



## ORIGINAL ARTICLE

# Family-based treatment for adolescents with anorexia nervosa: A long-term psychological follow-up

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**Aim:** Family-based treatment (FBT) has the greatest evidence base for the treatment of adolescents with anorexia nervosa (AN). However, little is known about the long-term outcomes for patients who receive FBT. The current study aimed to investigate the long-term psychological health of former patients who received FBT for AN during adolescence.

**Methods:** Former patients diagnosed and treated for AN at the Royal Children's Hospital and Monash Children's Hospital ( $N = 36$ ) in Melbourne, Australia completed self-report questionnaires to assess eating, exercising, mood and the impact of the coronavirus (COVID-19) pandemic. Patient scores were compared to healthy controls ( $N = 29$ ) and normative data.

**Results:** The eating and exercising behaviours of the patients who formerly had AN were comparable to controls. However, the former patients experience significantly greater levels of depression, anxiety, and stress than the controls ( $P < 0.05$ ). The COVID-19 pandemic appeared to impact the former patients and controls to a similar extent across quantifiable criteria.

**Conclusions:** This study extends previous research highlighting FBT as an effective intervention for adolescents with AN. Positive short- and long-term patient outcomes can be achieved with this form of treatment.

**Key words:** adolescent health; anorexia nervosa; family-based treatment; mental health; psychology.

## What is already known on this topic

- 1 Family-based treatment (FBT) is the leading treatment for adolescents with anorexia nervosa (AN).
- 2 Depressive and anxiety symptoms are common among patients who have recovered from AN.
- 3 Individuals with a history of a mental health condition may be particularly vulnerable to the adverse effects of high-level stressors.

## What this paper adds

- 1 Former patients who received family-based treatment (FBT) for anorexia nervosa (AN) during adolescence experience positive long-term outcomes, with indices of eating disorder behaviour and psychology which were indistinguishable from healthy controls.
- 2 A clinically elevated level of stress was present among individuals formerly diagnosed and treated for AN, in addition to higher levels of depression and anxiety than the general population.
- 3 The skills learnt through FBT held former patients in good stead when dealing with the high-level stressors of the COVID-19 pandemic.

Anorexia nervosa (AN) is a psychiatric disorder characterised by restrictive eating that results in excessive weight loss.<sup>1</sup> Onset predominantly occurs during adolescence and has a profound impact upon physical and psychological health.<sup>2</sup> The long-term prognosis

for AN is poor. Only 33% of the patients sustain full recovery; while half develop a chronic course and many die as a direct consequence of starvation-related medical complications or suicide.<sup>3</sup> Furthermore, despite achieving and maintaining a healthy body weight and medical stability, many recovered individuals continue to be plagued by disordered cognitions regarding food and body image.<sup>2,4</sup> This poses questions regarding how to best deliver clinical interventions to achieve positive long-term patient outcomes.

Family-based treatment (FBT), also known as the Maudsley approach, is one form of intervention that has a strong evidence

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base and is recommended by the United Kingdom Institute for Health and Care Excellence, and the American Psychiatric Association, for the treatment of AN in children and adolescents.<sup>5</sup> This is a three-phase treatment consisting of sixteen–twenty one-hour family sessions over a 6- to 12-month period that educate family members about the eating disorder (ED) and empower parents to take charge in leading their child's nutritional recovery. Research has shown that FBT achieves rapid weight gain, reduces medical repercussions and increases the chances of complete recovery compared to other forms of treatment.<sup>6–8</sup>

Despite the positive evidence for FBT, follow-up periods used in clinical studies tend to be short (6–12 months)<sup>3,4</sup> even though AN recovery is a slow and gradual process. This study is part of a larger investigation aiming to look at long-term outcomes, including cardiovascular and psychological morbidity 5 or more years post clinical remission, in patients diagnosed with AN during adolescence.

