# Fighting It From Both Angles:

A Qualitative Study of Adolescents, Parents, and Clinicians Involved in Adolescent & Parent Treatment for Anorexia Nervosa.

Holly Skylar Sharplin

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#### Abstract

## Background

Anorexia Nervosa (AN) is an eating disorder that has the highest mortality rate among all mental disorders. It is referred to as having a significantly low body weight due to restricting one's energy intake (American Psychiatric Association, 2013). Family-Based Treatment (FBT) is recognised as the first-line approach for young people with this illness, despite only 38% of all patients achieving full remission. Therefore, there is a need for alternative treatments for individuals who do not benefit from this approach which focuses primarily on refeeding. Adolescent and Parent Treatment (APT) is a new intervention that simultaneously addresses the physical aspects of recovery through refeeding and the psychological aspects of recovery through individual treatment modules.

# Aim

This study aims to investigate the experiences of patients, parents, and clinicians about APT in the recovery from AN. This was explored by identifying what specific components of APT participants found helpful or unhelpful, as well as how they viewed APT compared to other treatments for AN.

# Method

Participants were recruited from private outpatient settings in Melbourne, Australia and in Auckland, New Zealand. The sample consisted of eighteen participants, all of whom had been involved in APT. This included six patients who either had AN or had already recovered, six parents of children with AN, and six clinicians practising APT. Semi-structured interviews were individually conducted with each participant and recorded using Zoom software. Qualitative data analysis was performed using the General Inductive Approach.

# Results

Three key themes were gleaned from the data, representing participants' perceptions of what they considered helpful or unhelpful in APT. These themes are 1.) APT delivers an effective therapy through therapeutic rapport, 2.) APT provides a tailored treatment experience for each patient and their family, and 3.) Dietetic input is essential for recovery from AN.

# Conclusions

Results revealed that APT provides patients with a holistic treatment experience with an emphasis on psychological recovery, which was essential for patients who did not recover under the FBT framework. Considering this study is the first of its kind, further qualitative and quantitative research is required on this treatment.

# Preface

My primary supervisor and I originally planned this thesis as a quantitative research study. It was envisaged as a case series based on a variety of patients observed at regular intervals and recruited solely through Nurture Psychology, a private eating disorder clinic in Parnell, Auckland, New Zealand.

With this treatment centre recognised as the official provider of the novel APT method in New Zealand, and treatment plans severely disrupted due to government-imposed restrictions during the global Covid-19 pandemic, we were unable to recruit a sufficient number of participants for the quantitative research approach in the required period.

When my primary supervisor was additionally forced to take extended sick leave, a co-supervisor was appointed who, along with a statistician, supported me to pivot by extending my research to Australia and basing it on a qualitative research method.

This required me to start from scratch, including seeking new ethics approval. Whilst it delayed my output, it provided a significant number of participants and invaluable input from the Australia-based founders (Maria Ganci and Dr Linsey Atkins) and the patients' wider treatment teams.

Thus, the result of this research is in accordance with the strengths of qualitative research; gathering indepth insights on a treatment approach that was not well understood prior. These were gleaned through open-ended questions in interviews and literature reviews that exposed concepts and theories rather than statistical numbers.

It is my sincere hope that my work will encourage more clinicians to research the benefits of APT and for it to become a viable intervention (here in New Zealand) for young people battling the most deadly of all mental disorders, Anorexia Nervosa.

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Most importantly, my participants, the young people who all share a personal journey with eating disorders, their parents, and clinicians. Thank you for your generous time and remarkable courage to talk so openly with me about your battles with Anorexia Nervosa.

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# Glossary of Abbreviations

AFT	Adolescent-Focused Therapy		
AN	Anorexia Nervosa		
APT	Adolescent and Parent Treatment		
BMI	Body Mass Index		
CBT-E	Enhanced Cognitive Behavioural Therapy		
CRT	Cognitive Remediation Therapy		
CFT	Conjoint Family Therapy		
DSM-5	Diagnostic and Statistical Manual of Mental		
	Disorders (5th Edition)		
ED	Eating Disorder		
EDE-Q	Eating Disorder Examination Questionnaire		
EOT	End of Treatment		
EOIT	Ego Orientated Individual Treatment		
FBT	Family-Based Treatment		
FT	Family Therapy		
FT-AN	Family Therapy for Anorexia Nervosa		
HS	Holly Sharplin (lead researcher)		
IFT	Intensive Family Therapy		
IPC	Intensive Parental Coaching		
IT	Individual Therapy		
MFT	Multi-Family Therapy		
NICE	National Institute for Health and Care		
	Excellence		
OCD	Obsessive-Compulsive Disorder		
PFT	Parent-Focused Treatment		
RCT	Randomised Control Trial		
SDT	Self Determination Theory		
SFT	Separated Family Therapy		
SyFT	Systematic Family therapy		
WHO	World Health Organisation		

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## 1.1 Thesis Outline

Eating disorders (EDs) are serious, life-threatening illnesses, with Anorexia Nervosa (AN) being the deadliest of all psychiatric disorders (Lock, 2019). AN became a prevalent disorder in the late 1960s, particularly in Western society, after having previously been rarely diagnosed (Polivy & Herman, 2002). Although incidence rates have escalated in the last 60 years, part of this increase could likely be due to greater awareness of the illness and a higher level of reporting than ever before (Wakeling, 1996). Contrary to early beliefs, there is no one cause to explain the occurrence of an ED. Instead, its' development is a combination of multiple factors that uniquely interact with every individual who experiences an ED. Some of these factors are externally driven, including sociocultural and familial influences, whilst others are internally driven, such as personal experiences, characteristics, level of self-esteem, cognitive factors, and biological factors (Polivy & Herman, 2002).

Young people under the age of 15 are increasingly diagnosed with AN (van Eeden et al., 2021). Elevated prevalence rates of AN in this age group necessitate early detection and intervention, particularly given that adolescents are particularly vulnerable to the medical consequences of AN (Espie & Eisler, 2015). Moreover, it is crucial that adolescents are treated promptly to avoid poor treatment outcomes that can occur if not dealt with in the first three years of the illness onset (Treasure & Russell, 2011).

In an outpatient setting, Family-Based Treatment (FBT) is the treatment of choice and is globally recognised as the first-line approach, according to NICE guidelines (National Institute for Health and Care Excellence, 2017). Parents play a critical role in their child's refeeding, helping them change the maintaining behaviours of AN until they can progress independently. FBT appears to have the most extensive evidential base and remains the most empirically effective treatment for adolescent AN to date (Lock, 2019). Nevertheless, research shows an average full remission rate of 38% for all patients at the end of treatment, with partial remission closer to 50% (Lock & Le Grange, 2019). Whilst other frameworks are emerging in treating adolescent AN, research within the literature is still in its infancy.

Considering that FBT focuses solely on refeeding and is only effective for less than half of patients being treated, alternative treatment avenues must be explored that consider adolescents' physical and

psychological well-being. Adolescent and Parent Treatment (APT), developed by Maria Ganci and Linsey Atkins, is a novel treatment available in clinical practice for adolescents aged 12-24 years (Ganci et al., 2021). The framework addresses the limitations of previous treatments in a holistic manner by delivering tailored psychological therapy alongside parental renourishment of the adolescent. Currently, APT is solely supported by clinicians within Australia and New Zealand who are trained to deliver APT therapeutically. Except for the commentary recently released by APT developers regarding the treatment as a "novel intervention prospect" (Ganci et al., 2021), no research has yet been published.

Motivated by the recommendations made within the commentary on APT, this study provides the first piece of research to empirically investigate how APT is perceived by its service users, including patients, parents of children who have undergone APT, and clinicians.

In the hopes of the lead researcher (HS) of the current study, conducting this research will inform clinical practice and provide the building blocks for potential larger-scale research to be performed in the future on APT.

# 1.2 Research Aim

To investigate the views and experiences of patients, parents, and clinicians about Adolescent and Parent Treatment (APT) in the recovery from Anorexia Nervosa.

# 1.3 Research Questions

- 1. What specific components of APT do participants identify as helpful or unhelpful in the recovery from AN?
- 2. How do participants view APT compared to other treatments for AN?

# 1.4 Overview of Chapters

This thesis is comprised of seven chapters. Chapter one is the introduction, which describes the research problem and the significance of this study.

Chapter two offers a broad overview of AN and how adolescents are impacted by it. This chapter will detail the diagnostics, epidemiology, medical consequences, psychiatric comorbidities, and psychosocial complications for adolescents with AN.

Chapter three takes a deep dive into some of the family therapies available to adolescents with AN. There is particular emphasis on FBT, including the treatment structure, the evidence base, remission rates, and how its service users perceive it. This chapter will then look at the framework of APT and why it is worthy of investigation in the current study.

Chapter four describes the methodology of the current study, including the participants and setting, ethics approval, recruitment of participants and study procedure, as well as how data was collected and analysed.

Chapter five provides the results from the study, which represent three key themes (also referred to as categories), as well as suggestions for further developing APT.

Chapter six describes the results in the context of the literature and outlines the limitations of the current study and what the study adds.

Finally, chapter seven gives insight into the conclusions that can be drawn from the study and also provides future recommendations for research.

#### Chapter 2: Anorexia Nervosa

#### 2.1 Diagnostics

According to the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), those with Anorexia Nervosa (AN) exhibit an intense fear of gaining weight and getting fat, bodily disturbances regarding their weight and shape, and are often unable to recognise the seriousness of their low weight due to anorexic cognitions (American Psychiatric Association, 2013).

There are two subtypes of AN; the restricting type, in which the individual achieves weight loss through a lack of eating and excessive exercise, and the binge-eating or purging type, which involves repetitively partaking in episodes of binge-eating or purging behaviour (American Psychiatric Association, 2013).

Individuals who have experienced a significant loss of body weight often get diagnosed with AN (American Psychiatric Association, 2013). For adults, body weight is defined by their body mass index (BMI), with the lower end of a healthy BMI being equal to or above 18.5 kg/m<sup>2</sup>, and moderate to severe weight being under 17.0 kg/m<sup>2</sup>, as indicated by the World Health Organisation (WHO), (World Health Organization, 1995). A BMI percentile is used for children and adolescents, as a BMI criterion is more difficult for this age group to meet (American Psychiatric Association, 2013). A BMI percentile is also used to account for a potential inability to gain weight due to common developmental reasons such as growth in height or not having an established menstrual period yet (Fisher et al., 2001), as opposed to necessarily losing weight (Rosen, 2010).

#### 2.2 Epidemiology

AN can develop at any age; however, the highest incidence rates occur in adolescents and young adults between 15 and 25 years of age, making it one of the most commonly experienced chronic disorders in adolescence (Schmidt et al., 2016). For females, the peak age of illness onset ranges from ten to 14 years, whilst onset for males tends to be around 16 years of age (Petkova et al., 2019). Although incidence rates are rising for both men and women (Smink et al., 2013), the research indicates that AN impacts primarily young women and adolescent girls, with a prevalence in females being reported as high as 4% and approximately 0.1% to 0.3% in men (van Eeden et al., 2021). However, this statistic is not likely representative of all males who experience the disorder (Gorrell & Murray, 2019). There is possibly a lack of detection due to males not seeking help for fear of being scrutinised for having a psychiatric disorder, only exacerbated by the stereotype that EDs

(eating disorders) are female-dominated illnesses (Raevuori et al., 2014). The average duration of AN is approximately six years (Schmidt et al., 2016). The risk of developing an ED is exceptionally high during major developmental stages of life. This is not exclusive to adolescence but also affects women during the peri-menopausal period when they undergo critical estrogen changes (Samuels et al., 2019). This stage is seen as a highly vulnerable period for ED symptoms to develop or persist, even after being in remission for many years.

AN is associated with significantly higher mortality rates, with individuals being almost six times more at risk than those who do not experience the illness (van Eeden et al., 2021). Half of these deaths are associated with medical complications, such as serum electrolyte disturbances with purging behaviours, whereas suicide is the second leading cause of death (Mehler & Walsh, 2016; Smith et al., 2018).

#### 2.3 Medical Consequences

The complexity of AN is displayed in its co-occurring psychological and physiological factors that affect a vast majority of organs in the body, rendering this disorder notoriously challenging to treat (Puckett et al., 2021). The extent of these medical complications is unique to every individual and depends entirely upon the severity of the illness they experience (Mehler & Brown, 2015). Individuals with AN engage in behaviours that offset many changes to psychological well-being and pregnancy, as well as the bone, endocrine, gastrointestinal, cardiovascular, and pulmonary systems (Puckett et al., 2021). Whilst most of these medical complications are reversible with appropriate refeeding and weight restoration, bone health and cognitive function are particularly susceptible to permanent damage (Puckett et al., 2021). If the body becomes starved, it adapts to a state of low energy, which leads to dysregulation in the entire endocrine system (Neale & Hudson, 2020). Even after just one year of being underweight, bone health can become seriously impaired, with the potential for a permanent reduction in bone mineral density and an increased risk for lifelong fractures (Misra et al., 2016). On a neurological level, AN has detrimental implications for the central and peripheral nervous systems (Cass et al., 2020). Whilst recovery in the peripheral nervous system is possible with renourishment, cognitive deficits may remain even after the affected individual is in remission, specifically, neurocognitive changes in cognitive flexibility and setshifting (Fuglset, 2019), as well as damage to some areas of executive functioning (Stedal et al., 2019).

In many cases, medical complications are even more concerning for those with adolescent-onset AN. It is a unique period of life whereby adolescents experience AN differently than adults due to the major level of growth and development that they must undergo (Espie & Eisler, 2015). If a teenager becomes underweight during pubertal development, AN can disturb their growth and delay the onset of puberty (Neale & Hudson, 2020). While catch-up growth is achievable for most people with the correct nutritional rehabilitation, younger individuals, or those who have suffered the illness for a longer time, may experience an increased risk of growth delay or even growth stunting in some cases. Adolescence also marks a critical period of bone mineral density accumulation, where 40-60% of bone mass is typically acquired (Misra et al., 2016). If underweight adolescents do not reach their peak bone mass, this can have lifelong consequences on their skeletal health and increase their risk for decreased bone health in adulthood (Misra et al., 2016). Even without a decrease in bone mineral density, adolescents with AN may still fall victim to a greater risk of fractures in later life (Faje et al., 2014). Medical complications of AN can also lead to alterations in the brain. Whilst there is currently no longitudinal data to support this, research has indicated a significantly greater reduction in the grey matter of the brain in adolescents (8.4% compared to 3.1% in adults) even after weight recovery for short-term weight recovery. (Dalle Grave, Sartirana, et al., 2021; Seitz et al., 2016). For adults, however, changes to brain structure and function appear reversible after long-term weight gain is achieved.

#### 2.4 Psychiatric Comorbidities

It is commonplace for individuals with AN to present with psychiatric comorbidities with strong links to mood and anxiety disorders, personality disorders, substance use disorders, self-harm, and suicidality (Kask et al., 2016; Moskowitz & Weiselberg, 2017). Amongst these psychiatric illnesses, individuals with AN typically experience between one and three comorbid anxiety disorders, particularly social phobia, specific phobia, and obsessive-compulsive disorder (Godart et al., 2002; Kendler et al., 1995; Walters & Kendler, 1995). Other anxiety disorders less commonly experienced in combination with AN are generalised anxiety disorder and post-traumatic stress disorder. For the most part, an anxiety disorder is developed before an ED (Bulik et al., 1997; Deep et al., 1995; Godart et al., 2000). A study consisting of 672 patients with an ED aged 13 – 65 years old, 97 of which had AN, found that 64% of the total sample had a lifetime diagnosis of one or multiple anxiety disorders, with 42% of the total sample having had developed an anxiety disorder in childhood, before their ED onset (Kaye et al., 2004). Even amongst participants who did not have a lifetime diagnosis of an anxiety disorder or had recovered from their ED at least 12 months ago, some still

reported having higher anxiety levels than healthy controls and were harm-avoidant and perfectionistic (Kaye et al., 2004). These findings reiterate the prevalence of anxiety traits amongst individuals with an ED, irrespective of having received a clinical diagnosis for an anxiety disorder. It also shows that anxiety continues to endure long after recovery. For the majority of individuals who have AN comorbid with other psychiatric illnesses, mortality rates are even greater than for those who experience AN exclusively (Himmerich et al., 2019). In a study of 1970 patients with AN, ranging from eight to 88 years of age, researchers discovered a moderately heightened risk for mortality, at least, in part, for people that had substance use disorders and personality disorders comorbid with their illness (Himmerich et al., 2019). When confounding variables were controlled, there was still a moderately elevated risk, but it was no longer significant.

#### 2.5 Psychosocial Complications in Adolescents

If AN is developed during the teenage years, it can affect individuals' psychosocial functioning longterm (Himmerich et al., 2019). An 18-year outcome study examining the long-term consequences of adolescent-onset AN included 51 adolescents who had developed AN before 18 (Wentz et al., 2009). Having received either family therapy (FT) or individual therapy (IT), participants were examined at ages 16, 21, and 24 and were then interviewed and compared to a comparison group 18 years after their diagnosis. Despite high recovery rates (only three out of 51 participants with AN maintained their ED), 39% of the original cohort had developed a psychiatric disorder unrelated to their ED (Wentz et al., 2009). One-quarter of participants, including those with ongoing AN, could not receive paid employment due to ongoing psychiatric issues. Additionally, all participants continued to display symptoms of over-awareness of body shape, weight, and tension during mealtimes. Ninetysix per cent of the original cohort agreed to participate in a follow-up study 11 years later, with almost equal outcomes (Dobrescu et al., 2020). Amongst these participants, 6% had ongoing AN and 38% had developed other psychiatric diagnoses. Good outcome criteria included an older age of onset and having premorbid perfectionism, despite this often being recognised as a risk factor for AN in the first place (Dobrescu et al., 2020). These results depict the broader implications that AN can have on an affected individual's life beyond the internal aspects of their ED, even after recovery.

