Family-based inpatient treatment for adolescent anorexia nervosa: A qualitative study of patients' and family-members' experiences with inpatient care

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Summary

The main aim of this doctoral dissertation was to investigate how patients, parents and siblings experienced family-based inpatient treatment for adolescent anorexia nervosa. Gaining insight into service users' personal and subjective experiences with treatment represents a valuable source of knowledge and helps inform future service delivery. The study reports from an understudied treatment setting and the dissertation should be useful for a) treatment providers working to optimize inpatient care, b) future patients and families, and c) generating new ideas for future research.

Family-based inpatient treatment for adolescent anorexia nervosa is a novel treatment approach designed to better support the whole family during an admission. Throughout treatment, parents, and sometimes siblings, are admitted together with the young person diagnosed with a severe form of anorexia nervosa. Several families receive treatment together. Although there is some research supporting the effectiveness of an inpatient family-based treatment approach, we know less about how service users experience treatment.

Family-based inpatient treatment represents a very complex treatment situation and treatment is reserved for complex and severe cases. Treatment is theoretically and practically informed by outpatient family-based treatment for anorexia nervosa, a manual-based treatment known for prioritizing collaborating with the young person's parents.

Although not adhering strictly to a family-based treatment manual, inpatient staff is guided by five core features that characterize evidence-based outpatient family-based treatment. These features include: 1) the therapists hold an agnostic view of the eating disorder's potential causative factors, 2) the therapists takes on a consultative, non-authoritarian stance during treatment, 3) parents are charged with responsibilities and empowered to bring about changes in meal management and aid recovery, 4) the eating disorder is rhetorically separated from the young person, and "externalized" as a means of alleviating guilt and shame, and to aid collaborations against the eating disorder's influences on the young person's mind and behaviors and the family, and 5) treatment is symptom-focused and predominantly oriented towards the here and now and developing future solutions. By intensifying collaborations with the family during admissions, one generally aims to co-create a treatment situation that enables more lasting change processes, as compared with admitting the young person alone.

The present research took place within a tertiary specialized inpatient eating disorder unit, providing a family-based inpatient treatment approach since 2008. The four original studies comprise part of a larger research project, known as "The Follow-up Study: ED outcome and family members'

experiences 1-7 years after family-based inpatient treatment”. Investigating user experiences involved conducting in-person, semi-structured, post-treatment interviews of former patients, parents and siblings. The research design is largely descriptive, inductive and exploratory. Transcribed interviews for all 61 study participants (N = 37 former patients, N = 14 parents, N = 10 siblings) were analyzed by applying the pragmatic framework known as, Thematic Analysis. Papers 1-3 provide views and perspectives from the position of young persons with lived experience of anorexia nervosa and family-based inpatient treatment, and Paper 4 includes perspectives from parents and siblings of patients.

The first paper explores young patients’ perspectives on taking part in the family-based inpatient treatment program. Four main themes were developed. Results show that taking part in family-based inpatient treatment could be viewed as double-edged, a treatment both “Enabling new ways of understanding and relating,” but also “Enhancing or maintaining negative power dynamics.” Further, findings showed that the event of being admitted, and oscillating between the hospital unit and the home environment during planned leaves represents highly “Vulnerable transitions,” with the potential of both aiding change and nurturing the eating disorder. Findings also captured how the adolescents reflected upon the importance of sibling involvement during admissions, “Sibling relationships and different ways of involvement.”

The second paper explores how young persons with lived experience from a family-based inpatient treatment setting viewed therapeutic aspects related to staff-patient collaborations and staff-related behaviors. It demonstrates how former inpatients prefer treatment to be flexibly tailored and experienced as collaborative. Eight subthemes constituting two main themes were constructed: 1) “There are no ready-made solutions. Staff should facilitate collaboration by tailoring treatment toward the young person’s perspectives” and 2) “Emphasizing skills that matter: Staff should display a non-judgmental stance, educate patients, stimulate motivation, enable activities and prevent iatrogenic effects during the stay.”

The third paper investigates patient perspectives on factors valued as important for the recovery process. A thematic structure entailing three levels were generated. The superordinate theme was “Recovery is a long and winding journey: Recognizing the need for support and highlighting the need for action.” This captured three main themes which emphasized the importance of 1) “Realizing you have a problem,” 2) “Being involved in important relationships,” and 3) “Giving treatment a real chance.” Although participants largely recognized the importance of support from others, including family, friends and health care professionals, the most striking finding in this study was their distinctive emphasis on their own self-responsibility and their own determination to recover.