## Methods

### Setting

This study took place at the specialist paediatric Eating Disorder programs (ED programs) operating at the Royal Children's Hospital (RCH) and Monash Children's Hospital (MCH) in Melbourne, Australia. All patients presenting to these ED clinics undergo multidisciplinary assessment involving interviews, psychological questionnaires and a physical examination, to be diagnosed according to the Diagnostic and Statistical Manual of Mental Disorders (DSM).<sup>1</sup> Both services utilise FBT as the preferred form of treatment.

### Participants and recruitment

Attempts were made to contact all former patients treated for AN and discharged with remission from the RCH and MCH ED services 5 or more years ago, and currently aged 18+ years ( $N = 156$ ). Of the 65 patients able to be contacted, 36 (55.4%) were successfully recruited. Twenty-six (40%) were contacted but declined participation due to ongoing eating and body image issues, a negative treatment experience, not wishing to reflect on their ED, or a lack of interest in participating in research. The remaining three (4.6%) were deceased. Other former patients could not be contacted due to absent or incorrect postal addresses or an inability to make phone contact. Overall, this recruitment rate is comparable with other follow-up studies of ED patients.<sup>2,9,10</sup>

Healthy control participants ( $N = 29$ ) were recruited from The University of Melbourne, Murdoch Children's Research Institute (MCRI), and RCH. Acquaintances of the former patients were also invited to participate and were screened for eligibility. Healthy controls were aged 18+ years, did not have a previous diagnosis of an ED themselves or among their first-degree relatives, and did not have any known chronic disease. Eleven volunteers were excluded from the sample due to exhibiting one or more of the exclusion criteria (e.g., <18 years and/or siblings with an ED).

If the outcome data are normally distributed (or can be logarithmically transformed to normality), then a sample size of at

least 25 in each test group has 80% power to detect an effect size of 0.74 of the standard deviation based on a two-sample *t*-test with a two-sided significance level of 0.05. This is clinically significant to the treatment and ongoing management of both current and former patients with AN.

### Study procedures

Participants completed a series of questionnaires via the MCRI REDCap online database platform (REDCap 10.1.2-2020 Vanderbilt University). This included the Eating Disorder Examination Questionnaire (EDE-Q),<sup>11</sup> Commitment to Exercise Scale (CES)<sup>12</sup> and Depression Anxiety Stress Scale (DASS).<sup>13</sup> A non-validated COVID-19 Impact questionnaire (Appendix I) was also included to account for the effect of the pandemic upon participants mental health and well-being. This entailed eight questions adapted from the EDE-Q, CES and DASS. Participants responded on a 5-point Likert scale to establish quantifiable outcomes. Participants were also asked to scale their fear, worry and hope in relation to the pandemic, and provide any additional comments on how they had been affected.

### Statistical analysis

General descriptive statistics of the former patients and controls were calculated. Due to the skewed nature of the data, median scores and interquartile ranges (IQRs) were reported for eating, exercising, mood and COVID-19 impact. Comparisons were made between the two groups using the Wilcoxon test for continuous outcomes and Fisher's exact test for categorical outcomes. Scores were denoted as heightened if the median group score was higher than normal as defined by the questionnaires.<sup>11–13</sup> All analyses were performed using the R software (version 4.0.1, R Foundation, Vienna, Austria).

### Ethical considerations

This study was approved by The Royal Children's Hospital (RCH) Research Ethics and Governance Committee, Monash Health Governance Committee, and complied with the World Medical Association Declaration of Helsinki. Participants were provided with an information statement outlining the requirements and

**Table 1** Characteristics of the study sample

	Former AN ( $N = 36$ )	Healthy controls ( $N = 29$ )
Age (years), mean (SD)	24.2 (2.4)	27.7 (5.8)
Ethnicity (%) Caucasian)	83	76
Sex (% female)	94	73
BMI ( $\text{kg}/\text{m}^2$ ), mean (SD)	22.36 (2.61)	25.29 (3.28)

AN, anorexia nervosa; BMI, body mass index.