A similar 10-year follow-up study was conducted with 39 inpatients who had adolescent-onset AN and were assessed three-, seven-, and ten years after their treatment (Herpertz-Dahlmann et al., 2001). Although 69% of participants had recovered from their ED, more than half were still suffering from other psychiatric disorders, mainly anxiety disorders, affective disorders, and substance use

disorder. The study also found a relationship between having persistent AN and developing a personality disorder, of which 23% met the full criteria. Whilst most recovered participants could adapt to a social lifestyle deemed appropriate for their age, 7.7% stated having occupational struggles because of their eating disorders and comorbid psychiatric illnesses (Herpertz-Dahlmann et al., 2001). Most individuals who experience AN achieve physical recovery, with many being able to return to a healthy level of functioning. However, a considerable proportion of physically recovered individuals continue to suffer the effects of AN psychologically and socially, as highlighted by the prevalence of psychiatric illnesses comorbid with the ED. This reinforces the need for a framework where the psychological aspects of recovery are prioritised in therapy. This is what has further inspired the current research to look into APT as one potential treatment option.

AN is a debilitating illness that has detrimental impacts on physical and psychological well-being, which plays into the significant mortality rate and high comorbidity for individuals who experience it. Given that adolescents tend to respond more favourably to treatment than their adult counterparts and that the medical difficulties impacting those with AN are particularly pertinent in young people, it is crucial that a diagnosis is made, and sufficient care is provided as efficiently as possible. It is also essential that AN is treated promptly, given that early intervention in AN leads to more successful treatment outcomes (Treasure & Russell, 2011).

#### Chapter 3: Family Therapy

Family therapy (FT) has been considered the mainstay of treatments for Anorexia Nervosa (AN) in adolescents (Lock & Le Grange, 2019). It initially gained popularity after the first randomised control trial (RCT) was published, comparing it with individual therapy (IT) (Russell et al., 1987). In the most recent guidelines released by the National Institute for Health and Care Excellence (NICE), FT was recommended as the first-line treatment approach for adolescents with AN (National Institute for Health and Care Excellence, 2017). Today, FT is internationally utilised both in its original framework, known as Family Therapy for Anorexia Nervosa (FT-AN), and its manualised framework, Family-Based treatment (FBT). Developed by Christopher Dare and Ivan Eisler in the 1980s, FBT is the most empirically supported and extensively researched treatment for eating disorders (EDs) and has become the gold standard for treating adolescents with AN in an outpatient setting (Ganci et al., 2021)

#### 3.1 Phases of Family-Based Treatment

During FBT, adolescents undergo three phases of treatment conducted over ten to 20 sessions, lasting approximately six to 12 months (Lock, 2019). The adolescent and their family work collaboratively with the therapist, with all treatment responsibilities initially assigned to parents to help restore their child's weight in the early stages of recovery. Parents are taught specific strategies to help their children overcome the maintaining behaviours of their ED by encouraging them to use existing parenting skills which have been impeded by AN and develop new ones as required (Lock, 2019).

The first phase of treatment involves assessing the patient's situation and establishing a treatment plan (Lock & Le Grange, 2015). Parents are explicitly reminded of the seriousness of the disorder and are encouraged to take complete control of refeeding their child. This recommendation assumes that parents know their children best and are dedicated to ensuring that they live a long and healthy life, thus are their most important resource. Although siblings are not involved in refeeding, they do play a minor role in treatment. During the second session, the family are invited to have a meal in the therapist's office, which enables the professional to continue to evaluate the family structure and give support where needed (Lock & Le Grange, 2015). This session is an opportunity for parents to recognise their refeeding efforts, which builds confidence in them that they can help their child recover. Phase 1 typically lasts about three months (Lock, 2019).

Transition into the second phase can begin once the patient is at least 90% of their expected weight and somewhat complies with their parents' refeeding expectations (Lock et al., 2005). Parents must also demonstrate a certain degree of self-belief in helping their child restore their weight. The second phase of treatment focuses on progressively giving the affected individual more autonomy over their food intake, which is contingent on their progress in their recovery (Lock & Le Grange, 2015). This process is undertaken gradually to avoid the patient slipping, which can be discouraging to both the family and the therapist (Rienecke, 2017). Parents continue to receive support from the therapist with their child's refeeding during phase two, which typically lasts about two to three months (Lock, 2019; Lock & Le Grange, 2015).

The third phase can begin once the patient is sufficiently eating without parental assistance and other ED symptoms are no longer evident (Lock & Le Grange, 2015). Adolescents should be at 95-100% of their mean body weight at this stage. Whilst there may still be some fears surrounding eating or their perception of their body, it is easier to tackle these issues when weight is under control and the disorder is no longer distorting their cognitions. At this point, the adolescent's development can be explored with their parents, and the focus no longer needs to be exclusively on the ED itself (Lock & Le Grange, 2015). The therapist should also work to restore family functioning, as AN often interferes with the structure of daily life within a family. Additionally, the therapist will discuss issues with the family in the context of the ED that may arise in the future and suggest ways of approaching these if and as they arise. This phase tends to be shorter than the first two phases, typically lasting around one to two months (Lock, 2019).

#### 3.2 Tenets of Family-Based Treatment

At the forefront of treatment are five tenets that set FBT apart from other frameworks used in ED recovery (Rienecke, 2017). The first is that FBT takes an agnostic view of how the ED has developed without blaming either the patient or family members for the illness. Rather than trying to identify the causes of the ED (as it is always a result of many factors coming together), the focus is put on determining what will be most beneficial in helping the patient achieve recovery (Rienecke, 2017). Rather than trying to determine what the root cause of the ED is, FBT instead focuses on reducing ED symptomology as effectively as possible (Rienecke & Le Grange, 2022).

The second tenet encourages the family to externalise the ED from their child (Rienecke, 2017). Family members are advised to treat the illness as separate from the adolescent, as the ED is the driving force behind their eating habits and how they view their shape and weight. Parents are reassured that their child is not in control of their ED; instead, their child is in the grip of a serious disorder influencing their thoughts, feelings, and behaviours (Lock & Le Grange, 2015; Rienecke & Le Grange, 2022). They are assured that their child did not choose to have AN, nor is it easy to stop the behaviour that accompanies it (Rienecke, 2017).

The third tenet involves the therapist taking a supportive approach rather than an authoritative approach during the patient's recovery which involves helping the family rely on their resourcefulness (Rienecke, 2017). Naturally, the therapist should provide psychoeducation and support. Still, the parents are seen as the experts on their child's eating habits as they are likely to be the most committed to their health and wellbeing (Lock & Le Grange, 2015; Rienecke & Le Grange, 2022). Whilst the therapist is there to provide guidance, the family is given the upper hand in devising a recovery plan that will work best for their child (Rienecke, 2017).

The fourth principle focuses on building self-efficacy in parents so they feel confident in their ability to bring about recovery in their child (Rienecke, 2017). AN influences the individual to function in a child-like manner; thus, parents are seen as their child's most important resource to guide them assertively in the right direction (Lock & Le Grange, 2015). This principle states that the ED will dominate and persist if parents lack the confidence to refeed their child, causing the individual to resist change (Rienecke & Le Grange, 2022). The therapist instils empowerment into parents by putting them at the forefront of their child's recovery and reaffirming their capability in helping their child overcome the ED (Rienecke, 2017).

Finally, weight restoration must be emphasised at the outset of the treatment (Rienecke, 2017). Malnourishment brings about a host of long-term consequences to bone and brain health if not dealt with efficiently. Hence, the initial focus is stopping food restrictions and returning patients to optimal physical health. Whilst parents are often concerned with issues secondary to the ED in their children, such as anxiety, social withdrawal, irritability, or a depressed mood, they are not treated in the first instance to ensure that the attention remains on restoring weight (Rienecke, 2017). Parents are reassured that many of these issues will resolve on their own so long as weight restoration remains the initial priority, which is achieved through a focus on behavioural change (Rienecke & Le Grange, 2022).

#### 3.3 The Evidence Base for Family Therapies

A literature search was conducted on the effectiveness of FTs for adolescents with AN having specific inclusion criterion in mind. Firstly, due to their methodological rigour, research must be comprised exclusively of randomised controlled trials (RCTs). Participants with AN must be mainly between 12 and 18 years of age, must have received a diagnosis of AN according to diagnostic criteria, as well as having been treated in an outpatient setting at the time of the study. The Cochrane Library database recently published a systematic review of FT approaches, including all relevant RCTs up until May of 2018 (Fisher et al., 2019). Seven RCTs from this review fit the inclusion criteria for the current study. Additional searches were performed on Medline, Scopus and Google Scholar databases (May 2018 – July 2022), however no further RCTs were found. The search terms used were 'family therapies', 'treatment', 'adolescents', 'anorexia nervosa', and 'outpatient'.

The systematic review performed by Cochrane establishes sources of potential bias for each RCT to assess the quality of evidence (Fisher et al., 2019). Risks of bias can be mitigated by group allocation (randomisation and concealment), blinding participants (including patients and therapists), addressing incomplete data, and avoiding selective reporting (Fisher et al., 2019; Moseley & Pinheiro, 2022). To achieve successful group allocation, participants should be randomly assigned to treatment groups. The allocation sequence should be concealed from the individual who determines participant eligibility for the trial (Moseley & Pinheiro, 2022). Blinding refers to participants and personnel being unaware of treatment allocation to avoid unwanted outcome effects. Incomplete data should be addressed by explicitly stating the amount of missing data and conducting an intent-to-treat analysis (Fisher et al., 2019). Selective reporting bias indicates that data or follow-up data that was collected from outcome measures were not reported. The risk of bias can either be low, moderate, high, or unclear. In the context of the current study, only moderate or high risk of bias will be mentioned.

It is noteworthy that the Cochrane report states that it is not possible to blind participants to treatment conditions in FT trials. Therefore, all RCTs described below have a high risk of bias for this category.

The first RCT to be published on family therapy was conducted by Russell and colleagues, who assessed the efficacy of FT for patients with either AN or bulimia nervosa (Russell et al., 1987). Participants included 80 individuals (73 females, 7 males), 57 of whom had AN,

with varying levels of illness severity. Participants initially received inpatient treatment and were then randomly assigned to receive either FT or IT at discharge. They were also divided into subgroups according to their age of illness onset and duration. One year after treatment, participants were reassessed using the Morgan Russell Assessment Schedule, as well as BMI and menstrual function. Nine out of ten patients within one of the subgroups treated with FT achieved good or intermediate outcomes (six patients when outcomes were considered alone). In contrast, only two out of 11 patients achieved good or intermediate outcomes when treated with IT (three patients when outcomes were considered alone). Results showed FT was more effective than IT if the diagnosis was made before 19 years of age and the illness duration was under three years (Russell et al., 1987). The study concluded that FT is more effective than IT for the recovery from an ED, mainly where patients were younger, and their illness was acute. Although more of a provisional finding, IT appeared to be the more effective treatment option for older patients over the age of 19. Although family functioning was not measured, older adolescents may have responded more favourably to the structure of an IT due to typically wanting more autonomy over their treatment and not being as reliant on their parents as younger adolescents typically are. There is a high risk of bias for incomplete outcome data and a high risk of selective reporting in this RCT.

Following the initial RCT, which found FT to be more effective for young people with an acute ED, researchers set out to examine the feasibility of using conjoint family therapy (CFT) and separated family therapy (SFT) (Le Grange et al., 1992). CFT involves treating one or more families in the same session, whereas SFT provides individual support for patients and counselling sessions for parents. The sample consisted of 18 participants (16 females, two males) between the ages of 12 and 17 who had been referred to an eating disorder unit for AN. Patients were randomly assigned to receive either CFT or SFT for six months. Changes in participant's biological (weight, height, and menstruation) and psychological (scores on the Morgan Russell Assessment Schedule) behaviours were assessed at baseline, 16 weeks, and 32 weeks into treatment, as well as family functioning. Results revealed that patients improved significantly across all measures within both CFT and SFT, yet there was no significant difference between the two treatment modalities. Despite no significant difference between treatment groups in family functioning scores, maternal criticism was found to be higher for those in CFT compared to SFT. This finding should be treated with caution, however, as this could be due to parents potentially having large scores of criticisms that were not controlled for by researchers, or different processes occurring within the frameworks influencing outcomes (Le Grange et al., 1992). As was found in the first RCT, there is a high risk of bias for incomplete outcome data and a high risk of selective reporting.

As an extension to the study by Le Grange and colleagues (Le Grange et al., 1992), an RCT was conducted to examine the end-of-treatment outcomes of CFT and SFT for adolescent AN (Eisler et al., 2000). The study consisted of 40 adolescent referrals for AN (39 females, one male) between the ages of 12 and 18. Participants were randomly divided into one of two treatment groups, with parental criticism controlled for using a stratified design and assessed using various family measures. Measure scores were taken at baseline, as well as reassessments at three and six months into treatment and at discharge one year later. Significant improvements in both CFT and SFT were found according to measures examining symptomatology, psychological state, and family functioning, with no significant differences between groups at end of treatment. Whilst not significant, SFT did demonstrate slightly more favourable scores in terms of symptom reduction and demonstrated to be a more effective framework than CFT for those who experienced high maternal criticism. This study illustrates the benefits of a family-based approach to treatment where patients receive individual treatment sessions without their parents always in the room. In line with findings from previous research (Le Grange et al., 1992), this is particularly the case where high levels of maternal criticism are apparent. There is a high risk of bias for incomplete outcome data and a high risk of selective reporting.

Following the publication of the original study on FT, which found this treatment approach to be superior to IT (Russell et al., 1987), an RCT set out to determine the ideal length of time receiving manualised family-based therapy, otherwise known as family-based treatment (FBT) (Lock et al., 2005). Participants consisted of 86 adolescent referrals (77 females, nine males) aged 12 to 18 who were randomly assigned to receive treatment either short-term (ten sessions in six months) or long-term (20 sessions in 12 months). Nine participants did not complete treatment, with an additional eight participants not completing the very last assessment. Results from intent-to-treat data demonstrated no significant differences between either treatment group, except in cases where adolescents came from separated families or had severe eating-related obsessive-compulsive characteristics. In these cases, participants benefited more from long-term treatment. Results suggest that short-term treatment is just as effective as long-term treatment where participants had a short illness duration and were assessed after one year. Despite these findings being preliminary and there being a need for comparison with alternative treatment options, this study provides early evidence of FBT being an effective treatment option for adolescents with AN. There is a high risk of bias for incomplete outcome data and a high risk of selective reporting.

Before the 21st century, there was little research available that systematically looked at different frameworks of IT and FT and their relative levels of effectiveness. Adolescent-focused therapy (AFT) is an individual therapy modified from the Ego-Oriented Individual Treatment (EOIT) with a developmental lens (Ganci et al., 2021). According to the AFT framework, patients with AN falsely believe that they are looking after their biological needs by asserting self-control over their eating (Dare et al., 2001). The treatment helps them to manage their emotions, and ultimately their affective states, rather than resorting to starvation as a control mechanism (Lock et al., 2010). In 2010, an RCT was published that aimed to determine the efficacy of FBT compared to AFT (Lock et al., 2010). Parental refeeding and dietetic support were removed from the original EOIT treatment model to create AFT as a comparison treatment for FBT. Participants included 121 adolescents (genders not revealed) aged 12 to 18 years who received 24 hours of either FBT or AFT in the space of one year. They were assessed at baseline, at end of treatment (EOT), and at six- and 12-month follow-up posttreatment. Despite no significant difference between FBT and AFT in terms of achieving remission at the EOT, significantly more adolescents in the FBT group were still in remission at both six- (40% vs. 18% in the AFT group) and 12 months follow-up (49% vs. 23% in the AFT group). However, individuals in the FBT group demonstrated a greater BMI percentile on average at EOT than for those in the AFT group, as well as significantly greater changes in their Eating Disorder Examination (EDE) scores. These differences between treatment groups for both assessments were no longer significant at follow-up points. There was a proportion of patients (37% with AFT and 15% with FBT) who were hospitalised during the treatment trials, yet weren't considered study dropouts, which is something to take into account when analysing the results (Dalle Grave, Sartirana, et al., 2021). There is a high risk of bias for incomplete outcome data.

