AN from the person and neglected to take into consideration the identity investments into the egosyntonicity of AN.

On the other hand, five of the participants found the process by which their therapists engaged them to externalize AN/ED to connect with a sense of identity outside the AN.

EXTRACTS 9

Phoenix: […] as I was restoring weight and as I was getting better and given more privileges and so on that I got to really find out who I was. […] they made us draw a Venn diagram with two circles. And they named one side “Phoenix” and one side anorexia and then throughout treatment they would make me draw where I thought the circles were overlapping and there was definitely a correlation between the distance of those circles and the amount of weight I restored. As I got healthier, the circles grew further apart and anorexia was separated from me

Rachel: They just called it, “the eating disorder.” […] And they’d be like, “What would your eating disorder say to this? Now sit in this chair and it’d be like, what would you say to this?” […] that was helpful, but they just didn’t do it enough. Like, it was just so much about food but they needed to care about my feelings.

Kate: […] the other good thing about the Maudsley method was, they did really try and separate the person from the eating disorder. So you weren’t ever talking about, like, you could tell when someone was talking through the voice of the eating disorder or talking through their own voice. That’s what they tried to really distinguish.

Abbey: The anorexia. This is me genuinely saying something to you. Um, and also just for my own identity, um, and seeing the shift and the balance go. Like my identity increase and that decrease um, that was, that was really helpful. But mainly it was expressing my opinion to others that it was most, most helpful.

Emerging across these participant narratives was their preference for a person-centred approach where the practice of externalization was focused on the person’s identity outside of the AN rather than primarily on elimination of the AN. Phoenix recounted a process of “finding out who I was” through the process of being given “privileges” as she gained weight and tracing her shifting relationship with AN as both individual and overlapping entities. Rachel was invited through a chair technique to have a dialogue with AN to enable her to reclaim her voice and preferences from AN; she argued that her preference was to do more of this work that indicated care for her feelings than being centred on eating. Kate outlined how therapy sought to enable her to distinguish between the voice of the ED and her own voice and Abbey talked about how externalization enabled her to reclaim both her voice and identity outside of the AN identity.

Theme 2(b) Life is worth saving – “No one was ever going to give up on me”

Interwoven in participant narratives a process of ascribing meaning to their parent’s commitment to their recovery.

EXTRACTS 10

Hayley: I think I don’t want to forget um, (pause), ah how much care I have seen shine through people in this, like my parents have been supportive the whole time and shows how great they are.

Phoenix: My parents are really good with supporting me. They keep reassuring me that it's okay. Like, if I'm struggling, they'll be really understanding and they won't force me to do anything that I don't want to do. But they will – they will encourage me.

Kate: […] even though I was really angry and did not want to eat anything, mum would still just sit me down and wait

Jessica: […] your parents do try to – they try their best to like understand what you’re going through but it’s difficult for them to do that.

Maisy: […] how hard it must have been for my parents and how - what a good job they did to persevere and get me to where I am today.

The participants ascribed a range of meanings to their parents' support during their treatment, including taking responsibility for their eating in the early phases of MFT/FBT. Recollections ranged from parent's support and reassurance (Phoenix) and their capacity to be with them when emotionally distressed (Kate). Reflecting back, Jessica connected with her parents' efforts to "understand" her experience of AN and Maisy with her parents' perseverance to "get me where I am today". Furthermore, three participants (Kate, Maisy & Abbey) specifically remembered their parents taking up this role in treatment to avoid them requiring inpatient treatment. These participant experiences highlight the importance of parental support in AN treatments.

For participants who discontinued MFT/FBT in the earlier phases, parental support was also noted in their parents' active collaboration with them to find alternative AN treatments that met their needs and preferences, including treatments that focused on addressing their psychological distress.

EXTRACTS 11

Lydia: I had some serious conversations with my parents and I think that I began to sort of get through to them and I think they to some extent also realised that this really wasn't working, and I needed a different sort of treatment, a different sort of support than what I was receiving.