The fourth paper explores a subsample of eight families, including perspectives from patients, parents and siblings. Five main themes were generated. Results demonstrate that individual family members enter the treatment setting with very different expectations, perceived needs and knowledge about the upcoming admission. Further, we found that most parents and siblings favored interacting with other parents and siblings during the admission, whereas peer interactions were viewed as challenging for the young person with anorexia. We also found variation in perspectives on staff expertise and the structure of the eating disorder unit. Most parents appreciated that the admission facilitated weight gain, and that treatment helped re-establish more normalized meal routines and strengthened parental authority. Both parents and siblings emphasized the benefit of gaining insight into the young person's challenges during treatment. Somewhat concerning was that some of the parents felt treatment could maintain them in a bystander position. This is a stark contrast to the hallmark of family-based treatment, which aims to empower parents. We also found that most participants experienced that treatment strengthened family relationships. Still, some noted the opposite, that treatment enhanced the experience of within-family fragmentation. We also found, aligning with Paper 1, that discharge represented a critical stage. Several questioned the rationale of transitioning back to a treatment setting where treatment had little or no effect in the first place. For most siblings, discharge represented ending treatment for good.

Collectively, this work has several treatment implications. First, results can inform strategies to better engage the entire family during treatment to maximize the benefit of family-based inpatient care. Findings also emphasize the importance of striking a balance between supporting parental empowerment with fostering the young patient's treatment engagement. Importantly, results suggest enhancing pre-admission preparations to facilitate an optimal treatment starting point, tailoring treatment to the clients' unique and individual needs, and ensuring treatment is collaborative. Additionally, findings emphasize the importance of staff cultivating relevant skills and competencies. Lastly, this thesis underscores the need to prevent negative peer dynamics during admissions, and carefully plan discharge to aid sustained improvements.

Abbreviations

AFT: Adolescent Focused Therapy

AN: Anorexia Nervosa

BMI: Body Mass Index

BN: Bulimia Nervosa

CIA: Clinical Impairment Assessment

DBT: Dialectical Behaviour Therapy

ED: Eating Disorder

EDE: Eating Disorder Examination

EDE-Q: Eating Disorder Examination Questionnaire

EDU: Eating Disorder Unit

EFT: Emotion-Focused Therapy

CBT: Cognitive Behavioral Therapy

CBT-E: Cognitive Behavioral Therapy Enhanced

FBT: Family Based Treatment

FBT-AN: Family Based Treatment for Anorexia Nervosa

FT-AN: Family Therapy for Anorexia Nervosa

MFT: Multi Family Therapy

MINI: Mini International Neuropsychiatric Interview

OSFED: Other Specified Feeding or Eating Disorder

PFT: Parent Focused Therapy

RASP: Regional Department for Eating Disorders

RCT: Randomized Controlled Trial

SyFT: Systemic Family Therapy

TA: Thematic Analysis

YP: Young Person

YP-AN: Young Person with Anorexia Nervosa

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Paper 1

Nilsen, J.-V., Hage, T. W., Rø, Ø., Halvorsen, I., & Oddli, H. W. (2019). Family-based inpatient treatment for adolescent anorexia nervosa: a thematic analysis of former patients' post-treatment reflections. *Eat Disord*, 1-18. doi:10.1080/10640266.2019.1656469

Paper 2

Nilsen, J.-V., Hage, T. W., Rø, Ø., Halvorsen, I., & Oddli, H. W. (2019). Minding the adolescent in family-based inpatient treatment for anorexia nervosa: a qualitative study of former inpatients' views on treatment collaboration and staff behaviors. *BMC Psychology, 7*(1), 72. doi:10.1186/s40359-019-0348-2

Paper 3

Nilsen, J.-V., Hage, T. W., Rø, Ø., Halvorsen, I., & Oddli, H. W. (2020). External support and personal agency - young persons' reports on recovery after family-based inpatient treatment for anorexia nervosa: a qualitative descriptive study. *Journal of Eating Disorders, 8*, 18-18. doi:10.1186/s40337-020-00293-5

Paper 4

Nilsen, J.-V., Rø, Ø., Halvorsen, I., Oddli, H. W., & Hage, T. (2021). Family members' reflections upon a family-based inpatient treatment program for adolescent anorexia nervosa: a thematic analysis. *Journal of Eating Disorders*, *9*(1), 7. doi:10.1186/s40337-020-00360-x

Background

First, I provide an overview of the eating disorder (ED) anorexia nervosa (AN) by highlighting research on prevalence, etiology, comorbidity, outcome, and treatment, with a focus on family therapy and family-based treatment (FBT) approaches. The core features of FBT are outlined, which highlights the key tenants of current efforts to strengthen the family therapeutic focus in higher levels of care. After outlining research on emerging research on FBT in higher levels of care, I end the section describing relevant qualitative research.