**Table 2** Psychological scores of former patients and controls

	Former AN (N = 36)	Controls (N = 29)
<b>EDE-Q</b>		
Restraint, median (IQR)	1.1 (0.4–2.4)	1 (0.4–2.4)
Eating concern, median (IQR)	1.2 (0.4–2.6)	1 (0.6–1.4)
Shape concern, median (IQR)	2 (0.8–3.5)	2 (1–3.1)
Weight concern, median (IQR)	1.4 (0.6–3.3)	2 (0.8–2.8)
Global EDE-Q Score, median (IQR)	1.4 (0.5–2.8)	1.6 (1.1–2.4)
<b>CES</b>		
Importance, median (IQR)	112.4 (83.3–139.5)	106.9 (81.4–124)
Upset, median (IQR)	85.2 (36.8–111.6)	83.7 (40.7–106.2)
Making up, median (IQR)	41.1 (12.4–93)	47.3 (24–86.8)
Set routines, median (IQR)	46.5 (17.8–100.4)	58.1 (19.8–106.6)
Tired or unwell, median (IQR)	38.8 (0–77.5)	31.8 (0.4–60.1)
Injured, median (IQR)	15.5 (0–77.5)	15.5 (0.8–46.5)
Guilt, median (IQR)	91.4 (36.4–129.4)	88.3 (34.5–107.7)
Social activities, median (IQR)	4.6 (0–25.2)	7 (0–28.7)
CES Total Score, median (IQR)	56.7 (31.5–83.4)	59.5 (49–76.5)
<b>DASS</b>		
Depression, median (IQR)	9 (5.8–15.2)*	4 (2–8.5)
Anxiety, median (IQR)	6.5 (3.8–12.8)*	3 (1–7.5)
Stress, median (IQR)	14.5 (8.5–20.2)*†	8 (5–13)
<b>COVID-19 impact</b>		
Limiting, median (IQR)	1 (0–2)	1 (0–2)
Excluding, median (IQR)	1 (0–2)	1 (0–2)
Binging, median (IQR)	0 (0–1.2)	0 (0–0.5)
Body image concerns, median (IQR)	2 (1–3)	2 (0.5–3)
Exercise importance, median (IQR)	2 (0.8–3.2)	2 (1–3)
Exercising more, median (IQR)	1 (0–3)	2 (0–3)
Sleeping trouble, median (IQR)	2 (1–4)*	1 (0–2)
Moody, median (IQR)	2 (0.8–3)	2 (0.5–2.5)
Fear, median (IQR)	32 (13.5–59)	34 (16.2–58)
Worry, median (IQR)	65 (39–73)	58.5 (42.5–70)
Hope, median (IQR)	56 (35.5–74)	50 (36.5–70.8)

AN, anorexia nervosa; CES, Commitment to Exercise Scale; DASS, Depression Anxiety Stress Scale; Eating Disorder Examination Questionnaire; IQR, interquartile range. \*  $P < 0.05$ . † Higher than normal.

## Results

Descriptive statistics for the patients who formerly had AN and the healthy controls are exhibited in Table 1. The healthy controls were approximately 3 years older, and their average body mass index (BMI) was approximately 3 kg/m<sup>2</sup> greater, than that of the former patients. The controls also represented a more heterogeneous group with a greater variety of ethnicities (76% vs. 83% Caucasian in former patients) and a more even distribution of sex (73% vs. 94% female). In addition, the time since the former patients had been discharged from their respective ED services ranged from 5 to 10 years.

Table 2 details the eating, exercising, mood and COVID-19 impact scores for the former patients and the controls. There was no significant difference in the EDE-Q or CES scores between the two groups. The DASS scores revealed that the patients who formerly had AN experience significantly greater levels of depressive symptoms, anxiety symptoms and stress than the controls ( $P = 0.014, 0.025$  and  $0.038$ , respectively). This is illustrated by the greater distribution of former patients towards the upper end of the depression, anxiety, and stress scales in Figure 1. Depression and anxiety scores were still within the normal clinical range, although the median stress score for the former patients exceeded normal limits, indicating a mild level of stress in this group.