Nora: […] I would say that our relationship [with her mother] now is better than ever and we are able to reflect on the experience and how traumatic it was and how much we both believe the more sick I am is quite harmful to our family and how great it was when we did get individual psychologists.

Implicit in both these extracts was the significance of these participants being validated in their treatment needs and preferences and specifically for Nora in "how traumatic" AN and its treatment with MFT/FBT and hospitalisations were for her and her family. Furthermore, all the participants talked about the significance of their parents standing for them as a person in the face of AN and its treatment.

EXTRACTS 12

Maisy: […] my parents […] were always there telling me that I would get through this and that I was a strong person and - and that no one was ever going to give up on me.

Kate: Oh, she's [Mum] just awesome! Like, she is always advocating for my best interest.

Charlotte: I don't want to forget that even though, ah, it was very, very traumatising for me, um, that I still have my family and they still stand by me and I stand by them, and even though we went through such a terrible and awful time, um, we still love each other and have each other's backs during the worst and best periods of our lives. That's what I - what I wouldn't want to forget".

Amy: Accept the changes that are necessary because ultimately, at the end of the day, people just care about you and they care so much about you that they're going to put you through this. And it's going to be hard, it's going to be really hard, but as soon as you come out the other side and start living your life again and being healthy, the thoughts go away.

These narratives highlight the significance of the parents standing for these individuals in cultivating a sense of teamwork (Abbey), care (Amy, Phoenix), and that they were not alone (Beth, Jessica). Implicit in all the adolescent narratives was that their parents' commitment to them and their treatment was hope for their futures and the sense that their lives were worth saving – for example, as depicted by Maisy - "no one was going to give up on me".

Discussion

Maudsley and Family-Based Therapies continue to be the frontline treatments for adolescent AN in Australia, although the evidence for their effectiveness in addressing both the physical and psychological symptoms of AN is incomplete. This study sought to understand and give voice to the experiences of adolescents who had either dropped out of MFT/FBT or continued to be distressed post-treatment to inform future treatment interventions and research. These young women reported that family support in the context of the treatment was instrumental in saving their lives and contributed to the sense that they were not alone and mattered as a person. Nutritional restoration is non-negotiable (35) in the early stages of any AN intervention to prevent potentially adverse medical outcomes (36); however, this study has highlighted that delaying interventions to address the individuals' psychological distress, including in the early stages of treatment, contributed to a loss of voice and/or an exacerbation of their distress.

The current study found the majority of participants experienced a loss of voice, particularly in the early stages MFT/FBT. This was evident in contexts where their voice was assumed to be the voice of the illness/AN (by parents and/or therapists) thereby externalizing their identities with the AN (16). Notable in this process, was a disordering of their identities where they were assumed to be incapable of having a valid voice or perspective on their own lives. Furthermore, the neglect of any substantive focus on their psychological distress in the early stages of treatment set the precedent that their internal struggles were of lesser significance. Their responses included anger and disengagement from treatment with the sense of themselves as outsiders to their own treatment. This concern has been echoed by Greg Dring (15):

"[…] if the therapist spends the first sixteen sessions of the work discouraging the discussion of feelings, relationship issues and developmental difficulties in a personal way, then it may be very difficult to revive such discussion at a later stage when, in any case, the work is about to be concluded" (p. 66).

The participants' narratives also exemplified how the treatment focus of MFT/FBT inadvertently obscured not only the young persons' distress but also their family's systemic distress, which had a recursive effect on their emotional distress. The efforts of parents (as supported by therapists) to encourage their child's nutritional restoration therefore, at times, inadvertently diverted their focus away from holding their child's less visible, emotional distress. Furthermore, the participants recounted distress and interpersonal stain on their family relationships in the context of parents taking responsibility for their nutritional restoration. They argued for a greater therapeutic focus on intra and inter-personal distress throughout treatment. The findings of this study are consistent with Medway and Rhodes (23) meta-synthesis into adolescent experiences of family therapy for AN who concluded that psychological interventions for adolescent AN would benefit from scope for interventions that focus more comprehensively on underlying and family issues. This may go some way to ameliorate the ongoing psychological distress post treatment reported in the current and prior studies (19) and may also prevent the progression on to severe and enduring AN (37).