An RCT compared the relative efficacy of FBT to systemic family therapy (SyFT), another form of FT (Agras et al., 2014). Prior to this research, there were relatively few studies comparing FBT to other FTs, with the research primarily focused on comparing FBT to ITs as opposed to other FTs. Within the SyFT framework, clinicians help adolescents with issues relating to their family functioning more generally, such as destructive communication patterns, rather than focusing on their ED behaviours per se (Lock, 2019). 164 adolescents (141 females, 23 males) with AN aged between 12 and 18 years were randomly allocated to either the SyFT or FBT group. Participants were assessed at baseline, six months into treatment, at one-year follow-up and at end of treatment. Results revealed that there were no statistically significant differences between FBT or SyFT for ideal body weight percentage or remission rates at the end of treatment (33.1% for FBT, 25.3% for SyFT) nor at the one-year follow-up (40.7% for FBT, 39.0% for SyFT). This is a large difference in

a clinical context, which could be suggestive of the small sample size producing a statistical type two error. There were also no differences between the treatment groups in terms of ED psychopathology or comorbid disorders. Nevertheless, those who received FBT gained weight faster early on in treatment, spent fewer days being hospitalised and dealt with fewer associated costs. Even after the first treatment session, parents significantly preferred FBT over SyFT, which could be suggestive of parents leaning more towards FTs that focus on weight restoration. It is mentioned that those with extreme obsessive-compulsive symptoms of AN may achieve more significant weight gain under the SyFT framework. However, treatments such as FBT that promote early weight gain generally help to avoid the risk of developing lifelong AN and minimise comorbidities (Carrot et al., 2019). Other than being unable to blind participants to their treatment group, there were no further risks of bias.

Two earlier RCTs (Eisler et al., 2000; Le Grange et al., 1992) illustrated that patients made significant improvements in their recovery when they were treated with separated FT rather than conjoint FT, whereby the therapist meets with the adolescent alone, followed by a separate meeting with their parents. The debate regarding whether adolescents benefit more from receiving therapy exclusive to their parents was further evaluated in an RCT comparing the relative efficacy of FBT to parent-focused treatment (PFT) (Le Grange et al., 2016). Within the PFT framework, patients are seen by their therapist separately from their parents and are supervised by a nurse who cares for their medical and mental wellbeing (Hughes et al., 2015). In the study, 107 adolescents (93 females, 14 males) aged 12 to 18 were randomly assigned to receive either FBT or PFT with assessments at baseline, end of treatment, as well as at six months and 12 months post-treatment (Le Grange et al., 2016). At end of treatment, remission was significantly greater for those receiving PFT (43%) than FBT (22%). However, there was no significant difference at six- (39% for PFT, 22% for FBT) or 12-(37% for PFT, 29% for FBT) month post-treatment assessments. Nevertheless, 12 months after treatment, FBT was demonstrated to be the superior model for participants who exhibited compulsions and ED-related obsessions to a greater extent at the baseline assessment. Controversially, these results are dissimilar to those found in the RCT conducted by Agras et al. (2014), whereby SyFT (a type of IT), was found to be more advantageous than FBT for patients with obsessive-compulsive tendencies (Agras et al., 2014). Evidentially, there are some mixed conclusions within the literature as to whether the presence of parents during adolescent treatment sessions is more beneficial to their recovery than having individual sessions. Nevertheless, these studies support the idea that separated frameworks of FT that give young people and their parents the opportunity for individual treatment sessions are beneficial. There is a high risk of bias for selective reporting.

#### 3.4 Remission Rates of Family-Based Treatment

By the end of treatment, approximately 75% of adolescents partially respond to treatment (defined as improvements in weight and symptoms of AN) and 38% achieve full remission (defined as a BMI larger than 94% and Eating Disorder Examination-Questionnaire (EDE-Q) score within one standard deviation of population means). When the seven RCTs on AN in adolescents are examined in chronological order, a decrease in treatment efficacy over time is observed. Research in psychotherapy indicates that it is not uncommon for treatments to lose effectiveness over time, yet this observation is concerning when considering that two-thirds of patients were able to achieve recovery under the original FT-AN framework (Ganci et al., 2021). Surprisingly, the treatment experiences that patients, primary caregivers, and clinicians have are often overlooked, and rarely represented in the literature. Thus, it is more important than ever to take their reflections into account to ensure treatment engagement is explored from all angles.

#### 3.5 Patient and Carer Experiences of Family-Based Treatment

Reflections on the acceptability of FBT vary amongst service users, with a range of perspectives revealing both the strengths and gaps that lie within this treatment. Generally, adolescents and young adults have indicated that they have been satisfied with the healthcare they have received in a physical context, that there is regular input from key workers, good therapeutic alliance, peer support and effective communication with ED specialists (Mitrofan et al., 2019). Taken together, qualitative studies on service users' perspectives illustrate parents being typically more satisfied with FBT than their adolescent children, despite adolescents acknowledging the benefits of the treatment (Hughes et al., 2020). Acceptability ratings for FBT have been as high as 82% for parents and 59% for adolescents (Ganci et al., 2021; Krautter & Lock, 2004). A retrospective study was conducted in a cohort of 175 families including parents and their adolescent children with AN, two years after discharge from FBT (Hughes et al., 2020). Parents reported being happy about the assessment and education of their child's ED, their interactions with the specialist team, and their child's physical recovery, unlike their adolescent children who did not feel as positively about their communication with their team. Approximately two thirds of adolescents expressed that their concerns were not being heard or acted upon by their therapist, and a quarter stated being generally unsatisfied with the care they received. Even after patients were discharged, less than half of the cohort felt like they knew what steps they had to take if they were to relapse. This difference in satisfaction levels between parents and their children is not exclusive to care during treatment, but also at discharge, as demonstrated in this study.

Issues with psychological well-being are treated with secondary importance to eating behaviours, and therefore are not typically considered in FT research for AN (Medway & Rhodes, 2016). Both adolescents and parents have attested to treatment being disproportionately tailored towards the physical elements of recovery, with minimal focus on the psychological aspects of their ED which more often than not cause the most distress (Hughes et al., 2020). Adolescents have said that treatment focuses primarily on their eating behaviours, which makes them feel as if their therapists are inattentive to their mental health concerns. Adolescents have also voiced desires for a framework tailored to their individual needs and vulnerabilities in a way that is sensitive to their developmental stage (Nilsen et al., 2019).

Parents have also expressed a desire for more instruction and guidance on how to best help their children come to terms with their weight gain as well as handle their distress throughout treatment (Hughes et al., 2020). There is a lack of research regarding the effects of FBT on distress of family members during or after treatment, which is desperately needed given the responsibility parents must take on in refeeding their child, particularly during the first phase of treatment (Wufong et al., 2019). In a study looking at parent narratives, parents revealed that the defined structure of FBT initially reduced their level of concern for their child and enhanced the functioning of their family (Wufong et al., 2019). Paradoxically, however, the non-blame rhetoric of treatment consequently made parents' pre-existing guilt even worse. Parents reported that being solely in charge of their child's physical recovery led to feelings of increased anxiety, especially when adolescents did not achieve or maintain weight gain. Even after adolescents were discharged, parents continued to struggle and feel uncertain of how to best support their children when they were granted back autonomy over their eating.

The first phase of FBT can be especially anxiety-provoking as it demands constant engagement from parents, particularly the 'intense scene' (Lock & Le Grange, 2015). The 'intense scene' is performed during the first treatment session and involves educating parents about the seriousness of AN and urging them to take charge of their child's ED. This seems inconducive to adolescents and their parents, who are already experiencing high levels of distress due to the ED (Wufong et al., 2019). Additionally, phase one of FBT can disrupt adolescents' sense of autonomy, as it brings about a temporary increase in dependency on their families (Medway et al., 2019). Although the research indicates that adolescents do acknowledge that parental involvement is beneficial to their recovery, it means they spend extended time with their parent or primary caregiver and less time participating in

activities that are important for their development, such as nurturing their friendships or playing sports (Chen et al., 2010).

Despite weight restoration being the utmost priority in ED recovery, there is clearly a need for a treatment that addresses the psychological distress felt by adolescents and parents. Such a model would focus on rebuilding a sense of self that is often compromised under the influence of AN.

# 3.5.1 Loss of Adolescent Voice in Family Therapies

Family therapies are praised for involving family members in their children's recovery journey, particularly their parents, who are initially given complete control in their child's weight restoration. Nevertheless, with a significant focus placed on equipping parents with strategies to implement into their child's treatment plan, young people end up losing their voice and their perspectives are often neglected. A study recounting parent's experiences of FT discovered that for parents whose children were unable to gain weight with MFT or FBT, these young people continued to experience symptoms of psychological issues beyond the eating disorder when they were discharged, as these were not addressed during treatment (Wufong et al., 2019). Despite parents' willingness to do anything to protect their child's well-being, they also voiced that this should not be at the cost of adolescents being able to have a say in their own treatment.

#### 3.6 Therapist Adherence to the Family-Based Treatment Manual

To ensure that ED treatment is implemented to a high standard, the 'three-legged-stool' metaphor can be utilised (Sackett et al., 1996). This metaphorical stool must be balanced equally across all three 'legs' of the stool, which encapsulate what evidence-based practice is comprised of; these include research evidence, clinical expertise, and patient factors such as their preferences, values and characteristics (Peterson et al., 2016). Within therapy generally, it is common for clinical behaviours to develop and for evidence-based practice to become outstripped. Whilst each of these stool 'legs' is known to bear witness to neglect at some point, research evidence is commonly disregarded in clinical practice.

The imbalance among the 'legs' of evidence-based practice in FBT is partially due to therapist's variability of preference for each of these three different aspects of care (Peterson et al., 2016). It is also possible that therapists are restricted in their ability to tailor treatments to each of their patients due to the inflexibility of the FBT structure. As a critical part of their training and supervision,

therapists are taught to strictly adhere to the FBT manual (Robertson & Thornton, 2021). This may influence clinicians to prioritise this element of treatment, thus losing the capacity to create a holistic treatment experience for their patients. However, it is also common for clinicians to experience 'therapeutic drift' whereby they choose to avoid following the manual rigidly. This may be due to resistance from patients or dealing with complicated cases with several comorbidities, where clinicians must be flexible to adjust treatment accordingly. Whilst there is a mutual agreement amongst most therapists that adolescents' weight restoration should be prioritised, a sole focus on refeeding alone can be highly distressing for parents, as has already been mentioned. Parents have expressed that their emotional distress is underemphasised, as well as feeling that their child's voice is lost in the treatment (Aradas et al., 2019). A study including 14 adolescents with AN examined therapist's fidelity to FBT (Couturier et al., 2010). It was found that adherence to treatment was strong during the first phase (74%), which dropped to approximately half of clinicians adhering to the manual during the second and third phases. Certain elements of FBT were performed with less fidelity, such as those involving engagement from siblings. Regardless, multiple studies have evidenced that the attendance of siblings during sessions (Ellison et al., 2012; Le Grange et al., 2016), as well as the family meal in the second session (Herscovici et al., 2017), are not essential for a successful recovery (Robertson & Thornton, 2021).

Non-adherence to the treatment manual is typically discouraged and has been stated as a reason for FBT "failing" where treatment has not been successful for families (Lavender, 2020). If FBT is unsuccessful in helping individuals with AN achieve weight restoration, therapists and families can consequently feel responsible for their lack of recovery (Robertson & Thornton, 2021). Despite the push for fidelity, there is a lack of evidence to suggest that high adherence levels are associated with more successful treatment outcomes. In fact, a large meta-analysis comprised of 36 studies illustrated that manual adherence has no significant impact on outcomes at all (Webb et al., 2010). FBT is still only effective for just under half of patients in helping them achieve full recovery, regardless of whether therapists strictly follow the manual. Patients have also described feeling that their therapist places more value on adhering to the treatment manual over acknowledging their individual needs (Nilsen et al., 2019). Considering the 'one-size-fits-all' framework of FBT does not promote recovery for all young people with AN, particularly not for those who remain ill under its rigidity, encouraging greater manual adherence amongst clinicians who administer the treatment may not necessarily be the most viable option.

Although the importance of prioritising physical recovery in the first instance is acknowledged, there is an urgent need for a treatment that takes a holistic approach to recovery by considering the psychological and physical aspects of AN simultaneously. Specific components of FBT have been alluded to as being unnecessary or even unhelpful to adolescents and their families, especially where their psychological well-being is treated with secondary importance. Suppose both the physical and psychological needs of patients could be considered from the outset of therapy and be maintained throughout treatment. In this case, there is a greater probability of adolescents achieving full recovery and a smaller chance of relapse (Mitrofan et al., 2019). It is also crucial to acknowledge the functioning of the adolescent's family, particularly parents who play a defining role in their child's recovery. Addressing both aspects of recovery in a single framework is a challenging prospect. However, it is a plausible antidote for adolescents who suffer a longer duration of the illness, or those who do not recover at all.

#### 3.7 Alternatives to Family-Based Treatment

It is necessary to consider alternative treatment options where FBT is either non-compatible with adolescents or is not made easily accessible to families. Multifamily Therapy (MFT) is an adjunction to FBT which is increasingly being utilised for adolescents with AN. Unlike FBT, MFT draws on resources from approximately four to seven families working together to relieve adolescents from their ED symptoms and bring about change within their families (Baumas et al., 2021; Lock & Le Grange, 2019). The first RCT to be conducted on MFT investigated the effectiveness of this treatment compared to single-family therapy (FT-AN) (Eisler et al., 2016). The study involved 169 adolescents aged 13 to 20 years old with either a clinical diagnosis of AN or ED not otherwise specified (restricting type). Participants were randomly assigned to receive either MFT or FT-AN and were assessed at baseline, three months follow-up, at end of treatment, and at 18 months follow-up. By the end of treatment, individuals across both treatment groups made significant clinical improvements, defined by weight gain as well as mood and ED psychopathology. More than 75% of participants in the MFT group had good or intermediate outcomes, outperforming just under 60% in the FT-AN group who achieved this outcome. However, at 18 months follow-up, there was no longer significant differences in primary outcomes between the two treatment groups.

A similar result was found in an RCT published two years later, comparing the effectiveness of MFT with FBT (Hughes, 2018). It was found that MFT had significantly better outcome rates (76%) than FBT (58%) at end of treatment, but this difference was rendered insignificant at 18 months follow-

up. While MFT has been demonstrated to be a promising alternative to single-family therapy, its execution in many service settings is a challenge (Hughes, 2018). Not only are various resources required to implement MFT, but it is also difficult to manage numerous groups of people and synchronise different family timetables. Whilst MFT offers families a shared therapeutic experience, unlike in FBT, more RCTs are needed for this treatment to be further considered and compared to FBT (Lock & Le Grange, 2019)

Whilst FBT is heavily utilised in countries within the Anglosphere and the Netherlands, healthcare insurance is not provided for this treatment in various European countries due to limited training for clinicians (Herpertz-Dahlmann et al., 2021). Instead, Enhanced Cognitive Behavioural Therapy (CBT-E), a type of individual therapy (IT), is offered to many adolescents in these countries. CBT-E is a form of cognitive behavioural therapy modified from the adult literature specifically for the treatment of eating disorders in adolescents (Fairburn, 2008). CBT-E is a flexible treatment that can be tailored to every patient's needs. Not only is CBT-E offered by psychologists in an outpatient setting, but it has also been designed to be provided by a multidisciplinary team for inpatient care. Sessions are initially conducted on a one-on-one basis, allowing the patient to have complete autonomy over strategies used in each stage of treatment. CBT-E also provides one session with the parents separately, and if the patient agrees, a few with the adolescent and their parents together right after.

NICE guidelines have labelled CBT-E as the recommended treatment for adolescents with AN or where FBT is rendered "unacceptable, contraindicated or ineffective" for young people (National Institute for Health and Care Excellence, 2017). In line with this recommendation, several case series and cohort studies have been analysed in a recent systematic review examining the effectiveness of CBT-E for adolescents with EDs (Dalle Grave, Calugi, et al., 2021). Whilst these types of studies are weaker forms of evidence than RCTs, it is important to mention where CBT-E has been successful given that it is the mainstay treatment for AN in European countries.

Research has alluded to CBT-E potentially being a more suitable treatment for adolescents than adults recovering from AN (Dalle Grave, Calugi, et al., 2021). In a study investigating the length of time required for adolescents and adults to achieve weight restoration, 95 participants were recruited including 46 adolescents and 49 adults (Calugi et al., 2015). Subjects were given 40 sessions of treatment over 40 weeks, which is standard for CBT-E. Amongst the 29 adolescents and 32 adults who completed all sessions of CBT-E, there were significantly more adolescents (65.3%) than adults (36.5%) who reached a healthy weight by discharge. Additionally, adolescents reached their BMI

goal after an estimated 14.8 weeks, whereas adults reached this in an estimated 28.3 weeks. Not only were adolescents generally able to gain more weight than adults, but they also achieved weight restoration more quickly.

Approximately two-thirds of adolescents with AN achieve recovery when treated with CBT-E in an outpatient setting, which has been highlighted in two clinical series (Dalle Grave et al., 2013; Dalle Grave et al., 2019). In both studies, average BMI-for-age percentile significantly increased whilst general and ED psychopathology decreased, as was still the case at the 20- and 60-week follow-ups. When observing intent-to-treat in the most recent of the two studies, however, only 45% of the original cohort had a good BMI outcome (> 18.5 BMI), which dropped to 29% at 20-weeks follow-up (Dalle Grave et al., 2019). It has been suggested that CBT-E is in fact more effective when delivered in an inpatient setting, where it is well accepted and completed by approximately 90% of adolescent patients with AN (Dalle Grave et al., 2014; Dalle Grave, Calugi, et al., 2021; Dalle Grave et al., 2019). Similarly, to what was found in outpatient settings, treatment delivered via inpatient care significantly increased BMI-for-age and general and ED psychopathology improvements. These outcomes tend to remain at follow-up despite the severity of these cases, with 80% of patients achieving normal weight and 50% achieving complete remission within a year (Dalle Grave, Calugi, et al., 2021). These are promising results considering that inpatients are typically medically unstable or severe and require the most urgent care.