Finally, COVID-19 Impact scores for eating and exercising behaviours were not significantly different between the former patients and the controls (Table 2). However, the former patients reported significantly more ( $P = 0.018$ ) trouble sleeping than the controls. Comments from some of the former patients recognised COVID-19 restrictions as a potential trigger for disordered attitudes and behaviours. This includes comments such as: 'COVID-19 lockdown has made me more anxious than usual', 'Covid 19 has definitely affected my body image issues and eating', and 'Lockdowns have made me feel trapped, and like I need to gain control - this usually is done through controlling food and exercise'. Due to 'stay at home' restrictions some of the patients who formerly had AN noted they began to 'obsess over exercise' and 'reduce portion size'. In contrast, the control group expressed a tendency to eat more and exercise less due to a lack of motivation and increased stress: 'I have found it harder to control what I eat and exercise regularly....I have less motivation'. Eating out of boredom and feelings of sadness due to loneliness and isolation were also prominent among comments from the control group.

## Discussion

Characteristics of the former AN sample population are consistent with previous studies on EDs. Most participants were female and Caucasian.<sup>10,14</sup> Greater heterogeneity among the control group could therefore be expected when sampling from the wider community rather than a specialised ED cohort. A higher average BMI for the control group is consistent with Australian Bureau of Statistics data in which 67% of Australian adults are overweight or obese, with 52% of 18–34 years old being overweight.<sup>15</sup> This study's control group was therefore considered to be an accurate representation of the general Australian public, suitable for comparison with the former patients.

risks of their involvement, and written informed consent was obtained.

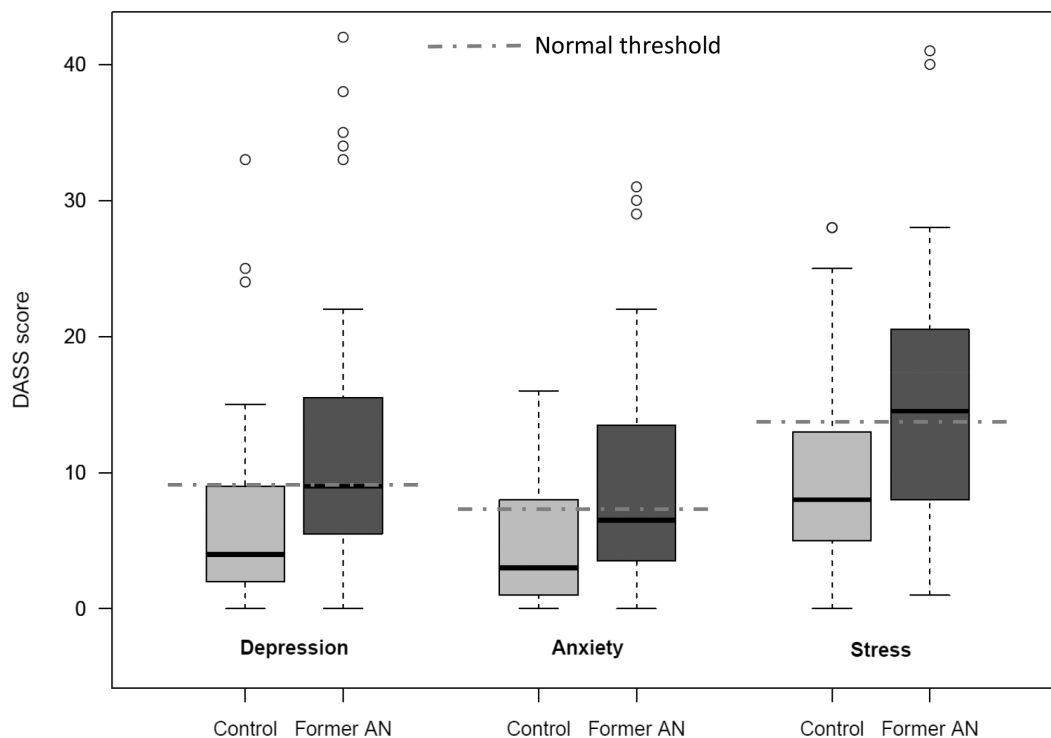


Fig. 1 Distribution of participant depression, anxiety and stress scores.