Anorexia Nervosa

AN is a severe and complex mental illness affecting the young person (YP) and their family in numerous ways (Eisler, 2005; Gilbert et al., 2000). Despite decades of research, the condition is still described as poorly understood (Kaye et al., 2013) and difficult to treat (Halmi, 2013; Strober & Johnson, 2012). Together with significant underweight due to restrictive eating, core features of AN include over-evaluation of weight and shape, combined with an intense fear of weight gain, despite the presence of underweight. Affected individuals often demonstrate a disturbed body image, and dietary restriction and/or other weight-regulating strategies (American Psychiatric Association, 2013; Zipfel et al., 2015). AN symptoms are often of an ego-syntonic nature (Gregertsen et al., 2017) and the person afflicted is often ambivalent toward changing behaviors and/or engaging in treatment (Abbate-Daga et al., 2013; Vitousek et al., 1998). Over time, AN often demonstrates a remarkably persistent hold on the person (Walsh, 2013), leading many to develop an enduring course (Fichter et al., 2017; Keel & Brown, 2010). For a detailed outline of the diagnostic criteria most used in research, see the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association, 2013).

AN is associated with an elevated risk of morbidity and mortality, and in fact, AN has the highest mortality rate among psychiatric illnesses (Arcelus et al., 2011; Herzog et al., 2000; Papadopoulos et al., 2009). Psychiatric comorbidity is common (Ulfvebrand et al., 2015), and AN is linked with severe disturbances in somatic, mental, and social functioning (Agras, 2001; Gowers & Bryant-Waugh, 2004; Halvorsen et al., 2012). AN during childhood can lead to irreversible harm on the person's physical and psychosocial development (Gowers & Bryant-Waugh, 2004), including an elevated risk for osteoporosis (Hartman et al., 2000). AN is also associated with suicidality (Bulik et al., 2008; Pompili et al., 2004) and reduced quality of life (Sy et al., 2013). Together with the many consequences for the individual, AN affects the family and interpersonal relationships in many ways (Gilbert et al., 2000). Further, accommodating behaviors within families are common (Fox & Whittlesea, 2017; Treasure & Schmidt, 2013). Not surprisingly, research has demonstrated high caregiver burden and parental challenges associated with caring for a loved one with AN (Stefanini et al., 2019). Adolescent AN is also associated with health consequences for parents (Anastasiadou et al., 2014; Patel et al., 2014) and siblings (Callio & Gustafsson, 2016; Latzer et al., 2002). Together with multiple health-related consequences, research has shown that AN is associated with high personal and societal costs, both due to direct consequences of expenses associated with health care services, and indirectly, as EDs can lead to substantial costs related to loss of productivity (Stuhldreher et al., 2015). While AN can affect people of all genders, ethnicities, and ages, research has consistently demonstrated that the adolescence represents the most common time of onset (Hoek, 2006). AN therefore usually develops during a vulnerable time period for both the YP and the family (Blum et al., 2014; Holder & Blaustein, 2014).

Prevalence

Accurate estimates of prevalence and incidence are difficult to obtain (Bakalar et al., 2015). Prevalence is usually reported as point prevalence, one-year prevalence and/or a lifetime prevalence, which again impact estimates, with lifetime prevalence producing the highest rates (Smink et al., 2012). Research has estimated a prevalence of AN in adolescent girls of about 0.3% (Hoek, 2006; Smink et al., 2012). Although potentially inaccurate, males account for about 10% of subjects with AN (Smink et al., 2012). A recent study reviewing the literature on AN epidemiology reported that the overall lifetime prevalence could be as high as 4% among females and 0.3% in males (van Eeden et al., 2021). In Norway, researchers estimated that about 50,000 women in the age group 15–44 years may have an ED at any given time. Of these, 2700 were calculated to have AN (Rosenvinge & Götestam, 2002).

Is the incidence increasing? Largely, epidemiological research has demonstrated that AN prevalence is remarkable stable (Hoek, 2006; Smink et al., 2012). Still, recent research has observed a potential trend of increasing incidence in the high-risk group of 15–19-year-old girls. It is not evident whether this reflects a true increase, an earlier detection of AN cases and/or a tendency towards an earlier age at onset (Smink et al., 2012). A recent Norwegian national register study investigating temporal trends in AN incidence found that even though the total number of new cases of ED remained stable (ages 10-49 years) across an 8-year period, there was an increase in AN among females aged 10-14 years (Reas & Rø, 2018).

Etiology

A wide range of risk factors have been implicated in AN. Still, we know less about the associations between risk factors and their specific contributions (Pike et al., 2008). It also remains uncertain if risk is specific to the development of AN or represents a trans-diagnostic risk for all EDs, or if risk is generalized for the development of mental health issues generally (Fairburn et al., 1999; Pike et al., 2008). AN etiology is therefore often described as largely unknown and relatively poorly understood (Kaye et al., 2013; Strober & Johnson, 2012).