Aspects of the MFT/FBT experience were also cited as important in participant recovery journeys. These included parental understanding of their AN experience and standing for them as a person, being treated outside of an inpatient setting and clarifying a sense of identity outside of the AN identity or "find(ing) out who I was" (Phoenix). These participant experiences highlight the importance of addressing questions of identity in AN treatments (27, 38) and how externalization as an intervention may, in some contexts, facilitate this process. On the other hand, in contexts where the adolescent themselves was excluded from the process of discernment and naming of the AN, externalisation was experienced as invalidating rather than having the intended effect of empowering the person to reclaim their identity from AN (39).

A number of adolescents in this current study reported comorbid depression, anxiety, and/or OCD and all the participants reported experiencing ongoing psychological difficulties irrespective of weight restoration. This is in contrast to recent research that has shown a significant reduction in co-morbid major depressive disorder, generalized anxiety disorder and panic disorder; proposed in those for whom these conditions are likely to be secondary to malnutrition (40). Notably, a third of participants retrospectively reported escalating suicide risk during the treatment intervention. This is of concern, given

the findings that half of all deaths in AN result from suicide (3, 4). Consistent with previous research (23) and an Australian Broadcasting Commission medical report in 2017 (https://www.abc.net.au/news/2017-05-04/australian-health-system-failing-patients-with-eating-disorders/8485300), the participants in this study argued for more holistic approaches to AN treatments and that, in their experiences, there was limited scope for MFT/FBT to be tailored to their individual needs and preferences, thereby contributing to the decision for some of the participants to cease treatment prematurely and/or continue with ongoing psychological distress post-treatment.

The importance of addressing an adolescents' psychological distress has been increasingly recognized over the past decade with a number of MFT/FBT treatment augmentations being proposed and researched. These have included multi-family therapy (41, 42), parent-to-parent consultations (43), separated-family therapy (44), addition of psychological interventions such as CBT (45) and Dialectical Behavior Therapy (DBT) (46) and therapist guided internet chat rooms (47). These augmentations have tended to focus on changing the context of treatment, providing additional or novel means of support in addition to treatment as usual, particularly for parents (48), rather than augmentation to the structure and/or transformation of content of the treatment intervention itself. One structural augmentation to separate parent and adolescent sessions, particularly in phase one, has found similar weight gain outcomes, irrespective of whether the adolescent is involved in the early phases, with increased retention and remission rates for some adolescents (49). Furthermore, the majority of augmentations involve phase one only and are reflective of the reluctance to change or 'tamper' with the manualized intervention, despite the call for more 'potent augmentations' to improve outcomes (43). There continues, however, to be a paucity of researched interventions that have scope to transform the landscape of treatment options for anorexia nervosa.

Clinical Implications

There is a need to consider broadening the treatment focus in all stages of therapy for AN to also address psychological symptomology and to map treatment effectiveness to these outcomes in addition to behavioural measures. Implications for the future treatment of adolescent AN from this research include consideration of a greater focus on addressing:

1. What is going on for the adolescent, including their emotional life with a prioritization of emotional holding, the voice and personal agency to maintain therapeutic engagement as they undertake the challenging task of nutritional restoration in the early stages of treatment within a treatment non-negotiable framework (35);
2. What is going on for the family, including addressing problematic family dynamics more comprehensively and assessment and re-assessment as to whether the intervention of parental responsibility for an adolescent's nutritional restoration is indicated or not within an individual family context;
3. Addressing the complex identity negotiations for adolescents including prioritization of the adolescents active involvement in discerning and naming the effects of AN on their life and rather than seeking to eliminate AN, facilitating the adolescent in reclaiming their life and identity from the AN (50); and
4. Scope for treatments to be more flexibly tailored to the adolescent and family needs and preferences within a treatment non-negotiable framework that prioritizes and supports the adolescent's physical and psychological safety, including their hope for the future.