Greater levels of depressive symptoms, anxiety symptoms and stress among the former patients than the controls were consistent with previous studies in which significant depressive and anxiety symptoms were reported in recovered AN groups.<sup>14,16</sup> The prevailing consensus to date has been that anxiety disorders tend to precede EDs,<sup>17</sup> but depressive disorders are more often a consequence of EDs.<sup>18</sup> Furthermore, a mild level of stress among the patients who formerly had AN, supports the notion that inherent traits may predispose individuals to developing an ED. There is strong interplay between depression, anxiety and EDs; how this affects short-term treatment and long-term morbidity requires further investigation.

Despite the COVID-19 pandemic affecting the former patients and the controls differently according to participant comments, the extent of this impact was indiscernible between the two groups. This was not anticipated given reports that individuals with existing or previous mental health conditions may be particularly vulnerable to the impacts of the COVID-19 pandemic.<sup>19</sup> The reports of trouble sleeping experienced by the former patients compared to the controls during the pandemic, may merely be a consequence of the constantly higher depressive symptoms, anxiety symptoms, and stress among this group. Overall, according to our sample, the skills learnt by those who received FBT have held them in good stead for managing their eating/exercising behaviours and mental well-being, as they have fared comparably to the general population during the pandemic.

Previous studies have proposed that full recovery is achieved when individuals with a history of an ED appear indistinguishable from healthy controls on indices of ED behaviour and

psychology.<sup>2,4</sup> According to this definition, the former AN cohort assessed in this study is fully recovered, with eating, exercising behaviours, and body image concerns which are comparable to the controls. These findings show that FBT is not only effective for weight gain and improving psychopathology among adolescents with AN short-term,<sup>6,8</sup> but also in achieving positive long-term outcomes for patients. This also aligns with findings that there has been a significant decrease in readmission rates since FBT implementation at other hospitals.<sup>20</sup>

To the best of our knowledge, this is the first study to conduct a long-term follow-up dedicated to patients who received FBT for AN during adolescence. However, there are several limitations which should be discussed. Former patients who had a positive treatment experience and are now fairing relatively well are far more likely to be involved in research relating to their illness. Our results possibly reflect this selection bias. Self-report questionnaires may be prone to both under- and over-reporting as well as social desirability bias. Even though only patients who were discharged with remission were included, any relapses in recovery or additional treatment sought since the time of discharge to the present study's testing could have affected our results. In addition, since the time of patient diagnosis to recruitment, the DSM has undergone multiple revisions and AN diagnostic criteria have thus been altered over the course of the years studied. Several former patients who were originally diagnosed EDNOS restrictive-type were retrospectively considered to have met diagnostic criteria for AN and were therefore included in this study. Finally, the RCH and MCH implement FBT in different settings with MCH patients treated within community child and

adolescent mental health clinics and RCH patients treated within a specialist service. Since the integrity of the treatment regime is maintained, any differences between the two services likely have greater impact upon weight gain and short-term rather than long-term recovery, but should be noted nonetheless. Comparing patient outcomes for the two services could further examine the effectiveness of different FBT strategies.

## Conclusion

This study underscores that FBT of adolescents with AN is an effective intervention for achieving positive short- and long-term outcomes. Our findings should instil confidence in clinicians, patients, and their families that if adolescents with AN are treated intensively, they can make a full recovery and maintain recovery. Future research prospectively monitoring the transition through-out stages of recovery could identify and refine the elements of treatment needed to achieve and maintain recovery long term.

## Ethics Statement

This study received ethics approval from The Royal Children's Hospital Research Ethics and Governance Committee (HREC 2019.119) and Monash Health Governance Committee (RES-20-0000-471X).

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## APPENDIX A

### A.1. COVID-19 impact questionnaire

**Instructions:** The following questions relate to your eating and exercising behaviours, as well as your thoughts, feelings, and mood since COVID-19 restrictions were put in place. Please read each question carefully.