AN is multi-determined. As we know AN is multi-determined, it is common to advocate for a biopsychosocial framework when theorizing etiological and maintenance factors (Bakalar et al., 2015; Le Grange, 2016). This integrative framework suggests that risk is complex and intertwined, as any potential risk factor coexist with multiple factors, not easily isolated. While cautiously considering the co-existence of different overlapping and interacting domains, including *biology* (age, gender, genetics, neurobiology, perinatal complications), *psychology* (individual temperament, personality) and the *social worlds* we all inhabit (culture, contexts, relationships), this broad framework can be useful in appreciating and managing complexity. A broad framework can also prevent both researchers and clinicians from making simplistic generalizations of what leads a person to develop AN (Lehman et al., 2017).

What are the most salient risk factors? As being a young female represents the most significant of sociodemographic risks (Lindberg & Hjern, 2003), biological vulnerability, together with gender and age, is clearly implicated. AN is linked with a family history of AN (Bulik et al., 2007; Strober et al., 2000) together with a family history of other mental disorders (Råstam & Gillberg, 1991; Steinhausen et al., 2015). Genetic components are thus frequently associated with AN development (Bulik et al., 2019; Bulik et al., 2007; Slof-Op 't Landt et al., 2005). Through twin studies, the heritability of AN is estimated around 48-74% (Yilmaz et al., 2015). Despite robust indications of genetic underpinnings, the specific neuro-biological-behavioral pathways, and how specific genes are associated with AN development, remains uncertain (Bulik et al., 2019).

How is family relations implicated in risk and theorizing on AN etiology? Past and current risk factor research has investigated the possible role of family dynamics in contributing to the development of EDs. Still, data does not support the assumption that families or specific family relational factors should be viewed as causal (le Grange et al., 2010; Råstam & Gillberg, 1991).

The psychosomatic family – locating pathology in the family system. Psychoanalyst and family therapy pioneer Salvador Minuchin coined the term "psychosomatic family" (Minuchin et al., 1975; Minuchin et al., 1978) to capture the allegedly observed presence of specific family relational dynamics in families of YPs with severe AN. These interpersonal patterns were outlined based on clinical observations, and specific family interactions were theorized as within-family dynamics characterized by either rigidity, enmeshment, over-involvement, and/or conflict avoidance (Minuchin et al., 1975). Thus, Minuchin and colleagues formed working hypotheses of potential causative relationship patterns for AN development within pathological family systems (Minuchin et al., 1978). Questioning *where* the pathology was located, they turned the spotlight toward the family system and the way the family was organized. Their influential reasoning of implicating family dynamics as potentially causative has led to considerable controversy and debate in family therapy and the ED field (Eisler et al., 2015; le Grange et al., 2010).

A shift towards viewing the family system as adapting to the illness. Despite attempts to validate Minuchin's proposed psychosomatic system model, specific causative patterns of within-family dynamics have not been confirmed in empirical research (Eisler et al., 2015; le Grange et al., 2010). The widespread assumption today is that observations of dysfunctional interaction patterns should be understood as a consequence of the family struggling with a multi-determined problem, like AN, without implying that AN is caused by the family system. Vital for this paradigm shift has been the demonstration of equally challenging interpersonal dynamics in families with severe somatic illnesses (Eisler, 2005; Whitney & Eisler, 2005). Hence, dysfunctional family patterns are not unique to families with a member with AN. Contemporary ED literature largely supports the importance of engaging the family in treatment and approaches the family system as a vital part of the solution, rather than being causative (Dodge, 2016).

Although research has failed to empirically demonstrate that certain family dynamics represent specific risk for AN, this does not mean that family relationships have no bearing on the emergence of AN. Nonspecific family factors may play a role, both in the genesis and maintenance of AN (le Grange et al., 2010). The ED literature has especially emphasized the importance of family life in relation to maintaining dynamics, which are essential to target in treatment (Treasure & Schmidt, 2013), including family functioning in general (Mensi et al., 2020; Rowa et al., 2001) and expressed emotions in particular (Rienecke, Accurso, et al., 2016; Szmukler et al., 1985). Another potential domain related to family relational vulnerabilities and the emergence of AN, is how attachment patterns have been associated with EDs (Ringer & Crittenden, 2007). Although insecure attachment seems prevalent in AN (Ramacciotti et al., 2001; Ward et al., 2001), there is not sufficient evidence to precisely describe these associations (Zachrisson & Skårderud, 2010). Interestingly, qualitative research exploring how persons with lived experience with EDs reflect upon causes, have implicated family dysfunction in their subjective and retrospective reflections (Nilsson et al., 2007; Tozzi et al., 2003).