Study Strengths and Limitations

The current study recruited a population of whom the majority had either dropped out and/or continued with ongoing psychological distress post treatment with MFT/FBT. With such targeted recruitment, the current study needs to be interpreted with this context in mind. For example, there exists a risk of negative bias in participants' recollection of their MFT/FBT treatment experiences in the event that participants subsequently engaged in more positively experienced

treatments. On the other hand, this study goes some way in mitigating against the risk of positive bias in participant recollection of their treatment experiences that may arise in the context of a positive outcome and recovery. A further strength of the study was two author extraction of data to reduce the risk of bias in interpretation of the transcript data. Furthermore, the scope of this study is in the development of a better understanding of why MFT/FBT does work for all and why.

Future research may seek to conduct similar research to explore the experiences and perspectives from a more diverse group of adolescents with a lived experience of adolescent AN. Further research would benefit from qualitative data triangulation (from multiple sources including adolescent, parent and clinician experiences of MFT/FBT) for completeness, convergence and dissonance of the key themes identified in this paper.

Concluding Remarks

This current study highlights the complexity that is involved in the treatment of adolescent AN and consideration of systemic family issues, adolescent psychological distress and identity formation in family-based treatments. The need for greater focus on addressing psychological distress, in all phases of treatment, was identified by all adolescents in this study as putative changes that would improve experiences and outcomes in AN treatments. Further research is needed to extend the current findings, including the tailoring of treatment to the adolescent and family needs and preferences (51) and addressing more comprehensively questions of identity, and how they may be applied in the development and evaluation of transformative AN treatment interventions.

List Of Abbreviations

AN: Anorexia Nervosa

BN: Bulimia Nervosa

ED: Eating Disorder

DBT: Dialectical Behavior Therapy

FBT: Family-Based Therapy

MFT: Maudsley Family Therapy

MFT/FBT: Despite some differences between the current manualised Family-Based Therapy (FBT; Lock & Le Grange, 2015), and Maudsley Family Therapy from which it is derived, for the purpose of this paper they will be referred collectively as MFT/FBT.

OCD: Obessive Compulsive Disorder

Declarations

Ethics approval and consent to participate: This research was approved by the Western Sydney University Ethics Committee (H11303).

Consent for publication: All transcript data has been de-identified through pseudonyms and participants were invited to remove any further identifying data and to review the analysis for consistency and resonance with their experiences.

Availability of data and materials: The datasets used and/or analysed during the current study are available from the corresponding author upon reasonable request.

Competing interests: The author(s) declare(s) that they have no competing interests.

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Authors' contributions: Each of the authors have made substantive contributions to this paper. JC conceived this research, interviewed participants, analysed the data, co-wrote and edited the manuscript. CJ analysed the data and contributed to the discussion, SN & KS analysed the data and contributed some of the sections of the paper, PH contributed to all sections of the paper including final editing.