CBT-E has been praised for its ability to treat a wide range of EDs both in adult and adolescent populations (Dalle Grave et al., 2020). This could benefit those in inpatient care where different treatments for adults and adolescents are provided within various care settings (Dalle Grave, Calugi, et al., 2021). This change in treatment can be confusing for inpatients moving between different levels of care or transitioning from adolescent to adult age. The downside of CBT-E being accessible to a wide range of age groups is that treatment does not address the specific developmental needs of adolescents (Ganci et al., 2021).

Under the CBT-E framework, adolescents are given autonomy in their treatment plans, with optional parental refeeding (Ganci et al., 2021). Yet, it has been extensively demonstrated that parental involvement is crucial in encouraging early weight gain (Herpertz-Dahlmann et al., 2021). Whilst preliminary findings have indicated that the psychological approach taken by CBT-E may be universally beneficial, adolescents who are undecided about treatment and recovery are not likely to be included in this outcome data (Ganci et al., 2021). As a result, this limits the external validity of results that come from data on CBT-E.

Despite there being a small choice of treatment options for adolescents, none of them has yet demonstrated to be as statistically efficacious as FBT. Although CBT-E is not as widely studied within the literature as FBT, it is the leading alternative for adolescents who cannot achieve remission under the FBT framework. In fact, it may even hold the key to unpacking some of the maintaining or predisposing aspects of AN, thus mitigating potential relapse (Ganci et al., 2021). However, parent-led refeeding is not obligatory under this framework, despite the evidence which suggests that it is a crucial element of effective weight recovery for adolescents. Considering that rapid weight gain during the initial phase of ED treatment is paramount to long-term recovery outcomes, there may be merit in exploring how refeeding in CBT-E could be given a higher priority within the framework (Bargiacchi et al., 2019). The case series and case reports conducted on CBT-E also have a non-controlled design, unlike the RCTs on FBT, which are more scientifically rigorous (Dalle Grave, Calugi, et al., 2021). Thus, precaution needs to be taken when comparing the effectiveness of CBT-E with FBT across these studies.

Additionally, the efficacy of CBT-E relative to other treatments is yet to be tested (Muratore & Attia, 2021). Adjuncts to FBT such as intensive family therapy (IFT), intensive parental coaching (IPC), and cognitive remediation therapy (CRT) exist, yet their effectiveness remains unclear, and are not standalone treatments as FBT is. Whilst other FTs and ITs are being further tested longitudinally and on a larger scale, there is a pressing need for alternative treatment options for adolescents whose recovery needs are not addressed in existing therapies. According to Ganci, Atkins & Roberts, such a treatment would incorporate the most effective aspects of FT and IT (Ganci et al., 2021). This kind of treatment would ideally draw on parentally-supported refeeding as is emphasised in FBT, as well as nurturing personal development in patients to maintain weight restoration, as is done in CBT-E (Ganci et al., 2021).

#### 3.8 Adolescent and Parent Treatment

Adolescent and Parent Treatment (APT) is a newly developed and manualised treatment that has been introduced to a few treatment teams across New Zealand and Australia (Ganci et al., 2021). The structure of APT may potentially address service users' concerns regarding a lack of psychological support within current treatments for AN, whilst maintaining parent-led refeeding. Thus, APT will be investigated in the current study. In APT, clinicians are taught to consider the maintaining factors of AN that keep the adolescent tied to their disorder (Atkins & Ganci, 2019). The treatment combines elements of FT and IT, addressing both the physical and psychological aspects of recovery (Ganci et al., 2021). This is achieved through intensive parental refeeding and the incorporation of treatment modules centring around the adolescents' psychological, emotional, temperamental, and developmental needs. Adolescence is a unique and critical stage of development that influences functioning in adult life. Therefore, APT recognises the importance of addressing physical and psychological recovery simultaneously, rather than waiting for full weight restoration to be achieved fully, to ensure the best outcomes are achieved by patients (Atkins & Ganci, 2019).

APT was born out of Ego Oriented Individual Treatment (EOIT), an individual psychotherapy framework that focuses on the development of ego strength, coping style, individuation, and identity (Ganci et al., 2021). Approximately ten years ago, EOIT was reworked by Maria Ganci and Dr Linsey Atkins alongside EOIT's original creator, Dr Ann Moye, to create APT. With these clinicians residing in Australia, this is naturally where APT was first practised before being shared with clinicians in New Zealand and taken up by psychologists practising at Nurture Psychology in Auckland (the official provider of APT). Within this framework, the focus on parental refeeding has been strengthened, and dietetic support has been re-emphasised. Dieticians support parents in their refeeding efforts while therapists provide them with psychoeducation around AN and equip them with tools to help guide their children through recovery. The individual treatment modules for adolescents have also been significantly updated to incorporate and reflect new scientific insights in the field.

There is an urgent need for a model that comprehensively addresses the needs of young people, many of whom are struggling to receive the appropriate support in existing frameworks. Thus, APT will be investigated in the current study.

# 3.8.1 Phases of Adolescent and Parent Treatment

Treatment typically includes 20-30 sessions, which cover three key phases spanning over nine to 12 months (see table five). APT is designed to be suitable for adolescents and young adults aged 12-24 years of age, though some clinicians decide to use APT with some of their younger clients, also. Additionally, APT is adaptable to every individual's developmental stage and level of parental involvement. The first phase is usually completed within six to eight weekly sessions, which involves a patient assessment followed by adolescent and parent work. Where circumstances allow, treatment sessions can last up to 90 minutes long. Typically, adolescents are seen for the first 30 minutes, parents for the next 30 minutes and both the adolescent and the parent are seen together for the last half hour. Depending on preference, the adolescent can be seen individually, with parents

joining at the end of the session. Assessment involves developing a detailed picture of the adolescent, including their AN symptomology, any existing comorbidities, attachment style, psychosocial functioning, and motivation to change. Family functioning is also explored, including parenting style, parental cohesion, and food culture. An individualised treatment plan is then put together, which is used to guide the family and therapist through the therapeutic journey.

As with FBT, refeeding is a crucial aspect of parental work in APT, especially during the first phase (Ganci et al., 2021). The level of responsibility assigned to parents to refeed their child is dependent on their capabilities as well as the adolescent's level of self-awareness and motivation to recover. The amount of control each adolescent gets over their refeeding depends entirely on the progress they make throughout treatment, which is regularly monitored. To support parents in their refeeding efforts, they are provided with four parental dietetic sessions and a skills training manual for APT. They are also equipped with strategies to help their children through distress as well as to help adolescent work can begin which involves rapport-building with their therapist and psychoeducation about their ED. It is crucial that therapists make a conscious effort to build a relationship with the adolescent and to motivate them to be an active participant in their own recovery, thus creating a therapeutic alliance. Not only do these strategies allow for a smooth transition into phase two, but adolescents have also stated that having a good relationship with their therapist is of most value in treatment (Zaitsoff et al., 2016). Phase two can begin only when rapport has been established, the patient is gaining weight, and is showing motivation to recover.

In the second phase, therapists can start to focus on individual work with the adolescent, and the focus no longer needs to be exclusively on refeeding (Ganci et al., 2021). Weekly session times drop down to 60 minutes, where more time is dedicated to seeing the adolescent exclusively. Whilst these sessions can be held together or separately with parents, they will usually become less present in their child's sessions as the treatment advances, perhaps only joining for the last ten minutes, for example. Parental refeeding is still being addressed, with adolescents ideally becoming more autonomous with their eating given that they are making progress. Adolescents 16 years and over are typically seen without their parents for treatment individually whilst taking into consideration their age, comorbid illnesses, developmental stage, personality traits, and coping style.

There are four modules covered during individual work. These are explored through ED psychoeducation, self-reflection through journaling and therapy, and the development of new skills.

The first is called 'standing up to the AN', which entails learning how AN influences the brain and body, externalising the ED, managing the AN 'voice', and finding alternative methods to better cope with it. The second module called 'Managing Emotions', is about learning how to recognise and label emotions and use the right tools to manage and self-regulate them. The third is 'building a core sense of self', which teaches adolescents to become familiar with their personality traits as well as their inner critics and how to combat them using their inner resources. The fourth and final module called 'developmental challenges' involves re-directing focus to developmentally appropriate tasks for the patient's age and exploring their physical and neurological development in their body confidence, reconnecting with their interests, and re-establishing their relationships. These modules are designed to help rebuild three components of adolescence that are disrupted by AN: identity development, managing emotions, and building relationships. In this second phase of treatment, adolescents are given three essential resources to encourage their development of a core sense of self. These are the Unpack Your Eating Disorder Workbook, Letting Go of ED – Embracing Me Journal, and the Trait, Critic and Sage Therapy Cards. Once adolescents have successfully worked through the four modules, their weight is mainly restored, and the clinician feels they are functioning at a level deemed developmentally appropriate, they can move into the final phase of APT.

In the third phase, patients typically receive around five to ten sessions, with the frequency of sessions ranging from fortnightly to monthly depending on how much more time is needed to recover (Ganci et al., 2021). Within this final phase, clinicians help adolescents cement strategies they have learnt in the last two phases whilst continuing to monitor their progress and support them through any maintaining factors such as clinical perfectionism or anxiety. At this point, adolescents should have complete autonomy over their eating, and any remaining comorbidities or AN-related behaviours or thinking patterns should be eradicated at large. Before the patient is discharged, a relapse prevention plan is established in case the patient slips.

	Phase One	Phase Two	Phase Three
Spacing of Treatment	Multiple times per	Weekly	Fortnightly or
Sessions	week		Monthly
Parental Involvement	High	Medium	Low

Table 1: Summary of APT Phases

Session Content	Assessment of AN symptomology, existing comorbidities, attachment style, psychosocial functioning, motivation to change, family functioning, and other	<ol> <li>Standing up to an ED</li> <li>Managing</li> <li>Emotions</li> <li>Building a Core</li> <li>Sense of Self</li> <li>Developmental</li> <li>Challenges</li> </ol>	Cementing strategies developed during initial phases (physiological and psychological)
Milestones	<ul> <li>Individualised treatment plan</li> <li>Focus is on refeeding the patient</li> <li>Building rapport between patient &amp; therapist</li> <li>Psychoeducation about patient's ED</li> </ul>	<ul> <li>Increased</li> <li>independence over</li> <li>patient's eating</li> <li>Weight restoration</li> <li>Healthy cognitive</li> <li>functioning</li> <li>(identity</li> <li>development,</li> <li>managing emotions,</li> <li>and building</li> <li>relationships)</li> </ul>	<ul> <li>Autonomy over patient's eating regained</li> <li>Patient is free of AN-related behaviours and thinking patterns</li> </ul>
Resources	<ul> <li>Four parental dietetic sessions and a skills training manual for APT</li> <li>Strategies for parents to help their children through distress</li> </ul>	- Unpack Your Eating Disorder Workbook - Letting Go of ED -Embracing Me Journal -Trait, Critic and Sage Therapy Cards	

# 3.9 Current Study

Research on APT is still in its infancy and has not yet been tested as a treatment package (Ganci et al., 2021). Currently, the benefits of APT are only supported by the developers of this treatment, Maria Ganci and Dr Linsey Atkins, and other clinicians across Australia and New Zealand trained to deliver APT therapeutically. Even so, APT does draw on strengths from IT and FT which are evidence-informed, including parent-led refeeding and individualised treatment modules, to provide holistic therapy for adolescents and their families fighting AN. While family members are heavily involved in the recovery journey of their affected child, the second phase of treatment allows adolescents to take back some of their power, harness their newfound insights, and start taking charge of their recovery. Considering the low remission rates for FBT (38%), a treatment that

focuses solely on refeeding, it is imperative to explore other treatment avenues which consider adolescents' physical as well as their psychological requirements.

# Chapter 4: Methodology

The methodology follows the guidelines from the SRQR (Standards for Reporting Qualitative Research) (O'Brien et al., 2014).

# 4.1 Participants and Setting

Eighteen participants were recruited from various outpatient services in Auckland, New Zealand and in Melbourne, Australia. The sample included six adolescents and young adults who had been treated or were currently being treated with Adolescent and Parent Treatment (APT), six parents whose children had been treated or were currently being treated with APT (though not necessarily related to the patients recruited in this study), as well as six clinicians who had treated or were currently treating young people with Anorexia Nervosa (AN) using APT. Limited numbers of teenagers fitted the age criteria of APT at the time of recruitment, and thus the age limit was increased to 30 years of age. It is important to note, however, that all young people interviewed fell in the required age range at the time of their treatment i.e., between 12 and 24 years of age. In the context of this thesis, participants in this age range will be interchangeably referred to as adolescents, young people, or patients. Adolescents and young adults were aged between 13 and 30 years. Parents were aged between 49 and 54 years. Clinicians' ages were not collected.

All young people were assessed by their treating clinician as appropriate to receive APT based on standard clinical inclusion criteria, including being medically stable, having had no previous brain injury and not having current suicidal ideation. Any risk concerns presented at the time or arose during the study were addressed by the psychologist as part of standard care.

Participants' demographics are displayed in table one, table two, and table three. It should be noted that all participants were given pseudonyms to protect their anonymity.

Participants (pseudonyms)	Age (years)	Gender	Anorexia Subtype	Anorexia Duration	APT Location	Time since APT	Tx received before APT (yes/no)
Nicole	18	Female	N/S	2 years	NZ	3 months	N/A

Table 2. Demographics of Young People

Margot	26	Female	Restricting	6 years	AU	3 years	Yes
Belle	26	Female	Binge/Purge	11 years	AU	Ongoing	N/S
Lauren	20	Female	N/S	2-3 years	AU	1 year	Yes
Emma	30	Female	Restricting, Binge/Purge	6 years	AU	2 years	Yes
Violet	13	Female	N/S	>1 year	AU	Ongoing	No

Key:

APT = Adolescent and Parent Treatment

N/S = Not Specified

N/A = Not Applicable

Tx = Treatment

NZ = New Zealand

AU = Australia

Table 3: Demographics of Parents

Participant	Age (years)	Gender	Employment	No. of child's siblings	Parent rel. status	Child's medication
Jennifer	52	Female	Full-time	1	Together	None
Ben	54	Male	Full-time	1	Together	None
Clarissa	49	Female	Homemaker	2	Together	None
Rita	50	Female	Full-time	1	Together	N/S
Sharon	54	Female	Full-time	2	Separated	Sertraline
Polly	51	Female	Part-time	1	Together	Fluoxetine

Key:

N/S = Not Specified

No. = number

Rel. = relationship

Table 4: Demographics of Clinicians

Participant	Gender	Discipline	ED experience	APT experience	Other prac. ED Txs	% of clients with an ED
Claire	Female	Clinical Psychologist	18 years	10 years	None	100%

Barbara	Female	Clinical Social Worker, Child and Adol. Psychoanalytic Psychotherapist	20 years	10 years	FBT, PFT, CBT-E	100%
Nadia	Female	Dietician	10-12 years	6 months	FBT, EFFT, AFT, Individual Counselling	100%
Sally	Female	Mental Health Social Worker / Family Therapist	11 years	5 years	FBT; FT- AN, CBT- E, SSCM, MANTRA	90%
Louise	Female	Heath Psychologist	4 years	3-4 years	ACT, CBT- E, CBT- AR, CFT	100%
Olive	Female	Clinical Psychologist	1 year 3 months	1 year 3 months	CBT-E, CBT-AR	100%

Key:

APT = Adolescent and Parent Treatment

ED = Eating Disorder

Prac. = Practising

Txs = Treatments

Adol. = adolescent

FBT = Family-Based Treatment; FT-AN = Family Therapy for Anorexia Nervosa; CBT-E = Enhanced Cognitive Behavioural Therapy; SSCM = Specialist Supportive Clinical Management; MANTRA = Maudsley Model of Anorexia Nervosa Treatment for Adults; PFT = Parent-Focused Treatment; EFFT = Emotion-Focused Family Therapy; AFT = Adolescent-Focused Therapy; ACT = Acceptance and Commitment Therapy; CBT-AR = Cognitive-Behavioural Therapy for Avoidant Restrictive Food Intake Disorder; CFT = Compassion-Focused Therapy

# 4.2 Ethics Approval

This study was reviewed and approved by HDEC on the 1<sup>st</sup> of July 2021. The reference number is 21/CEN/144 (see Appendix A for ethics approval form). Amendment to ethics to extend recruitment to Australia was approved, as well as changing the study design from quantitative to qualitative.

## 4.3 Recruitment and Procedure

Before the study commenced, all participants were emailed a Participant Information Sheet (PIS) and a Consent form (CF) by the lead researcher (HS), both of which were tailored to adolescents, parents, and clinicians, respectively (see appendices H, I, and J for participant information sheets and appendices B, C, and D for consent forms). All participants involved were also given the opportunity to ask any questions they may have had prior to the study. If they agreed to participate, participants were asked to give informed consent by signing their CFs and emailing them back to HS. All CFs also needed to be signed by HS, confirming that the participant in question understood all the information they had been given regarding the study. After their participation in the study, subjects were asked to complete a demographics form, which was then to be emailed back to HS.

Clinicians practising in public and private care settings either in New Zealand or Australia were recruited via email. The developers of APT, Maria Ganci and Linsey Atkins assisted in providing the contacts of other clinicians practising in Australia. Participating clinicians assisted HS in recruiting young people treated with APT, as well as parents whose children received this treatment. All participants were first consulted by treating clinicians to share their details before they were put in touch with HS through email. Recruitment was conducted in May and June of 2022.