Comorbidity

AN often coincides with other mental disorders, contributing to case complexity and a challenge to treatment (Halmi, 2013; Halmi et al., 1991). Mood disorders and anxiety disorders, including obsessive-compulsive disorder, are the most common comorbid mental disorders for adolescent AN (Herpertz-Dahlmann & Dahmen, 2019; Hughes, 2012). The exact influence of psychiatric comorbidities on treatment and outcome is largely unknown and more research is warranted (Eskild-Jensen et al., 2020; Hughes, 2012). One study concluded that premorbid symptoms of depression are linked with a poorer outcome of AN in the general population (Keski-Rahkonen et al., 2014). Follow-up studies also demonstrates that weight-restored and ED-recovered patients still often meet criteria for at least one psychiatric disorder (Dobrescu et al., 2020; Halvorsen et al., 2017; Löwe et al., 2001).

Complex relationships. The relationships between comorbidity, like depression and anxiety, and AN is complex, and the relative chronology of onset is not well understood (Godart et al., 2015). Although research demonstrates inconsistent findings (Swinbourne & Touyz, 2007), studies have indicated that for many, anxiety disorders precede ED onset (Godart et al., 2000; Hughes, 2012; Kaye et al., 2004). Although depression is predominantly described following AN onset, and often diminishes with weight restoration (Hughes, 2012), research has also shown that mood disorders can predate AN onset (Godart et al., 2015).

Other comorbidities. Other reported comorbidities for AN include autism spectrum disorder (Baron-Cohen et al., 2013; Huke et al., 2013), attention-deficit/hyperactivity-disorder (Bleck et al., 2015), and personality disorders, which are most frequently researched within adult populations (Martinussen et al., 2017), as well as post-traumatic stress disorder (Brewerton, 2007; Tagay et al., 2014).

Outcome

> “Despite decades of research, what we don’t know about remission and recovery from anorexia nervosa could fill libraries” (Bulik, 2021, p. 786).

Although complete recovery from AN is possible, outcome research frequently demonstrates that recovery represents a long and winding road for most persons afflicted (Dobrescu et al., 2020; Steinhausen, 2002). In a recent paper, authors underlined that treatment outcomes in AN are generally modest, with end-of-treatment remission rates ranging from 23 – 33% for adolescents and 0 – 25 % for adults (Murray et al., 2018). Another paper reporting on six randomized controlled trials (RCT) of outpatient FBT for adolescent AN (FBT-AN) demonstrated that remission, stringently defined as weight reaching a minimum of 94% body mass index (BMI) together with scores on Eating Disorder Examination-Questionnaire (EDE-Q) within 1 standard deviation of population means, was found in 22–49% of cases (Lock & Le Grange, 2019). Over time, up to 50% of patients are thought to reach full recovery, with about 30% experiencing substantial improvements, and 20% developing a longstanding course (Steinhausen, 2002; Steinhausen & Weber, 2009). Some studies, however, have suggested that for adolescents who receive recommended evidence-based treatments, the remission rate could be as high as 50-70% (Keel & Brown, 2010; Keel & McCormick, 2010).

Defining recovery. An important consideration related to AN outcome is how we define recovery. Remission and recovery are often used interchangeably in the literature. Recovery is usually viewed as requiring a longer absence of ED-symptoms as compared with remission, which is more frequently used to refer to the relative absence of symptoms at end of treatment. Hence, the latter usually involves a shorter time period (Khalsa et al., 2017). Questioning definitions of remission and recovery in research is important. Several authors have remarked upon the inconsistency in definitions and lack of precise classifications in the outcome literature (Bardone-Cone et al., 2018), and as a result, estimates of recovery and remission are highly contingent upon the criteria applied.

Interestingly, one study showed that by simply changing the criteria for defining a good outcome, estimates of recovery ranged from 57% to 94% for the same population of patients (Couturier & Lock, 2006). A recent study comparing two modes of delivering family therapy for adolescent AN confirmed this tendency. In this study, authors performed a secondary analysis comparing remission rates at the end of treatment using eleven different sets of criteria based on definitions previously applied in family therapy research for adolescent AN. Results demonstrated remission rates ranged from 22% to 88%. Authors warned that using a more lenient definition of remission could result in false inferences concerning the efficacy of family therapy (Le Grange et al., 2019).