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Tables

Table 1
Demographic and treatment details

Participant Pseudonym	Family structure	Age at interview	Age at diagnosis	MFT/ FBT age	MFT/ FBT mths	Individual therapy during MFT /FBT	Phase completed	Weight restored after treatment
Abbey	Parents + 3C	27	13	13	12	Yes psychiatrist & psychologist	3	Yes
Amy	Parents + 4C	18	16	16	24	Psychologist -depression/ anxiety	3	No (recent AN hospitalization)
Beth	Parents + 2C	16	14	14	7–8	No	1 (D/C)	No
Charlotte	Parents + 3C	19	16	16/17	12	Psychiatrist	2 (D/C)	No
Harley	Parents + 3C	17	14	14	6	No	2 (D/C)	Yes (temporary) then lapsed
Hayley	Parents + 2C	14	10	11	24	At end MFT/FBT – CBT	2 then lapsed (D/C)	No
Jessica	Parents separated + 3C	16	14	14	12	No	1 (D/C)	Yes
Kate	Parents separated + 3 C	18	17	17/18	3–4	No	1 (D/C)	No
Kaylee	Parents + C	20	16	16	6	No	1 (D/C)	Yes
Lydia	Parents + 3C	19	14/15	15	12	No	1 (D/C)	No
Maisy	Parents+ 2C	19	14	14	24	CBT, mindfulness, Psychiatrist	3	Yes
Nora	Parents + 2C	21	14/15	15		No	1 (D/C)	No
Phoenix	Parents + 2C	18	15/16	15/16	7	No	3	Yes
Rachel	Parents + 2C	20	17	17	6–8	No	1 (D/C)	Yes

Abbreviations—C: children; D/C: discontinued; ED: eating disorder.

Table 2
Additional treatments for Eating Disorder (ED) and other psychological problems

Participant Pseudonyms	Other eating disorder treatments	Eating disorder behaviours	Treatment for other problems
Abbey	Psychological therapy (including during MFT/FBT) Inpatient (P), BN day program	Restriction, over-exercise	Group Dialectical Behaviour Therapy
Amy	3 inpatient admissions (P), about to recommence hospital treatment, individual therapy(including during MFT/FBT)	Restriction, overexercise, Purging and binge eating	Psychiatrists/psychologists/school counsellor (P) for Depression, anxiety (included anti-depressants)
Beth	Nil	Restriction, over-exercise	Nil
Charlotte	Inpatient, psychiatrist	Restriction, purging	Nil
Harley	Inpatient then MFT/FBT (P), outpatient, multi-family therapy (P)	Restriction, overexercise, Purging	Psychiatrist/psychologist (C): Self-harm, Conversion Disorder, depression with psychosis: medication including SSRI's, Seroquel (+"atypical antipsychotics").
Hayley	Psychologist (Narrative Therapy) (C) Inpatient admission (P)	Restriction, overexercise	Psychologist (C): Anxiety
Jessica	Inpatient then MFT/FBT (P)	Restriction, over-exercise,	Saw Psychologist as a child (unsure why)
Kate	Psychologist (Narrative Therapy), dietitian, psychiatrist (C)	Restriction, overexercise	Psychologist and Psychiatrist (C): Anxiety; Family counselling before ED (P)
Kaylee	Inpatient then MFT/FBT (P) then inpatient	Restriction, over-exercise, Prior AN: purging, binge eating	Parent reported diagnosis ASD ("Asperger's"), depression
Lydia	Inpatient then MFT/FBT (P) then inpatient (total 8 admissions), ED day program (C)	Restriction, over-exercise,	Nil
Maisy	Psychological therapy (including during MFT/FBT) + ED support group	Purging - reported once	Psychiatrist OCD – current treatment lithium, recently ceased escitalopram
Nora	Psychologist and psychiatrist (C) Inpatient admissions (P)	Restriction, overexercise, Purging	Psychologist and psychiatrists for depression, OCD (C)
Phoenix	Psychologists (P&C), paediatrician, dietitian, school counsellor	Restriction, overexercise Purging, binging	Depression, OCD
Rachel	Outpatient Psychologist and Dietitian, Group Therapy	Restriction	Counsellor for OCD (age 10 years), current anti-depressants