Semi-structured interviews were conducted on an individual basis, with each lasting approximately 30-45 minutes. All interviews were conducted and audio-recorded using Zoom software. Participants were asked sets of open-ended questions that were tailored to their role in treatment as patients, parents, or clinicians (see appendices E, F, and G for interview guides). Follow-up questions that weren't pre-established were asked depending on the nature of the interview. Open-ended questions were slightly modified during the interview process as a result of becoming more familiar with participants' perspectives on the functioning of APT.

#### 4.4 Data Collection and Analysis

Audio recordings were transcribed verbatim in Microsoft Word using the transcribe function. All transcripts were then carefully checked and manually corrected whilst simultaneously listening to the audio recording. At the end of each interview, participants were given the choice to have their transcripts emailed to them for approval before being uploaded into NVivo software (released in March 2018) for data analysis.

Participants' names were replaced with pseudonyms prior to analysis to ensure their anonymity was protected. The chosen method of data analysis was a General Inductive Approach (Thomas, 2006). This type of analysis is commonly used in health science research and therefore was a good fit for the data that was collected in this study. The General Inductive Approach was developed by David Thomas and utilises a simplistic set of procedures whereby findings emerge from the raw data itself. Data analysis is guided by the research questions or objectives, as opposed to being defined by predetermined hypotheses or theories (Thomas, 2006). In the current study, the research questions were used to guide data coding and the initial analysis of the data, which were then refined to better emulate the data. Data analysis involved multiple close readings of the text, identifying and labelling categories, and coding relevant segments of text into the appropriate categories. Codes within these categories were then revised, and categories that shared common ideas were linked (Thomas, 2006). Themes were then created out of these categories which represented the key ideas that arose from the interviews. Themes could either be ordered into a model, where subcategories within these themes followed a hierarchical ordering for example, or themes could stand alone. Data collection and analysis were conducted entirely by the researcher (HS). David Thomas provided support and guidance around using the general inductive approach in data analysis.

To enhance ensure trustworthiness and data credibility, Maria Ganci and Linsey Atkins agreed to conduct stakeholder checks on one of the themes that came out of the data. This involved the clinicians reading over a small section of the lead researcher's (HS) interpretations of the data and making suggestions as to where amendments could be made. Maria Ganci and Linsey Atkins are referred to as stakeholders in this context due to their specific interest, experience, and expertise in APT.

## Chapter 5: Results

# I feel that we're fighting it from both angles, which is the point, isn't it? The physical and the mental. (Rita, Parent)

Findings from the interviews with patients, parents, and clinicians were organised into three key categories (otherwise referred to as themes). The first category is labelled 'Delivering Effective Therapy' which consists of three subcategories. These subcategories (or subthemes) form a sequential model, whereby the first subcategory must be performed before progressing to the second and third subcategories. It should be noted that there is a subcategory *of* a subcategory within this first category (labelled *Communicating the Treatment Plan*). The second main category is called 'Providing a Tailored Treatment Experience' which consists of three subcategories that are not sequential. This means that the subcategories do for them to satisfy the category description. The third and final category, 'Dietetic Input', also consists of three subcategories that are not sequential. This is followed by suggestions for developing Adolescent and Parent Treatment (APT), which have been recommended by clinicians that were interviewed. The table below summarises the categories, and associated subcategories, with category descriptions.

Categories/Themes	Subcategories/Subthemes	Category/Theme descriptions
1: Delivering Effective Therapy	Facilitating Communication - Communicating the Treatment Plan	APT has a strong emphasis on establishing therapeutic rapport which is essential for delivering effective therapy.
	Fostering Trust Reconnecting with the Self and Others	This is in contrast to FBT where rapport is less emphasised.
<b>2:</b> Providing a Tailored Treatment Experience	Flexibility in PatientInvolvementSupporting Parents/Carers inTreatmentProviding Physical andPsychological CareSimultaneously	APT provides a unique treatment experience for families that accommodates different patient needs whilst also supporting parents.
3: Dietetic Input	Prescriptive Meal Plans	Dieticians provide support to patients and parents depending on different

# Table 5: Categories from Interviews

Team Communication and Collaboration	levels of need for support. Dieticians' involvement in refeeding also has
Dietician-led Renourishment	advantages for both parents and clinicians.

# Category 1: Delivering Effective Therapy

The first theme consists of three subcategories representing what participants identified as being conducive to patients benefiting from APT: facilitating communication (as well as communicating the treatment plan), fostering trust, and reconnecting with the self and with others.

# Subcategory 1: Facilitating Communication

Establishing therapeutic rapport was considered critical for recovery by service users of all types (patients, parents, and clinicians). This is demonstrated when the treating therapist enables informal and open communication to take place with their patient. Young people value when their therapist takes a genuine interest in the different aspects of their lives. By comparison, the quality of the therapeutic relationship cultivated with patients during traditional Family-Based Treatment (FBT) is typically quite different according to clinicians, where rapport-building is not as heavily emphasised. The lack of communication often demonstrated in FBT has made patients and parents feel dismissed, or according to one parent, "like a number in the system".

She's [APT therapist] just addressing things that nobody even talked about in the FBT. It was sort of, oh yes, we can sense some anxiety, here's some medication to sort of give you some peace and then you can work on that in some one-to-one sessions. The one-to-one sessions never happened. (Rita<sup>1</sup>, Parent)

One clinician disclosed that she had a lived experience with an eating disorder (ED), which she would occasionally share with her patients during treatment sessions because it encouraged them to "open up tenfold". These patients described feeling "understood", "comfortable", "more at peace", or being more "connected" to her, empowering them to be transparent about their own ED. Since their therapist could relate to their symptoms on a personal level, many of their thoughts and

<sup>&</sup>lt;sup>1</sup> All names given are pseudonyms.

behaviours were normalised, which allowed them to feel like less of an anomaly and validated the patients' experiences.

You don't really hear someone really being open about, oh, I had an eating disorder or, I also had OCD [Obsessive-Compulsive Disorder], that's not really like talked about, but hearing it from a psychologist herself, being open about it with me, made me a lot more comfortable. It really helped me feel like I am still normal at the end of the day, I just have issues that I need to work on and strategies to help. (Lauren (20), Patient)

#### Subcategory of Subcategory 1:Communicating The Treatment Plan

Clinicians also described the importance of clearly communicating the treatment plan with the family. In the first instance, parents should be given a summary of what treatment will entail, as well as be actively guided throughout each phase. For APT, this was achieved for two out of the six parents who mentioned that the treatment plan was communicated effectively from the beginning. On the other hand, two parents claimed they were given no indication of the treatment phases that were planned in APT. They wished they had been informed from the beginning so that they could have physically and emotionally prepared in advance for what was going to come.

#### Subcategory 2: Fostering Trust

Patients reported trusting their therapist because a secure base was provided, which allowed them to feel safe and emotionally supported in treatment. The therapeutic alliance that is established encourages patients to be transparent because they know they will be understood in return. This was seen with the example of the therapist who related to her patients her personal story about recovering from an ED.

Half of the young people interviewed received FBT before APT, and all described feeling they were not fully heard by professionals who worked under the FBT framework. This was particularly frustrating because they believed that the treatment would support them on the road to their recovery. Their experiences with FBT ultimately led to a lack of faith in the healthcare system. Therefore, they were initially reluctant to trust APT. One clinician stated that APT is often more effective when it is performed in the first instance because FBT often negatively impacts patients' ability to be receptive to a new treatment structure. In this instance, it takes time for trust to be rebuilt; thus, the focus should be on establishing rapport and fostering trust with patients from the outset. I'd been through treatment [FBT] before and it didn't really work, and I was kind of like, what do you people know if it didn't work the first time? (Margot (26), Patient)

By creating space for open and honest communication, mutual respect is cultivated between the patient and therapist. For older adolescents, it instils confidence in them to confront their therapist if some aspects of treatment are not working for them. Older adolescents indicated a sense of autonomy, as they feel they have more say in treatment decisions. This also motivates them to come back to see the same therapist. This point is not so relevant for most young adolescents who, for the most part, are typically still reliant on their parents and need more extensive guidance from their therapist. Considering APT is still a family-orientated therapy, older adolescents are still expected to be largely supported by their parents. However, there is flexibility for more independence if they are ready for it.

*I always knew that if I said something that raised concerns or anything like that, she'd* [APT therapist] *be able to really talk to me about it, and I'd be able to trust her on it.* (Lauren (20), Patient)

#### Subcategory 3: Reconnecting with the Self and Others

Clinicians describe Anorexia Nervosa (AN) as an isolating illness that commonly causes adolescents to disconnect from the people in their lives, leaving them feeling alone and misunderstood. Learning to trust their therapist, who has created a safe and non-judgmental space for them to recover, becomes the "lynchpin" to "connect back with the people in their life" (as stated by a clinician). Through this healing process, patients also learn to reconnect back with themselves. As the observers of change, parents and clinicians see this being displayed in two ways in particular:

a.) the adolescent wanting to participate in the enjoyable aspects of their life again that were once neglected during their illness.

b.) 'regaining' a sense of self that is no longer attached to the ED which once dominated their entire personality.

I love Janet Treasures' analogy of, you know, an eating disorder being someone stuck in an ice cube. And I think it's so true, you know, they're freezing cold, and they're isolated in that way. So, I think it breaks down, I think it thaws the ice cube a bit, that's what I think. (Claire, Clinician)

To summarise, patients, parents, and clinicians described APT to be effectively delivered due to its focus on therapeutic rapport throughout treatment. This is evident when therapists prioritise open and honest communication with their patients as well as explicitly communicating the treatment plan with their parents. In turn, establishing rapport fosters trust in the patient, which in turn allows them to reconnect back in with 'the self' which has been neglected by the ED, as well as with others in their network.

#### Category 2: Providing a Tailored Treatment Experience

The second theme is again comprised of three subcategories which demonstrate how APT provides a tailored treatment experience for each patient, including flexibility in patient involvement, supporting carers/parents in treatment, and providing physical and psychological care simultaneously.

## Subcategory 1: Flexibility in Patient Involvement

Clinicians acknowledge that adolescents typically grow and develop in the context of their family, making parents an essential resource in their child's recovery. APT caters to young people from 12 to 24 years of age and acknowledges that developmental differences exist within this age range. Clinicians recognise that, as a result, there is variability amongst young people in their readiness for autonomy in treatment. Older adolescents have stated that they value being able to have more independence and input in their treatment whilst still having their parents by their side to support them.

What I think is really good about the model is that it's flexible. So, you've got the younger person, the 11-year-old, very happy to have the parents sit in on the session if that's what the young person wants. Whereas you've got the 17-year-olds, they're desperately trying to individuate from their parents. (Claire, Clinician)

Whilst less representative of autonomy and more demonstrative of self-expression, parents could also attest to their child being given a voice in treatment. By allowing patients to get involved in treatment, either through self-expression or actively contributing to their treatment, clinicians describe patients as being more cooperative as a result. In FBT, parents are assumed to be in control of their child's recovery and are usually the agents of change. This approach has been described by clinicians and patients alike as being rather punitive at times, especially for those with the desire and the ability to take on a more active role in treatment. Clinicians mention that the APT approach is less of a takeover from parents but more of a collaborative process whereby adolescents, their parents, and clinicians should all work together in order to ensure the best treatment outcomes are achieved for the patient.

That person knows that they have a voice and they're able to talk about how that renourishment is going. They're able to sort of contribute to that as well. (Olive, Clinician)

## Subcategory 2: Supporting Carers/Parents in Treatment

Clinicians also acknowledge that every family has different abilities and levels of capacity to bring about weight restoration in their child. For this reason, APT is flexible in equipping families with additional support if required. For example, some parents stated that they requested individual parent sessions aside from family sessions, which APT was able to provide. There is also evidence for expecting to provide parents with more extensive support than was offered in their APT experience. Specifically, two parents expressed a desire for more guidance on how to be available and present to the rest of their family whilst remaining an active member in their child's demanding treatment plan.

The way I use it the most is having the flexibility in the structure of the sessions to be able to Play around with individual parent and family difficulties, and that flexibility isn't really there for FBT or CBT-E. (Sally, Clinician)

Clinicians also emphasised the importance of helping parents to understand how the ED is uniquely affecting their child since every young person presents differently. When parents are more attuned to their child's needs, this gives them a sense of accomplishment and instils confidence in them to continue to help their child fight their illness. This reinforces the importance of supporting parents who are often responsible for upholding their child's treatment plan.

I think it's just such a scary experience to go through, that you just are looking for anybody to guide you through it and to tell you that you're doing OK, or that you should be doing this, or this is what to expect, and so it's been a huge relief for us. (Clarissa, Parent)

## Subcategory 3: Providing Physical and Psychological Care Simultaneously

APT strives to create a holistic experience for families where the physical and psychological aspects of recovery are addressed simultaneously through refeeding (physical) and individual treatment modules (psychological). According to clinicians, this contrasts with manualised FBT, which focuses exclusively on weight restoration through refeeding for the vast majority of treatment. A few clinicians, as well as patients and parents who had been treated with FBT prior to APT, indicated that FBT took a comparatively one-sided approach. In their opinion, weight restoration was prioritised over looking at the precursors of the ED. One clinician expressed that by providing predominantly medical care through refeeding, professionals risk discharging those who still have strong anorexic cognitions despite being renourished and weight restored. Two clinicians indicated witnessing many other clinicians struggling to strictly adhere to the manualised FBT framework because it fails to accommodate the various complexities and comorbidities that their clients are increasingly presenting with.

Although we obviously focus on refeeding, the psychological work also happens quite upfront as well, so it's not sort of just left until someone reaches a certain weight, you know? It's really done alongside. (Louise, Clinician)

Whilst renourishment should remain the priority, clinicians describe that there is more flexibility in APT to introduce psychological support much earlier in treatment than in FBT, particularly for those who need more psychoeducation around the inner workings of their ED. This creates meaning for patients in their recovery because they can better understand the importance of renourishment and the implications their disorder has on their health. When patients are informed about their ED rather than being dictated what to do without explanation, clinicians describe patients as being generally more compliant in adhering to the treatment plan. Providing psychological treatment earlier on also motivates patients to return to therapy because they don't want to lose the emotional support that they are receiving, which has been established from the outset during rapport-building. If this psychological support is not provided, clinicians say their patients risk losing treatment engagement.

I think it's [APT] more flexible. And obviously, it's all based on the individual; for some young people, you really have to have quite an intensive phase of thinking about mainly food. But yeah, I think it allows that psychological work to come in a bit earlier if you can." (Olive, Clinician)

To summarise, interviews with participants revealed that APT provides a unique treatment experience for each family. All participants described it as being flexible to patients' developmental stages and differing needs for autonomy and was successful in providing psychological care alongside refeeding. Some clinicians and parents stated that APT also accommodates to parents needs who also require different levels of support.

## Category 3: Dietetic input

The third and final theme illustrates how dietetic input is perceived by participants, also represented by three subcategories. These include prescriptive meal plans, team communication and collaboration, and dietitians leading renourishment.

#### Subcategory 1: Prescriptive Meal Plans

Patients, parents, and therapists by profession generally perceived dietetic involvement in treatment to be beneficial. Participants were all in agreement that dietetic sessions were highly food-focused, with non-negotiable meal plans that were often repetitive. Patients and parents agreed that despite meal plans being rigid and tough to follow, it holds patients accountable to their structured treatment plan and keeps them consistently working towards recovery. However, one patient had a negative perspective on their meal plan and described it as being too restrictive, where they felt their food choices were more limited as a result. A couple of patients said they felt their food choices were dismissed over a highly prescriptive meal plan that left no room for personalisation. For example, one patient was vegan which was not always acknowledged by her dietician, who made food recommendations that were misaligned with her usual diet.

I think despite the fact that [the meal plan] is my biggest bugbear, if I get back to that meal plan, you know, three meals and three snacks, it seems to be something that maybe that's what's kept us – maybe that rigidity in some ways has actually helped because it's not negotiable on some levels. So, it has helped with getting my daughter to eat again. (Polly, Parent)

#### Subcategory 2: Team Communication and Collaboration

Parents and clinicians stated the importance of having professionals specialising in different areas working on the same team. Parents commented that having a close-knit team of professionals meant that the information that was communicated to them was consistent, which is important when you have multiple professionals providing support from various fields in healthcare. One therapist stated

that there are currently major delays in accessing dieticians, which makes it difficult to find dieticians that work independently. This means that therapy and dietetic sessions cannot always begin at the same time, despite this being beneficial for treatment outcomes. Clinicians also mentioned that it was easier to communicate with other professionals when working as a team because they are more likely to be on different pages when working independently. In one example, a therapist and dietician had different treatment ideas about how to best ensure their patient would gain weight whilst keeping them engaged in treatment. It is noteworthy, however, that clinicians can still have varying opinions even when they work in the same team. If this were the case though, it allows room for discussion amongst treatment professionals to ensure an aligned message is communicated to the family. Clinicians also acknowledged that communication between specialists is particularly important, given that connection is much more difficult in private care as opposed to in a public health setting where all clinicians work under the same roof. Therapists also mentioned that despite patients benefiting from having access to various specialists, APT tends to create a lot more work for therapists who are responsible for liaising with the other professionals involved.