Treatment of child and adolescent AN

Therapeutic pluralism

There are many pathways towards a good ED outcome, and clinicians working with adolescent AN can seek out inspiration from different treatment modalities. Although family therapy and FBT approaches are usually recognized as the gold standard or first choice treatment (Rienecke, 2017), there exist different ED-specific, individually-oriented treatment models, based on emerging research to aid clinicians working with YPs with AN (Herpertz-Dahlmann & Salbach-Andrae, 2009). Empirically-supported treatment models include enhanced cognitive behavioral therapy (CBT-E) for AN (Dalle Grave et al., 2016; Dalle Grave et al., 2019), adolescent-focused therapy (AFT) for AN (Fitzpatrick et al., 2010), and dialectical behavior therapy (DBT) adapted for both AN and bulimia nervosa (BN) (Salbach-Andrae et al., 2008). Another development is seen in integrating aspects from emotion-focused therapy (EFT) into FBT for AN (Sala et al., 2016; Strahan et al., 2017). In conjunction to these treatments, non-ED-specific psychotherapy models can also be of high relevance to clinicians. In particular, interventions aiming to enhance clients' motivation and treatment engagement are suggested as potentially fruitful to integrate in ED treatments (Geller, 2002; Vitousek et al., 1998; Ziser et al., 2021). Recently, mentalization-based interventions, originally developed for adult patients with borderline personality disorder, have also been adapted to therapeutic work with EDs (Robinson et al., 2014). Still, empirical research is insufficient to draw conclusions regarding treatment efficacy (Pedersen et al., 2015; Zeeck et al., 2021).

The Norwegian context – A FBT framework is recommended

Clinicians working with adolescent AN in specialized outpatient clinics in Norway are expected to provide YPs and families treatment within a FBT framework. This national strategy of providing FBT as a first-choice treatment mirrors national treatment guidelines (Helsedirektoratet, 2017) and the development of a specific pathway ("Pakkeforløp") for treatment of child- and adolescent EDs (Helsedirektoratet, 2018). The national treatment guidelines do not recommend the provision of a specific treatment manual, as the British manual – often referred to as Maudsley Family Therapy for AN or Family Therapy for Anorexia Nervosa (FT-AN) (Eisler et al., 2016), or the American manualized version of the approach originating from the Maudsley hospital, Family-Based Therapy for AN (FBT-AN) (Lock & Le Grange, 2012). Instead, Norwegian guidelines encourage clinicians to provide a family-based approach specifically tailored for AN as the first-line treatment (Helsedirektoratet, 2017). The two most disseminated FBT models briefly mentioned above are further outlined below.

Family based treatment for adolescent AN

Family therapy, and engaging the family in treatment, has a long and rich history in the treatment of adolescent AN (Eisler et al., 2015). To date, the most researched and disseminated manualized treatment models are the above-mentioned FT-AN (Eisler et al., 2016) and FBT-AN (Lock & Le Grange, 2012). Although there are subtle differences between the manuals, authors seem to agree that they share core features. Throughout this thesis, the acronym FBT refers to family-based treatment in the broadest sense, with FT-AN (Eisler et al., 2016) and FBT-AN (Lock & Le Grange, 2012), referring to the specific manuals most utilized in research. Of note, it is also relevant to mention that there do exist other manualized family therapy models for AN. Such as systemic-family therapy (SyFT) (Agras et al., 2014), parent-focused therapy (PFT) (Hughes et al., 2014), and a not-yet published manual adaptation of FBT-AN tailored to transitional aged youth (Dimitropoulos et al., 2015). In addition, multi-family therapy (MFT) is often used as a supplement to outpatient FBT (Baudinet et al., 2021).

Two leading treatment models sharing a common ground in family therapy and the work at the Maudsley hospital. FT-AN (Eisler et al., 2016), often portrayed as «the Maudsley-model» in the literature, was originally developed by Christopher Dare, Ivan Eisler, Gerald Russell, and George

Szmukler at the Maudsley hospital in London, during the end of the 1970s and beginning of the 1980s. This seminal model inspired most succeeding ED-specific family therapeutic interventions, and has undergone several revisions (Eisler et al., 2016). In the US, James Lock and Daniel Le Grange, who previously worked at the Maudsley hospital from the mid-eighties, manualized the original treatment approach developed at Maudsley in 2001 in order to conduct research. They later revised the manual and named it, “Treatment Manual for Anorexia Nervosa. A Family-Based Approach”(Lock & Le Grange, 2012). This model is abbreviated FBT-AN. FBT-AN is based on several RCTs of family therapy of AN (Lock & Le Grange, 2019). To date, FBT-AN is the treatment model that by far has the largest body of evidence. By 2018, about 75% of adolescents with AN included in RCTs were treated using this manualized version (Lock, 2018).

Generally, FT-AN (Eisler et al., 2016) and FBT-AN (Lock & Le Grange, 2012) represent hybrid treatment models integrating interventions and therapeutic stances recognized by most family therapists or systemic practitioners. These treatment manuals incorporate theories and approaches stemming from various non-ED specific family therapeutic schools, including structural family therapy (Minuchin et al., 1978), strategic family therapy (Madanes, 1991), solution-focused therapy (de Shazer et al., 2007), Milano-systemic therapy (Campbell, 1999), language systemic approaches (Anderson, 1997), and narrative practice (White, 2007). An important difference with FT-AN and FBT-AN, as compared with family therapy in general, is that both models are ED-specific, which means they are ED-symptom focused and developed specifically for alleviating the influence of EDs on both the YP and the family (Eisler et al., 2016; Lock & Le Grange, 2012).