Abbreviations—C: current; P: past; OCD: Obsessive Compulsive Disorder

Figures

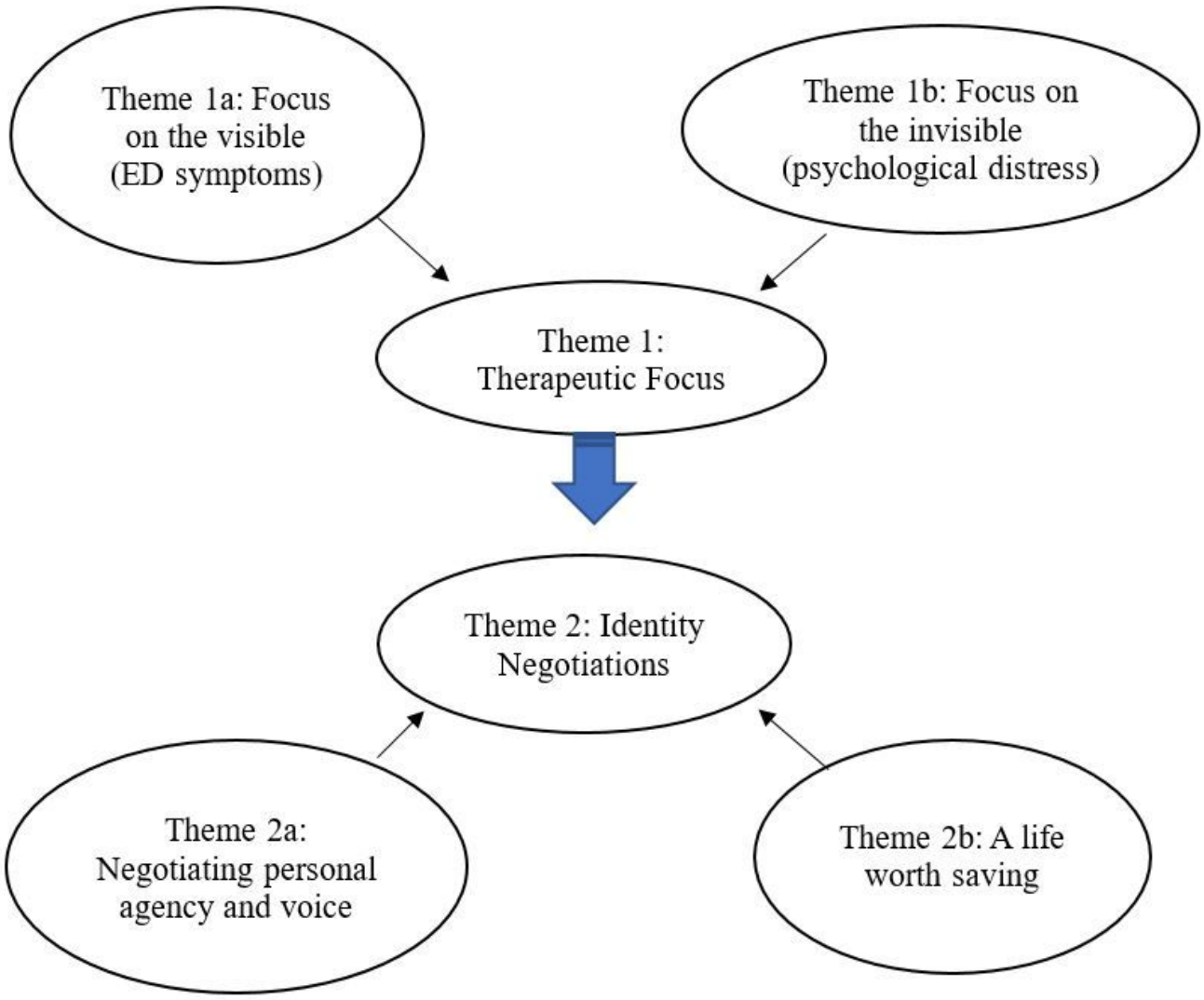

Figure 1

Thematic Map: Participants' MFT/FBT experiences and identity negotiations

Supplementary Files

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- Appendix.docx