I tend to use one dietician because I know that they're going to be on the same page as me, but even so, that's, you know - sometimes communication is really hard. I struggle to get in touch with the dietitian which makes treatment a little bit more difficult because I might not know the weight that particular week or they may have missed a dietetic session, so I don't know what the weight is. (Sally, Clinician)

#### Subcategory 3: Dietician-led Renourishment

Having dieticians involved throughout APT was advantageous to both parents and therapists. For parents, they described that it took the pressure off them to be exclusively controlling their child's refeeding. Because meal plans and food negotiation are managed from an 'outside source', it preserves familial relationships from being adversely affected by food rules being determined by parents. Clinicians stated that having food choices determined by a dietician also ensures that adolescents receive expert nutritional advice, rather than from parents where there is more room for second-guessing the accuracy of their food suggestions. All dieticians that were interviewed specialise in EDs and therefore were able to provide extensive nutritional education for families supporting a young person with AN. In fact, one parent described wishing they had received more nutritional support than they had, after discovering that their child was struggling to maintain weight due to an irritable gut lining and gallbladder issues. Whilst these issues are not as relevant to dietetics per se and should be primarily dealt with by a gastroenterologist, regular sessions with a dietician

could have potentially led to this issue being flagged a lot sooner. Therapists stated that they valued having dieticians drive renourishment and manage patients' meal plans as it allows them to give more attention to their patient's psychological well-being and work through the treatment modules.

I think the dietitian has been really helpful too because I think that she really pushes her, and instead of me making the rules it's an outside force, which I think helps keep our relationship good too. And that there's somebody else weighing her in every week, somebody else holding her accountable, I think that's really helpful. I can't imagine doing it at home by myself. (Clarissa, Parent)

To summarise, this category illustrates participants' perspectives regarding the role that dieticians play during treatment. Participants describe the nature of the meal plan to be rigid yet crucial for weight maintenance, the importance of professionals communicating and collaborating to provide the best treatment outcomes, as well as the dietician taking on an active role in the patient's physical recovery, which has benefits for both parents and clinicians who are involved.

## Suggestions for Developing APT

APT is still in its infancy without a detailed manual, readily available training sessions or a treatment book. Whilst the concept of APT is generally understood by clinicians, they describe the guidance around treatment delivery as being vague. Where training is provided, the advice clinicians are given is too broad. Loose guidelines play into the strength of APT allowing for flexibility in how clinicians choose to administer it. For the most part, though, clinicians feel unsupported by the lack of structure within the treatment program.

There isn't a manual per se, or more guidelines on how to do APT. So, I get the concepts, but I think the execution of it hasn't really – I don't feel as supported to know how to do APT in comparison to say something like FBT or CBT-E. (Sally, Clinician)

Working in private care, the developers of APT are currently the only clinicians driving its implementation into private clinics, where little is known about its availability. There is also hesitation in picking it up due to its novelty and not being evidence-based.

Therefore, clinicians practising APT, or utilising aspects of it have a few suggestions for its development. Firstly, there is a need for a more comprehensive treatment manual that is somewhat standardised to ensure clinicians are consistent in how they provide treatment. There is also a need for more training sessions or workshops with access to more regular supervision for clinicians. Not only will this provide clinicians with further education around APT, and encourage confidence in them to use it, but it will also help spread awareness about APT and connect attending professionals specialising in the field. One clinician also suggested providing a brochure-style handout to give to families who are about to begin APT, so that they are informed of what the treatment entails. This would not only provide clarity, but also reassurance for families who have had an unsuccessful attempt with a different treatment.

I guess the one thing that would be super helpful is having a really nice little summary of what APT is. Like, I've kind of put something together to give to families, but it would be really nice to have something that is consistent. (Olive, Clinician)

Another clinician acknowledged that adolescents with an ED typically have a strong inner critic. Thus, it would be of benefit to incorporate self-compassionate narratives into treatment, and perhaps dedicate an entire module to this.

## Chapter 6: Discussion

The present study investigated the views and experiences of young people, parents, and clinicians about Adolescent and Parent Treatment (APT) in the recovery from Anorexia Nervosa (AN). In doing so, participants were asked a series of semi-structured interview questions to assess a.) what specific components of APT they identified as being helpful or unhelpful, and b.) how participants viewed APT compared to other treatments for AN, particularly Family-Based Treatment (FBT).

All participants were recruited in either Melbourne, Australia or in Auckland, New Zealand. Young people ranged in age between 18 and 30 and included both recovered as well as non-recovered individuals who were still in treatment and working towards recovery. Participants also included parents with adolescent children who were either still in treatment or had already been discharged (though not all were related to the adolescents who were interviewed), as well as clinicians practising APT.

APT is a novel intervention that has not yet been tested as a treatment package. Thus, it is particularly important to contextualise the current findings within the eating disorder (ED) literature, in order to compare and contrast existing treatments. Findings from these studies highlight that aspects of ED frameworks considered as being desirable components of therapy are also deemed as essential to recovery under the APT framework.

# 6.1 Theme 1

The first theme that emerged from the data depicts the importance participants place on effective therapeutic rapport from the outset of treatment, which establishes trust between the therapist and patient and in turn, enables patients' reconnection with themselves and with others in their community.

#### **6.1.1** Participant Perspectives

A qualitative study examined what aspects of ED treatments young people with AN and their parents identified as being positive or negative (Mitrofan et al., 2019). Patients either had an ED at the time of being interviewed or were already recovered. Participants outlined several recommendations for ED treatments based on their experiences, which are consistent with what participants in the current study identified as being strengths of APT. In congruence with the current study, findings demonstrate that the psychoeducation patients received in APT allowed them to better understand the

importance of renourishment, thus creating meaning for their recovery (Mitrofan et al., 2019). However, participants in the research also consistently described feeling as if judgements were made about them by their treating therapist. This was linked to situations in which clinicians lacked specialist knowledge about EDs and were unable to understand their patients' individual experiences. This is in direct contrast to how most patients, interviewed by the lead researcher (HS), described their therapeutic relationship with their therapist, where a safe, non-judgmental space was created for open and honest communication. Additionally, all interviewed clinicians specialised in EDs, with one having experienced an ED themselves, which significantly contributed to patients feeling understood, thus establishing trust. Patients and parents in the 2019 study mentioned that mutual storytelling was an important aspect of treatment which allowed patients to learn more about their ED and fuelled their motivation to recover (Mitrofan et al., 2019). Despite patients being generally appreciative of the professional help that they received, patients felt they were not as genuinely understood as when they spoke to fellow patients who had or were also experiencing what they were going through.

Another qualitative study explored the experiences of former adolescent patients whilst they were receiving inpatient FBT (Nilsen et al., 2019). One of the two main themes that were extrapolated out of the data concerned participants' views on the attitudes of the treatment team, which influenced their motivation for recovery. All participants agreed on the importance of clinicians treating their patients with kindness and respect and them taking a non-judgemental stance to issues presented to them. Reflections on whether this was always demonstrated varied amongst participants. Some described that these behaviours were evident most of the time, which motivated them to become more invested in their treatment. However, other patients thought their clinicians had approached their situation with preconceived ideas about them without inquiring about their unique struggles. They emphasised the necessity of clinicians needing to get properly acquainted with their patients, without casting the stereotype of an 'anorexic' upon them. Patients (and parents) within the current study felt that their therapists took an interest in getting to know them beyond their ED symptomatology, without casting judgement, which strengthened therapeutic alliance. One therapist also disclosed to her patients that she had experienced an ED herself, which allowed her patients to feel validated and cultivated mutual respect.

Researchers investigated adolescents' and parents' experiences of care in Family-Based Treatment (FBT) (Hughes et al., 2020). Whilst participants in this study were generally satisfied with FBT overall, parents appeared to be more pleased with their treatment experience than adolescents were.

During the initial assessment, the majority of parents (95%) agreed that they were given the chance to share concerns regarding their child in treatment, whereas just over half of adolescents (55%) felt safe or comfortable enough to share their ED experiences (Hughes et al., 2020). Whilst most adolescents (82-94%) felt respected by their team of clinicians and that their well-being was managed, markedly less (64-67%) had faith in their team to bring about real change and did not believe that their concerns were listened to or followed-up on (Hughes et al., 2020). This contrasts with what was expressed by patients in the first theme of the current study, whereby the secure base that was provided by their therapists allowed them to feel comfortable enough to be transparent about their children felt heard by their APT therapist, who was someone whom they could openly share their concerns with. In congruence with the research, half of the young people in the current study who had been previously treated with FBT also did not feel they were fully heard under this framework. In the research, therapeutic alliance was suggested as an area of improvement by participants who were involved with FBT, whereas this appeared to be a particular strength of APT according to participants who were interviewed.

#### 6.1.2 Therapeutic Alliance

Findings from the current study revealed that participants perceived rapport-building as being a core strength of APT, which allows for therapeutic alliance to be cultivated between therapists and patients. Therapeutic alliance is also considered to be an important component of other treatments for EDs, where its presence or absence can have an impact on how patients describe their treatment experience overall. The importance of therapeutic alliance on treatment outcomes has not only been demonstrated qualitatively but also on a quantitative level. A meta-analysis was conducted examining the relationship between early alliance, early symptom improvement, and treatment outcome (Graves et al., 2017). Results showed that therapeutic alliance directly correlated with more successful treatment outcomes. Therapeutic alliance was further improved by early symptom reduction, though only partially. There was an even greater relationship between early alliance and treatment outcomes for younger patients compared to older patients, demonstrating the impact that rapport-building has on younger people in particular.

## 6.2 Theme 2

The second theme in the current study illustrates APT as being a flexible treatment model, where patients' level of independence and need for autonomy is acknowledged, parents are adequately

supported in guiding their children through treatment, and patients' psychological requirements are considered alongside their physical needs for recovery.

## **6.2.1** Participant Perspectives

Participants in the study by Mitrofan et al. (2019) described FBT as being standardised with little consideration for individual differences in patients' EDs and recovery processes (Mitrofan et al., 2019). They also expressed that they would have wanted more psychoeducation about their ED and suggested treatment be personalised to patients to encourage them to find their own motivations for recovery. Participants further expressed a desire for a holistic approach to be adopted towards treatment, where the psychological aspects of care are addressed alongside refeeding (Mitrofan et al., 2019). They described treatment as being too focused on weight restoration, which often led patients to relapse due to an inability to cope with their emotions and lack of control. This contrasts with APT, where participants described psychological support as being available for patients at a much earlier stage compared with FBT, for example. This was particularly the case for patients requiring more help at the front end of treatment in understanding the nature of their ED.

Findings in the research by Hughes et al. (2020) illustrate that there were differing opinions as to whether parents felt adequately supported in guiding their children through treatment. Whilst a significant proportion of parents agreed that they received enough support around how to best support their child on a physical basis (i.e., food choices and exercise), nearly half of these parents did not feel they were given the help that was needed to deal with their children's distress or negative response to weight gain (Hughes et al., 2020). Additionally, just over half of parents voiced that they would have appreciated more support with their own distress during the treatment process. These findings are comparable with what was expressed in the current study, where there were inconsistencies between parents' perceptions of the support they received during APT. While some parents thought this was achieved, others stated that they would have appreciated more extensive guidance, particularly around how to give the rest of their family more attention whilst also leading their child's treatment plan.

Following the results previously mentioned in the study by Nilsen et al. (2019), most participants highlighted that treatment teams should aim to provide each patient with a tailored treatment plan that is tailored to their developmental stage (in this case as an adolescent), individual needs and vulnerabilities, as well as family dynamics (Nilsen et al., 2019). These suggestions are in line with

patients' findings of the treatment structure being too standardised and rigid with little room for personalisation. Additionally, a significant proportion commented on the importance of inpatient treatment allowing for collaboration with the affected young person and taking their ideas into account during treatment planning. APT appears to address both suggestions, where treatment flexibility is considered by all participants as being a notable strength of APT. Not only is there room to modify treatment slightly to suit the patient in question, but patients are also given the opportunity for independence (alongside their parents' support) and providing their input.

A qualitative study examined the experiences of therapists in treating adolescent AN using FBT, or its non-manualised version, FBT-AN (Aradas et al., 2019). Considering traditional FBT follows a rigid structure that enforces adherence to the treatment manual, therapists described being both 'relieved' and 'constrained' by its methodological approach (Aradas et al., 2019). The clearly defined treatment protocol provided comfort to clinicians, particularly when faced with complexities that they struggled to navigate, as well as putting clinicians at ease; particularly those with less ED experience. On the other hand, the rigid nature of the model often meant prioritising the manual over considerations for patient factors or one's own clinical judgement. Clinicians mentioned that this resulted in having to disregard important topics that came to light, such as a patient's psychological distress, in favour of focusing primarily on weight restoration (Aradas et al., 2019). These situations were described as particularly difficult due to the inner conflict this caused with clinicians' morals to emotionally support their patients. A couple of clinicians in the current study expressed that the highly flexible nature of APT sometimes impeded their confidence and that they had at times wished it was slightly more standardised. Despite this, clinicians unanimously agree that the flexibility of treatment also allows for the psychological aspects of care to be addressed in parallel with the physical aspects, where patients' concerns are prioritised alongside the urgent need for weight restoration.

## 6.2.2 Self-Efficacy

Results from the current study revealed the importance of providing support for carers of children with AN, who are guiding their child through treatment. Clinicians emphasised that educating parents on the nature of their child's ED (which has a unique presentation in every individual) is essential in providing their young person with the most effective support. With parents often playing a pivotal role in their child's recovery, their choice of how to support has major implications on young people's treatment outcomes. It is well documented in the literature that providing parents

with adequate psychoeducation both increases their knowledge as well as self-efficacy, which in the context of EDs, refers to the belief in their ability to bring about weight restoration in their child and to help them recover (Robinson et al., 2013). Self-efficacy in parents has also been acknowledged as predicting positive treatment outcomes in adolescents, specifically in FBT (Robinson et al., 2013). Researchers investigated whether parent self-efficacy influenced adolescents' ED as well as associated depressed mood and anxiety. Findings showed that an increase in parents' self-efficacy predicted a reduction in adolescents' ED symptoms as well as a depressed mood. Interestingly, an increase in the father's self-efficacy specifically, led to a decrease in anxiety symptoms in adolescents. Whilst these results are in relation to FBT, they illustrate that self-efficacy brings about confidence in parents to take responsibility for their child's recovery, but also has a direct impact on adolescents' treatment outcomes. This highlights the fundamental need for therapists to support parents throughout treatment as it empowers them to guide their child through their recovery. In the context of APT, this validates the importance of therapists providing psychoeducation to parents around EDs as well as holding additional sessions with parents independently, given the flow-on effect this will have to their children battling AN.

## 6.3 Theme 3

The third theme highlights the integral role dieticians play in APT, who provide structured meal plans for patients which hold them accountable and whose expertise in nutrition provides relief for both families and therapists upholding the treatment. Therapists and clinicians also mentioned that communication and collaboration with other specialists (including dieticians) were more effective when they all worked together as a team (rather than independently) and allowed for better communication back to the family.

## 6.3.1 Participant Perspectives

In qualitative research, parents and adolescents have demonstrated to have different views on their interactions with their treatment team (Hughes et al., 2020). In the study by Hughes et al. (2020), most parents (89-99%) thought the treatment team was knowledgeable and communicated effectively with them. Although the majority of adolescents also commented on the expertise of the team (94%), a smaller number of adolescents (70%) thought the team facilitated effective communication with them. Within the current study, clinicians who practice APT expressed that communication amongst other professionals was certainly more difficult when they worked independently from one another, with potential implications on the communication back to the

family in treatment. Along with these insights shared by clinicians, parents and patients also touched on the benefit of having a team of specialists supporting their recovery.

A qualitative study by Wufong et al. (2019) explored parents' perceptions of FBT, specifically where their children did not continue with their treatment or where psychological distress was still experienced after being discharged (Wufong et al., 2019). This research sheds an important light on the significant emotional burden parents of young patients undergoing treatment for an ED carry. Parents described feeling distressed when assigned the role as their child's primary 're-feeder', which is typically overlooked in traditional treatment approaches. Given this task allocation, parents felt they were to blame when the child's targeted weight gain was not maintained or achieved, leading to feelings of guilt and shame (Wufong et al., 2019). This load on the parent was counterproductive to playing a supportive role in the recovery of their children. Given the discovery of parents' emotional struggles and guilt load during their adolescent's treatment journey with an ED, it is easy to understand why therapists and parents place such high value on dietetic input when going through APT. Contrary to the observation in the above-mentioned study, parents involved in APT describe how the involvement of dieticians takes the pressure off them to be exclusively controlling in their child's refeeding. Because meal plans and food negotiations are managed from an 'outside source', it preserves familial relationships from being adversely affected by parents determining rules around food. Given findings from the current study on APT, this guilt could be lessened, if not eliminated, if the parent had specialist dietetic input, freeing them from a sense of carrying the sole responsibility for their child's weight restoration. Results from the current study show clearly how the input from a dietician plays a vital part in both the restoration of the adolescent's weight and familial relationships.

## 6.4 Setting the Current Findings Within the Wider Healthcare Literature

Considering the novelty of APT, it also made sense to consult the medical and health sciences literature, to gain an understanding of what constitutes best practice in wider healthcare. Many aspects of APT deemed important by its service users are also recognised as being vital in other areas of healthcare. Of mention are studies in diabetes, nursing, and nutrition, as well as theories in social psychology.