The common core features of a FBT approach

> FBT is a manualized treatment. At its core, FBT empowers parents to directly manage ED behaviors (eg, excessive exercise, dietary restriction, purging, and binge eating) that maintain AN. This treatment includes positioning parents as authorities on their child, with the therapist serving as a consultant around the nuances of AN. Family structures are only modified if they interfere with parental ability to support their child in gaining weight (Forsberg & Lock, 2015, p. 618).

The core features of outpatient FBT represent key therapeutic stances and approaches that guide clinicians – as a road map – during the collaborative work with the YP and the family. As the key features overlap and form an integral whole, they should be viewed as highly intertwined and “engaging with each other.” The order of the features described below does not signify a hierarchy of importance. All the different FBT frameworks share these features in common. This means that they guide and inform clinicians, whether they are working jointly with the family, separately with parents alone, or within a multi-family group format (Baudinet et al., 2021; Eisler et al., 2016; Lock & Le Grange, 2012; Rienecke, 2017).

Externalizing the ED. Advocates of a FBT approach emphasize the usefulness of externalizing the ED when collaborating with the YP and their family. Externalizing in this context means clinicians conceptualize and talk about the ED as something external, as separate from the person (White, 2007). Clinicians therefore underscore that the YP as a person is not the ED, but under the influence of a potentially life-threatening ED. A frequently used metaphor to explain this core feature to families is that it is "as if" the ED has entered in, from the outside, and temporarily possessed the YPs mind and behaviors. This position of rhetorically separating the ED from the person is viewed as especially important to communicate to parents early on in treatment, in order to stimulate their efforts of working goal-oriented and collectively against the EDs influence, and not against their loved one. Clarifying that it is the "anorexia mindset," or anorexia's "way of thinking and behaving," that has temporarily occupied the YPs mind, it becomes clear that the YP needs their parents' support and care more than ever. This is important, as their parents are less directly afflicted or less under the direct control of AN compared to their child.

Externalizing as a strategy is assumed to alleviate blame and guilt and reduce caregiver strain (Eisler et al., 2015). Although externalizing the ED can be a highly useful rhetoric strategy in many instances, this stance or way of talking about AN should be used with caution and wisdom. This is especially the case because externalizing the ED (as some "thing" separate from the YP "as a person") can be quite provocative for many YPs (Voswinkel et al., 2021). From their standpoint, they themselves might be deeply connected to AN, and experience significant benefits of their ED (Voswinkel et al., 2021). From the YPs perspective, clinicians should therefore remain aware that AN can be subjectively experienced as a free choice or even a life savior, a friend or a much-needed coping strategy, that treatment or their parents threaten to take away.

A predominant symptom-focus throughout treatment – attention on the here and now. In brief, this means that conversations and interventions during FBT are predominantly aimed toward breaking symptom behaviors that maintain AN, as mirrored in the quote above (Forsberg & Lock, 2015). Being under the influence of AN, the YP behaves in symptomatic ways, and treatment aims to disrupt these symptom behaviors in supportive ways. From the outset, problem solving reverberates very much around the necessities of supporting parents in managing meals, in order to secure necessary weight gain together with supporting the YP to accept the position held by parents. Interventions are thus aimed at supporting parents to disrupt and manage ED behaviors that have become an obstacle for health and function. From a bird's perspective, FBT is therefore very much oriented toward alleviating AN symptom-behaviors and minimizing the EDs influence on the YP and the family (Eisler, 2005).

Although being collaborative and non-directive is a favored therapeutic stance, as outlined below, the treatment manual serves as a relatively direct normative guide for clinicians (Rienecke & Le Grange, 2022). This is especially reflected in directing therapists to adhere rather strictly to the phased logic embedded in both FBT-AN/FT-AN, and being symptom-focused throughout treatment (Eisler et al., 2016; Lock & Le Grange, 2012).

The therapist as a non-directive consultant. Taking on a non-authoritarian, non-directive consultative stance toward especially the parents, means that although therapists relegates the parents with new responsibilities, they do so without instructing them too clearly on *how* to manage these new responsibilities. This feature emphasizes that although clinicians are experts on EDs, they are not experts on the families' lived experiences. This implies that therapists should not be too prescriptive on how parents choose to make choices on behalf of their child. This is, after all, a parental responsibility important for fostering parental empowerment and decision-making, another core feature of FBT (Forsberg & Lock, 2015).