**Questions 1–8:** Please select the appropriate number on the right. **Remember the questions are comparing the time**

		Definitely not	Probably not	Possibly	Probably	Definitely
1.	Have you been deliberately limiting the amount of food you eat more often or to a greater extent?	0	1	2	3	4
2.	Have you been excluding foods from your diet that you would normally eat?	0	1	2	3	4
3.	Have you had episodes of binge eating (eating an unusually large amount of food given the circumstances) – more so than before the COVID-19 pandemic?	0	1	2	3	4
4.	Have you experienced body image concerns – more so than before the COVID-19 pandemic?	0	1	2	3	4
5.	Has exercise become more important to you?	0	1	2	3	4
6.	Have you been exercising more often?	0	1	2	3	4
7.	Have you been having trouble sleeping?	0	1	2	3	4
8.	Are you feeling more moody than normal?	0	1	2	3	4

prior to the COVID-19 pandemic (i.e. January, February 2020) to present.

The rating scale is as follows:

0 = Definitely not, 1 = Probably not, 2 = Possibly, 3 = Probably, 4 = Definitely.

**Question 9:** To what extent do you experience the following when thinking about the COVID-19 pandemic? Please mark your response along each scale.

**Fear?**

Not fearful

**Worry?**

Not worried

**Hope?**

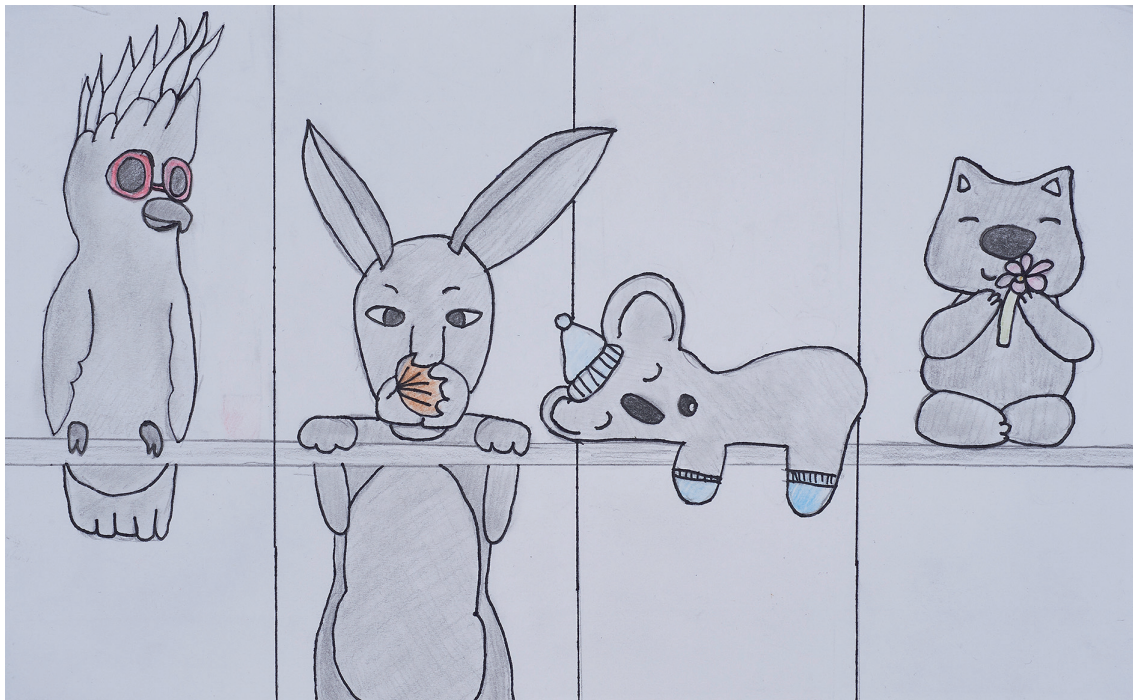
Not at all hopeful

Very fearful

Very worried

Very hopeful

**Question 10:** Any additional comments on how COVID-19 has impacted you? Please share all additional thoughts (e.g. COVID-19 has caused significant stress **or** COVID-19 has enabled me to focus on my health).



Seasonal Australia by Catherine Holmes (aged 14) from “A Pop of Colour” art competition, Youth Arts, Children’s Hospital at Westmead