The first theme that emerged from the data is organised into a sequential model of steps clinicians should follow in order to deliver effective treatment. This theme can be likened to a model developed a qualitative study examining nurse-patient relationships (Williams & Irurita, 1998). Findings

revealed that establishing therapeutically conducive relationships was essential to providing quality nursing care. This model was also organised into sequential steps, starting with 'initiating rapport', followed by 'developing trust', 'identifying patient needs', and 'delivering quality nursing care' (Williams & Irurita, 1998). Rapport-building was facilitated through informal communication and determining common interests, which allowed patients to develop trust, demonstrated by the mutual exchange of information with nurses. This in turn helped nurses to distinguish patients' physical and psychosocial needs, thus providing quality nursing care. Theme one of the current study closely resembles the model described in the research, particularly regarding how effective rapport-building cultivates trust. This similarity between themes shows that these stages of delivering effective therapy are likely to be broadly applicable to therapeutic relationships and do not appear to be exclusive to APT. Considering this emerged as a critical theme in the current study, it also emphasises the importance that service users place on connectedness and alliance between patients and their medical carers.

Facilitating communication was identified as being the first crucial step in providing effective treatment. An example of how clinicians connect with their patients can be demonstrated by the one therapist who shares her lived experience with an ED with her patients. Therapist disclosure creates trust, reduces the social distance between client and patient, and contributes to developing a therapeutic alliance. This shows up in the chronic illness literature, with one study investigating the effectiveness of storytelling in disease self-management among people with diabetes (Gucciardi et al., 2021). In this qualitative study, adults with type two diabetes participated in story-telling interventions, sharing stories of their choice about their illness with other people with diabetes. Results revealed that, over time, these peer support groups fostered friendships between patients, where mutual storytelling encouraged patients to relay their experiences with diabetes without fear of judgement from others (Gucciardi et al., 2021). Ultimately, the sharing of stories allowed patients to feel validated by each other's experiences and the process of self-disclosure assisted the healing process. The same effect is experienced in the current study of this thesis, whereby the therapist's disclosure of her personal stories with an ED allows her patients to feel validated and encourages them to be more transparent about their experiences with AN. Similarly to patients with AN, participants in this research describe diabetes being an isolating illness whereby storytelling allows patients to relate to one another, thus creating a strong sense of togetherness and community. It was mentioned that as a result, this may enhance disease self-management, where patients are backed by a team of supporters going through the same experience. The research reviewed, combined with the

current study highlights the power of mutual storytelling and the benefit this has on treatment outcomes across multiple healthcare settings, such as in EDs and diabetes.

Developed by researchers in social psychology, Self Determination Theory (SDT) proposes that all individuals have a basic psychological need for autonomy, competence, and relatedness (Deci & Ryan, 2012). SDT acknowledges that individuals have different levels of intrinsic motivation, which involves drawing upon one's internal sources (internalisation) to acquire more knowledge or independence. This theory also recognises that different social contexts influence human motivation, as well as performance and well-being. SDT is said to be one of the most applicable theories in social psychology to a wide range of social issues and contexts such as in learning, healthy behaving, job satisfaction and most notably therapeutic outcomes in multiple treatment settings (Deci & Ryan, 2012). To ensure psychotherapy is successful and for treatment effects to be maintained beyond therapy, patients need to demonstrate a motivation to change and a willingness to reflect and work on issues in treatment (Ryan & Deci, 2008). SDT outlines that in order for therapeutic change to last beyond treatment, and be applied to other behavioural or psychological contexts, there needs to be support for internalisation and autonomy (Pelletier et al., 1997). Thus, therapists are encouraged to nurture their patient's different levels of need for autonomy. This theory provides support for the results of the current study, specifically for the first subcategory of the second core category, which describes the importance of valuing patients' desire for autonomy in treatment. Therapists spoke to the importance of recognising the developmental variation that exists among patients, especially given the large age range of patients they take on (12 to 24 years old). This means that patients vary in their levels of readiness for autonomy in treatment, with older adolescents having a particular desire for more independence. Research into SDT provides valuable insight into how providing an autonomy-supportive context for change has positive impacts on treatment outcomes in psychotherapy more broadly. This is congruent with APT, where flexibility in the treatment plans allows for each patient's level of autonomy to be accounted for.

As mentioned in the third theme of this study, patients, parents, and clinicians all agreed that dietetic input was essential to recovery. Of note was the nutritional knowledge that dieticians shared not only with patients but also with parents who vary in their levels of knowledge regarding food. The rigidity and repetitive nature of the meal plans were often emphasised by patients and parents, with one patient expressing it being not conducive to their recovery. A couple of patients described the meal plans as being misaligned with the type of food they were used to eating, even when their diets were based on health and ethical choices such as veganism, creating further anxieties around food. One

parent described issues with their daughter's gut health and gallbladder making it difficult for her to gain weight, which had major implications on her ability to physically recover. Personalised nutrition is an up-and-coming idea in the field of nutrition, which refers to an approach that "assists individuals in achieving a lasting dietary behaviour change that is beneficial for health" (Gibney et al., 2016). Essentially, it aims to consider the unique interplay of genetic, phenotypical, nutritional, medical, and other personal aspects of health to provide tailored guidance around food or dietary management to best suit the individual in question (Gibney et al., 2016). Personalised nutrition can be utilised for healthy people to better or preserve their health, as well as in a clinical context for patients experiencing an illness or disease, which may or may not have genetic components. While more research is needed in this space before conclusions can be drawn, the principles of personalised nutrition may be implemented in order to create more personalised meal plans. This may be particularly of benefit for those experiencing an ED alongside other health issues, such as the patient previously mentioned who suffered from gastrointestinal problems.

#### 6.5 Strengths and Limitations

A few strengths have been identified for this piece of research. Firstly, this study embodies the first (known) piece of research that empirically investigates APT and the perceptions that service users hold who have encountered it, either through delivering or receiving the treatment. As this study is the first of its kind, it also provides the building blocks for quantitative research to be carried out, as was initially planned for this thesis.

Considering that little is currently known about APT in the field, this study benefits from using a qualitative methodology, whereby a broader lens is applied to data analysis. In the field of psychology, quantitative research was historically preferred over qualitative research due to its scientific rigour (Gelo et al., 2008). Whilst this mentality still exists amongst researchers today, qualitative research is now held in higher regard as it is recognised as contributing important findings to research. Through the process of interviewing, the lead researcher (HS) was able to extract salient patterns or behaviours that exist amongst participants and combine them into a framework that helps provide an explanation as to why APT should be given primary consideration. The findings that emerged from the data are directly grounded in the experiences of patients, parents, and clinicians who are or have been involved with APT. Quantitative studies would be unable to do this since this approach requires data analysis to be led by testing a set number of hypotheses.

Overall, positive feedback was obtained from service users in regard to APT, warranting further qualitative investigation into the experiences of patients, parents, and clinicians. The experiences shared by patients, parents, and clinicians are a testament to the influential impact that APT is having on adolescents and young adults in the recovery from AN. This study is merely the first step in assessing whether APT is a viable treatment alternative to FBT.

Six limitations are also outlined in this study. Firstly, given that APT is a novel framework, the young people interviewed were directly recruited through their psychologists. This means that there is potential for the data to be biased as there is the risk that psychologists only put forward their most responsive patients currently being treated or those that successfully recovered.

It is noteworthy that two of the clinicians that were interviewed were the developers of APT. Whilst this was foremost a benefit to the researcher as they were able to glean first-hand insights into APT, they are potentially more biased in their judgement as to why it is more beneficial than other treatment methods.

A further limitation is constituted by several young people interviewed for this research having been treated by the same psychologist. This could have implications for the reliability of results, where there is more opportunity for data to be skewed. This risk could have been minimised if patients who saw a more extensive range of psychologists were recruited. In the context of this thesis, however, there was limited time to recruit patients through several more of the psychologists who participated in this study.

Participants consisted of young people who were both recovered and who were still being treated at the time of data collection. Whilst results from recovered patients are more affirmative, more caution needs to be exercised when analysing the results of those who were still in recovery during data collection. This was not controlled for, given that the aim was to gain a broader understanding of perspectives on APT for all participants involved in treatment. Future research could examine whether treatment experience is influenced by hindsight, by controlling for patients who have recovered and those who are still being treated with APT and comparing the two groups.

Amongst the participants that had recovered, there was variability in the length of time that had surpassed since being treated. Depending on how long-ago patients had recovered, this could have contributed to memory bias where perhaps the recounts of their APT experiences are not entirely accurate. Ideally, therefore, a group close in time to their therapy should have been recruited. On the other hand, speaking in hindsight may also enable participants to have a more mature perspective on their experience.

The research process for the thesis was disrupted and delayed by the lead researcher's (HS) supervisor having to take extended sick leave. Unlike the previous supervisor, the newly appointed co-supervisor was not a clinical psychologist and did not have the specialist knowledge of APT or eating disorders in general. Thus, further specialist insight was gleaned externally from the developers of APT, who are based in Melbourne, Australia.

## Chapter 7: Conclusion

The findings of this study demonstrate that Adolescent and Parent Treatment (APT) is generally well received by all service users, including patients with Anorexia Nervosa (AN) who are receiving or have received APT, parents of adolescents who have been involved as well as clinicians who have administered it. This deems APT as being worthy of further investigation.

According to service users, particularly clinicians, the most effective sequence of therapy is delivered when, firstly, therapists initiate solid therapeutic rapport with their patients from the outset of treatment. Patients found mutual storytelling particularly helpful in allowing them to be transparent themselves, thus creating a shared understanding. Unlike their experience with APT, patients who had been previously treated with Family-Based Treatment (FBT) described the FBT framework as having a comparatively uncompassionate approach. When a non-judgemental space is created that encourages patients to be transparent, APT becomes the "lynchpin" in connecting patients "back with themselves and the people in their life".

APT is designed for a wide age range of adolescents with various levels of desire for autonomy and involvement in treatment. By accommodating for these different needs with a flexible treatment plan, patients are more likely to cooperate in therapy. Clinicians utilising APT also recognise the vital role parents play in controlling their child's treatment plan, and thus it is crucial that parents also feel supported. Help to parents is provided through psychoeducation around the ED and how it uniquely affects their child, as well as allowing for extra parent sessions if needed, which parents described as being beneficial. Additionally, there is more flexibility for the psychological aspects of recovery to be addressed alongside the physical aspects of recovery. In contrast, traditional FBT focuses primarily on weight restoration. However, when clinicians discharge patients on the basis that they are weight restored, they risk letting patients go who may still have strong anorexic cognitions. Furthermore, providing patients with psychoeducation about their illness earlier on in treatment allows patients to be more compliant in treatment because they understand the reasoning behind needing to recover as opposed to being told what to do without explanation.

The dietitian is recognised by all participants as being instrumental in helping patients achieve recovery. Therapists benefit from having dieticians onboard because it allows them to focus more on providing psychological support to their patients. Dietetic input is also valued by parents as not only does it take some of the pressure off around refeeding, but also allows food rules to be controlled by

an outside force, thus maintaining familial relationships. Specialist support from dieticians as well as other professionals in the field such as psychiatrists and paediatricians is particularly effective when they are working together as a team with the treating therapist. This allows for easier communication with professionals, and it is more likely for them all to be on the same page, compared to when working independently. This team approach does create more work for the treating therapist, however, who is in charge of liaising with the other clinicians involved in treatment.

#### 7.1 Future Research

The current research is the first known study of its kind to empirically examine APT and how it is perceived by its service users. In line with the feedback given by clinicians who were interviewed, it is suggested that there be a focus on further developing the treatment so that there is more uptake by clinicians independently, or, become an established treatment model in more outpatient private practices. Currently within New Zealand, Nurture Psychology (based in Auckland) is the official provider of APT. In regards to future research, it would be beneficial for another qualitative study to examine whether treatment experience is influenced by hindsight, including sufficient numbers to compare patients who have recovered with those who are still being treated with APT. Future research could also investigate whether there is a correlation between AN duration and the length of time it takes to recover when individuals are treated with APT. Considering the novelty of this treatment and little research being available at this stage, studies using either a qualitative or a quantitative approach would provide useful insight.

Appendices

Appendix A. Ethics Approval

Health and Disability Ethics Committees Health Ministry of Health and 133 Molesworth Street Disability PO Box 5013 Ethics Wellington 6011 Committees hdecs@health.govt.nz 01 July 2021 Dr Marion Roberts 28 Park Ave Grafton Grafton 1023 Dear Dr Roberts

Re:	Ethics ref:	21/CEN/144
	Study title:	Exploring the feasibility of Adolescent and Parent Treatment (APT) for Adolescent Anorexia Nervosa in a Private Psychology Clinic

I am pleased to advise that this application has been <u>approved</u> by the Central Health and Disability Ethics Committee with conditions. This decision was made through the HDEC-Expedited Review pathway.

#### Conditions of HDEC approval

HDEC approval for this study is subject to the following conditions being met prior to the commencement of the study in New Zealand. It is your responsibility, and that of the study's sponsor, to ensure that these conditions are met. No further review by the Central Health and Disability Ethics Committee is required.

#### Standard conditions:

- 1. Before the study commences at *any* locality in New Zealand, all relevant regulatory approvals must be obtained.
- 2. Before the study commences at *each given* locality in New Zealand, it must be authorised by that locality in Online Forms. Locality authorisation confirms that the locality is suitable for the safe and effective conduct of the study, and that local research governance issues have been addressed.

Non-standard conditions:

- 3. Please adjust the "study design" in the Clinician's participant information sheet and consent form (PIS/CF) as follows; add specifically where the data will be stored for 10 years and who will have access to all the PIS/CFs.
- 4. The Committee advises that if a participant that turns 16 years old during the course of the study, the Researcher will need to obtain their consent for continued use of their data as the parental consent no longer stands. This will require a separate adolescent PIS/CF for HDEC review. Please either upload one now, or submit one later (before one of the 15-year-olds turns 16) through the post approval amendment pathway.

Non-standard conditions must be completed before commencing your study, however, they do not need to be submitted to or reviewed by HDEC.

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If you would like an acknowledgement of completion of your non-standard conditions you may submit a post approval form amendment through Online Forms. Please clearly identify in the amendment form that the changes relate to non-standard conditions and ensure that supporting documents (if requested) are tracked/highlighted with changes.

For information on non-standard conditions please see section 125 and 126 of the Standard Operating Procedures for Health and Disability Ethics Committees (available on www.ethics.health.govt.nz)

#### After HDEC review

Please refer to the *Standard Operating Procedures for Health and Disability Ethics Committees* (available on <u>www.ethics.health.govt.nz</u>) for HDEC requirements relating to amendments and other post-approval processes.

#### Your next progress report is due by 30 June 2022.

Participant access to ACC

The Central Health and Disability Ethics Committee is satisfied that your study is not a clinical trial that is to be conducted principally for the benefit of the manufacturer or distr butor of the medicine or item being trialled. Participants injured as a result of treatment received as part of your study may therefore be elig ble for publicly-funded compensation through the Accident Compensation Corporation (ACC).

Please don't hesitate to contact the HDEC secretariat for further information. We wish you all the best for your study.

Yours sincerely,



Mrs Helen Walker Chairperson Central Health and Disability Ethics Committee

Encl: appendix A: documents submitted appendix B: statement of compliance and list of members

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#### Appendix B. Consent Form for Clinicians



#### PARTICIPANT CONSENT FORM (CLINICIANS)

I have read and understood the participant information sheet for this study. I have been given enough time to consider my participation in the study. Any questions I have had so far have been answered to my satisfaction. I understand that I can ask for more information at any point during the study. I also understand that:

- 1. Taking part in the study is completely my choice.
- 2. I may withdraw from the study at any point.
- 3. The interview will be recorded, and a transcript will be produced.
- 4. I will be sent the transcript and given the opportunity to correct any factual errors.
- Access to the interview transcript will be limited to the research team, auditors from HDEC, regulatory bodies and academic colleagues and researchers with whom we might collaborate as part of the research process in New Zealand and Australia (where APT was first developed).
- 6. Any summary interview content, or direct quotations from the interview, that are made available through publication or other academic outlets will be anonymized so that I cannot be identified.
- 7. My participation in the study is confidential and any material that could identify me will not be used in any reports on the study.
- The collective results of this study will be published (e.g., in academic journals and presented at conferences).
- Data from this study may be used anonymously in future research or in collaboration with other researchers either in New Zealand or in Australia.
- 10. I know whom to contact if I have any questions about the study in general.
- 11. I am aware of my responsibilities as a study participant.

If I decide to withdraw from the study, I agree that the information collected about me up to the point when I withdraw may continue to be processed.

	Yes / No (please circle)
I wish to receive a summary of my results from the study.	
	Yes / No (please circle)
I agree to be quoted directly if my name is not used and a coded number is used instead.	
	Yes / No (please circle)
I wish to receive the transcript during the research pertaining to my participation.	
	Yes / No (please circle)

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#### Declaration by participant:

I hereby consent to take part in this study.

Name:

Signature:

Date:

#### Declaration by researcher:

I have given the required study information and have answered any questions that the participant may have had. I believe that the participant understands the information well enough to give informed consent.

#### Name:

Signature:

Date:

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#### Appendix C. Consent Form for Patients



#### PARTICIPANT CONSENT FORM (ADOLESCENTS)

I have read and understood the participant information sheet for this study. I have been given enough time to consider my participation in the study. Any questions I have had so far have been answered to my satisfaction. I understand that I can ask for more information at any point during the study. I also understand that:

- 1. Taking part in the study is completely my choice.
- 2. I may withdraw from the study at any point.
- I have had the opportunity to ask my family, whanau, friends, or healthcare providers to help me ask questions and understand the study.
- In the event of my parents and/or clinician answering questions during their interviews, my participation in APT will be spoken about.
- 5. I may withdraw from the study at any point without it affecting my treatment care.
- 6. The interview will be recorded, and a transcript will be produced.
- 7. I will be sent the transcript and given the opportunity to correct any factual errors.
- Access to the interview transcript will be limited to the research team, auditors from HDEC, regulatory bodies and academic colleagues and researchers with whom we might collaborate as part of the research process in New Zealand and Australia (where APT was first developed).
- 9. Any summary interview content, or direct quotations from the interview, that are made available through publication or other academic outlets will be anonymized so that I cannot be identified.
- 10. My participation in the study is confidential and any material that could identify me will not be used in any reports on the study.
- 11. The collective results of this study will be published (e.g., in academic journals and presented at conferences).
- 12. Data from this study may be used anonymously in future research or in collaboration with other researchers either in New Zealand or in Australia.
- 13. I know whom to contact if I have any questions about the study in general.
- 14. I am aware of my responsibilities as a study participant.

If I decide to withdraw from the study, I agree that the information collected about me up to the point when I withdraw may continue to be processed.

Yes / No (please circle)
I wish to receive a summary of my results from the study.
Yes / No (please circle)
I agree to be quoted directly if my name is not used and a coded number is used instead.
Yes / No (please circle)
I wish to receive the transcript during the research pertaining to my participation.

Yes / No (please circle)

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## Declaration by participant:

I hereby consent to take part in this study.

Name:

Signature:

Date:

## Declaration by researcher:

I have given the required study information and have answered any questions that the participant may have had. I believe that the participant understands the information well enough to give informed consent.

#### Name:

Signature:

Date:

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## Appendix D. Consent Form for Parents



### PARTICIPANT CONSENT FORM (PARENTS)

I have read and understood the participant information sheet for this study. I have been given enough time to consider my participation in the study. Any questions I have had so far have been answered to my satisfaction. I understand that I can ask for more information at any point during the study. I also understand that:

- 1. Taking part in the study is completely my choice.
- 2. I may withdraw from the study at any point.
- 3. The interview will be recorded, and a transcript will be produced.
- 4. I will be sent the transcript and given the opportunity to correct any factual errors.
- Access to the interview transcript will be limited to the research team, auditors from HDEC, regulatory bodies, and academic colleagues and researchers with whom we might collaborate as part of the research process in New Zealand and Australia (where APT was first developed).
- Any summary interview content, or direct quotations from the interview, that are made available through publication or other academic outlets will be anonymized so that I cannot be identified.
- 7. My participation in the study is confidential and any material that could identify me will not be used in any reports on the study.
- The collective results of this study will be published (e.g., in academic journals and presented at conferences).
- Data from this study may be used anonymously in future research or in collaboration with other researchers either in New Zealand or in Australia.
- 10. I know whom to contact if I have any questions about the study in general.
- 11. I am aware of my responsibilities as a study participant.

If I decide to withdraw from the study, I agree that the information collected about me up to the point when I withdraw may continue to be processed.

	Yes / No (please circle)
I wish to receive a summary of my results from the study.	
	Yes / No (please circle)
I agree to be quoted directly if my name is not used and a coded number is used instead.	
	Yes / No (please circle)
I wish to receive the transcript during the research pertaining to my participation.	
	Yes / No (please circle)

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## Declaration by participant:

I hereby consent to take part in this study.

Name:

Signature:

Date:

## Declaration by researcher:

I have given the required study information and have answered any questions that the participant may have had. I believe that the participant understands the information well enough to give informed consent.

### Name:

Signature:

Date:

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# Appendix E. Clinician Interview Guide

- 1. From your point of view, how effective is this treatment for adolescents in their recovery from AN?
- a. *Prompt*: And why is that?
- 2. From your point of view, how well does the treatment balance the physical health aspects with the psychological aspects of recovery?
- 3. In your experience, how does APT compare to other treatment modalities you have used?
- a. In what scenarios would you choose APT over another treatment modality for adolescents with AN?
- 4. From your perspective, how do you think families are responding to APT?
- a. Prompt: Are there certain elements that they take to particularly positively or negatively?
- b. Prompt: Do parents and their children have opposing views on the treatment?
- 5. To what extent did you feel there was enough guidance and support during your training of APT?
- 6. Among those who you have treated with APT, what was the most successful outcome?
- a. Prompt: What were the factors that lead to that successful outcome?
- 7. Tell me about a case you found the most difficult to treat?

Appendix F. Adolescent Interview Guide

- 1. Please could you share your story with me about your treatment experience?
- a. *Prompt*: Were there any parts of treatment that you found particularly helpful?
- b. Prompt: Were there any parts of treatment that you found particularly unhelpful?
- 2. What aspects of the treatment process were the most important to you?
- a. *Prompt*: Why were these important?
- 3. Tell me about how it went with your therapist?
- 4. How did you feel about the involvement of a dietician in your treatment?
- 5. Is there anyone else who has influenced your recovery?
- a. Prompt: Who was it and what role did they play
- 6. On the other hand, did anyone create any problems for you?
- 7. Were there any particularly memorable moments during your treatment journey?

Appendix G. Parent Interview Guide

- 1. How have you found the treatment experience as a parent?
- a. *Prompt*: Were there any parts of treatment that you found particularly helpful?

- b. Were there any parts of treatment that you found particularly unhelpful?
- 2. From your point of view, how well does the treatment balance the physical health aspects with the psychological aspects of recovery?
- 3. From your perspective, how did your child respond to the treatment?
- a. Prompt: Do you feel like your child was supported through their experience?
- 4. How did you feel about the involvement of a dietician in treatment?
- 5. Do you have any comments on how body image distress was managed?
- 6. Did you feel supported as a parent throughout treatment?
- 7. How much did you learn about AN during the treatment process?
- 8. How involved were you as a parent throughout your child's treatment?
- 9. [Without child present] What was the effect of your child's anorexia on your family?

## Appendix H: Participant Information Sheet for Patients



### PARTICIPANT INFORMATION SHEET FOR ADOLESCENTS

### ADOLESCENT AND PARENT TREATMENT (APT) FOR ADOLESCENT ANOREXIA NERVOSA

You have been invited to take part in a study assessing a psychological treatment for adolescents with Anorexia Nervosa.

Please read this information sheet carefully before deciding whether you would like to take part. If you do not wish to take part, this will not affect the care you receive. Thank you for considering the study. If you decide to take part but change your mind later, you are welcome to withdraw from the study at any point. You may also wish to talk to your family/whanau, friends, or healthcare providers before deciding to participate.

If you agree to participate, you will be asked to sign the included Consent Form.

#### **VOLUNTARY PARTICIPATION & WITHDRAWAL FROM THE STUDY**

Your participation in this study is completely voluntary. You are free to decline this invitation to participate, as well as withdraw from the study at any point without experiencing any disadvantage.

## WHAT IS THE PURPOSE OF THE STUDY?

The purpose of this study is to investigate how effective APT is as a treatment for adolescents with anorexia nervosa.

APT is an emerging treatment that addresses both physical and psychological aspects of eating disorder recovery. It works collaboratively both with the adolescent and with parent/s, acknowledging the vital role that both parties play in treatment. This study will be the first of its kind to empirically assess APT in an outpatient setting.

### HOW HAS THIS STUDY BEEN DESIGNED?

This is a mixed-methods study that has already involved collecting data from a patient who has undergone APT, as well as from their parents and their treating clinician. We are now interviewing 6 clinicians who are practising APT, as well as 6 patients and 6 parents. These participants will not necessarily be connected.

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#### WHY HAVE I BEEN INVITED TO TAKE PART IN THIS STUDY?

You have been invited to take part in this study because your perspective on APT is valuable to us as researchers. Taking part in this study will not change your care in any way. To participate, you must be medically stable, have no previous brain injury and not currently have suicidal ideation.

### WHAT WILL MY PARTICIPATION INVOLVE?

The researcher will ask you a series of questions using semi-structured interviewing techniques. These questions will encourage you to share your experiences with APT and your perspective on the effectiveness of the treatment. This interview will be conducted via Zoom and will be recorded and transcribed through the software. Transcripts of the interview will be sent back to you so that you can fact-check your answers to the interview questions.

## WHAT WILL HAPPEN TO MY INFORMATION?

The research team will record your information about your study participation. You will not be identifiable in the study results. Access to data will be limited to the research team, auditors from the HDEC, regulatory bodies, and academic colleagues and researchers with whom we may collaborate in New Zealand and Australia (where APT was first developed). Every effort will be made to ensure that you will not be identifiable in any publications, reports, or presentations that this research may appear in. Any summary interview content, or direct quotations from the interview, that are made available through publication or other academic outlets will be anonymized so that you cannot be identified. Your name shall be kept confidential and instead, you will be assigned a code number. Any material that could identify you will not be used in any reports on the study. Your information will be stored electronically and shall be password secure and any hard copies stored in a locked filing cabinet. All raw data on which the results of the project depend will be retained in secure storage for ten years, after which they will be destroyed. Your data may also be used in future studies as part of a larger data set either in New Zealand or in Australia.

#### WHAT ARE THE BENEFITS AND RISKS OF PARTICIPATING?

You would be one of the first patients to participate in a research study on APT. The interview questions may also provide a beneficial tool for you to reflect on your treatment journey with APT. Whilst we do not anticipate any risks in taking part in this study, we ask for your consent that you are willing to be talked about in the event that your parents and/or treating clinician are also interviewed.

### WHO HAS APPROVED THE STUDY?

This study has been reviewed and approved by an independent group of people called HDEC. They ensure that studies meet the required ethical standards of carrying out research. The Central Health and Disability Ethics Committee has approved this study.

## WHO IS DOING THE RESEARCH?

This study is being conducted by researchers at the University of Auckland. If you have any questions or concerns about the nature of this study, please contact the study researcher Holly Sharplin in the first instance, otherwise the Primary Investigator, Professor Bruce Arroll from the Department of General Practice and Primary Healthcare:

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Holly Sharplin MSc research student Professor Bruce Arroll Head of Department

School of Population Health, Level 3, Building 507, Park Road, Grafton, Auckland

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## Appendix I: Participant Information Sheet for Parents



## PARTICIPANT INFORMATION SHEET FOR PARENTS

## FEASIBILITY OF ADOLESCENT AND PARENT TREATMENT (APT) FOR ADOLESCENT ANOREXIA NERVOSA

You have been invited to take part in a study assessing a psychological treatment for adolescents with Anorexia Nervosa.

Please read this information sheet carefully before deciding whether you would like to take part. If you do not wish to take part, this will not affect the care you receive. Thank you for considering the study. If you decide to take part but change your mind later, you are welcome to withdraw from the study at any point.

If you agree to participate, you will be asked to sign the included Consent Form.

## VOLUNTARY PARTICIPATION & WITHDRAWAL FROM THE STUDY

Your participation in this study is completely voluntary. You are free to decline this invitation to participate, as well as withdraw from the study at any point without experiencing any disadvantage.

#### WHAT IS THE PURPOSE OF THE STUDY?

The purpose of this study is to investigate how effective APT is as a treatment for adolescents with anorexia nervosa.

APT is an emerging treatment that addresses both physical and psychological aspects of eating disorder recovery. It works collaboratively both with the adolescent and with parent/s, acknowledging the vital role that both parties play in treatment. This study will be the first of its kind to empirically assess APT in an outpatient setting.

## HOW HAS THIS STUDY BEEN DESIGNED?

This is a mixed-methods study that has already involved collecting data from a patient who has undergone APT, as well as from their parents and their treating clinician. We are now interviewing 6

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clinicians who are practising APT, as well as 6 patients and 6 parents. These participants will not necessarily be connected.

### WHAT WILL MY PARTICIPATION INVOLVE?

The researcher will ask you a series of questions using semi-structured interviewing techniques. These questions will encourage you to share your experiences with APT and your perspective on the effectiveness of the treatment. This interview will be conducted via Zoom and will be recorded and transcribed through the software. Transcripts of the interview will be sent back to you so that you can fact-check your answers to the interview questions.

#### WHAT WILL HAPPEN TO MY INFORMATION?

The research team will record your information about your study participation. You will not be identifiable in the study results. Access to data will be limited to the research team, auditors from the HDEC, regulatory bodies, and academic colleagues and researchers with whom we may collaborate in New Zealand and Australia (where APT was first developed). Every effort will be made to ensure that you will not be identifiable in any publications, reports, or presentations that this research may appear in. Any summary interview content, or direct quotations from the interview, that are made available through publication or other academic outlets will be assigned a code number. Any material that could identify you will not be used in any reports on the study. Your information will be stored electronically and shall be password secure and any hard copies stored in a locked filing cabinet. All raw data on which the results of the project depend will be retained in secure storage for ten years, after which they will be destroyed. Your data may also be used in future studies as part of a larger data set either in New Zealand or in Australia.

#### WHAT ARE THE BENEFITS AND RISKS OF PARTICIPATING?

You would be one of the first parents to participate in a research study on APT. The interview questions may also provide a beneficial tool for you to reflect on your child's treatment journey with APT. We do not anticipate any risks in taking part in this study.

### WHO HAS APPROVED THE STUDY?

This study has been reviewed and approved by an independent group of people called the Health and Disability Ethics Committee (HDEC). They ensure that studies meet the required ethical standards of carrying out research. The Central Health and Disability Ethics Committee has approved this study.

## WHO IS DOING THE RESEARCH?

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Holly Sharplin MSc research student Professor Bruce Arroll Head of Department

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School of Population Health, Level 3, Building 507, Park Road, Grafton, Auckland

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## Appendix J: Participant Information Sheet for Clinicians



## PARTICIPANT INFORMATION SHEET FOR CLINICIANS

## FEASIBILITY OF ADOLESCENT AND PARENT TREATMENT (APT) FOR ADOLESCENT ANOREXIA NERVOSA

You have been invited to take part in a study assessing a psychological treatment for adolescents with Anorexia Nervosa.

Please read this information sheet carefully before deciding whether you would like to take part. If you do not wish to take part, this will not affect the care you receive. Thank you for considering the study. If you decide to take part but change your mind later, you are welcome to withdraw from the study at any point.

If you agree to participate, you will be asked to sign the included Consent Form.

### VOLUNTARY PARTICIPATION & WITHDRAWAL FROM THE STUDY

Your participation in this study is completely voluntary. You are free to decline this invitation to participate, as well as withdraw from the study at any point without experiencing any disadvantage.

### WHAT IS THE PURPOSE OF THE STUDY?

The purpose of this study is to investigate how effective APT is as a treatment for adolescents with anorexia nervosa.

APT is an emerging treatment that addresses both physical and psychological aspects of eating disorder recovery. It works collaboratively both with the adolescent and with parent/s, acknowledging the vital role that both parties play in treatment. This study will be the first of its kind to empirically assess APT in an outpatient setting.

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clinicians who are involved in APT, as well as 6 patients and 6 parents. These participants will not necessarily be connected.

## WHAT WILL MY PARTICIPATION INVOLVE?

The researcher will ask you a series of questions using semi-structured interviewing techniques. These questions will encourage you to share your experiences with APT and your perspective on the effectiveness of the treatment. This interview will be conducted via Zoom and will be recorded and transcribed through the software. Transcripts of the interview will be sent back to you so that you can fact-check your answers to the interview questions.

#### WHAT WILL HAPPEN TO MY INFORMATION?

The research team will record your information about your study participation. You will not be identifiable in the study results. Access to data will be limited to the research team, auditors from the HDEC, regulatory bodies, and academic colleagues and researchers with whom we may collaborate in New Zealand and Australia (where APT was first developed). Every effort will be made to ensure that you will not be identifiable in any publications, reports, or presentations that this research may appear in. Any summary interview content, or direct quotations from the interview, that are made available through publication or other academic outlets will be anonymized so that you cannot be identified. Your name shall be kept confidential and instead, you will be assigned a code number. Any material that could identify you will not be used in any reports on the study. Your information will be stored electronically and shall be password secure and any hard copies stored in a locked filing cabinet. All raw data on which the results of the project depend will be retained in secure storage for ten years, after which they will be destroyed. Your data may also be used in future studies as part of a larger data set either in New Zealand or in Australia.

#### WHAT ARE THE BENEFITS AND RISKS OF PARTICIPATING?

You would be one of the first clinicians to participate in a research study on APT. The interview questions may also provide a beneficial tool for you to reflect on your experience practising APT. We do not anticipate any risks in taking part in this study.

#### WHO HAS APPROVED THE STUDY?

This study has been reviewed and approved by an independent group of people called the Health and Disability Ethics Committee (HDEC). They ensure that studies meet the required ethical standards of carrying out research. The Central Health and Disability Ethics Committee has approved this study.

## WHO IS DOING THE RESEARCH?

This study is being conducted by researchers at the University of Auckland. If you have any questions or concerns about the nature of this study, please contact the study researcher Holly Sharplin in the first instance, otherwise the Primary Investigator, Professor Bruce Arroll from the Department of General Practice and Primary Healthcare:

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