Thus, parents are given real responsibilities for action while invited to create new health-promoting solutions. Importantly, being too authoritarian or prescriptive could risk conveying an unfortunate message, as if there was one correct way of doing things, for instance, planning for managing a family meal the upcoming weekend. It is assumed this is not the case. The therapist acknowledges there are many potential pathways toward a good outcome and conveys a sense of basic trust that parents can find their specific path. By being trusted with real responsibilities, parents are assumed to better regain and develop their self-efficacy and agency, which is assumed to be reinforced when they master difficult situations with support from their therapist. This stance therefore intends to communicate a deep trust in parents' competency for problem solving, if they are provided with proper education and much needed support. The latter is crucial as most parents facing severe AN feel disempowered and have lost trust in themselves as caregivers (Eisler et al., 2016; Lock & Le Grange, 2012). Thus, they need active support, both emotional and practical.

The non-blaming stance. This aspect of FBT is contrary to what many people in society believe, that families are to blame (le Grange et al., 2010). The non-blaming stance also underscores that AN is not a choice, and no matter how the YP or their parents may feel or think, AN is neither a result of free choice nor bad parenting. Aligning with this reasoning, no one is to blame, except AN itself. This feature conveys that if we reconsider the issue of blame, we should blame chance, bad luck, genetic vulnerabilities, or contemporary society that puts such a great pressure on YPs and families.

Importantly, although parents and the YP are not to blame for the development of AN, this does not mean that parents or the YP do not have to change their behaviors during treatment. On the contrary, much of the symptom-focused therapeutic work during FBT do reverberate around promoting behavioral change (Forsberg & Lock, 2015; Rienecke, 2017). To simplify, treatment is aimed at enabling family members to do more of what works and less of what does not work (Madanes, 1991), in order to alleviate the maintaining influence of AN on family life.

The agnostic, or non-etiological stance. As research has yet to demonstrate the specific etiology of AN, FBT therapists assume a non-etiological stance. Again, this is strategically performed to support the overarching aim of joining resources at developing new solutions, rather than scrutinizing potential causative factors. This might seem paradoxical, as parents often repetitively search for answers to "why did this happen to us and our child?". Importantly, this stance does not mean that therapists are not curious about what parents feel and think. Neither do therapists actively neglect the YPs own ideas or thoughts on etiology. Still, clinicians aligning with the FBT framework are advised to assume etiological uncertainty and refrain from developing or maintaining "thin" explanations of the multiple causative factors that are likely involved. Thus, by working within a FBT framework, it is assumed that it is clinically more useful be transparent and admit that we do not know the cause of AN. Instead of claiming to know, focus is on joining forces toward moving AN out of the family's home environment (Lock & Le Grange, 2019).

Empowering parents to more efficiently care for their child. Relatedly, empowering parents to manage the many challenges and repeatedly difficult situations encountered is a therapeutic core stance throughout treatment. This feature, fostering parental empowerment, is especially predominant in the earliest stages of treatment when treatment is focused upon weight restoration and meal management. Still, as a principle, this core feature guides clinicians throughout the whole treatment process. Empowering parents to take better charge of refeeding and meal management has been hypothesized as a potential mechanism in successful treatment (Dimitropoulos et al., 2017; Loeb & le Grange, 2009) and many of the therapeutic efforts in FBT converges upon facilitating these processes. Thus, from a bird's perspective, this feature has likely contributed to several authors viewing FBT as predominantly parent-oriented (Forsberg & Lock, 2015) with the misunderstanding that the YP is of less importance. This is not necessarily the case. The FBT model is at its heart a family therapeutic approach, and each family member is viewed as equally important. Even siblings are given a supportive role during treatment, although they are not included in the parent's responsibilities of taking care of weight restoration and decision-making around meals (Eisler et al., 2016; Lock & Le Grange, 2012).

Outpatient FBT - Aiming to move treatment through different phases

In real-world practice, treatment is usually not a straightforward process. From the perspective of both FBT-AN (Lock & Le Grange, 2012) and FT-AN (Eisler et al., 2016), treatment progresses ideally through different phases in which the key therapeutic features guide therapists in their conversations with the YP and the family. Both manuals are characterized by an initial emphasis of increasing parental responsibilities, with a gradual transfer of greater responsibility back to the YP, as treatment proceeds. In the final stages, treatment is more oriented around supporting the family while they return to a more normal situation while maintaining the changes achieved, addressing developmental issues, and planning how to end treatment. Although overlapping, each phase is considered to reflect different overarching therapeutic goals (Eisler et al., 2016; Lock & Le Grange, 2012).

In brief, **Phase 1** in FBT-AN is predominantly oriented toward resolving issues around parental meal management, weight gain restoration, breaking behaviors that maintain the ED, and supporting parents in caring for their child, who is going through a very difficult phase characterized by ambivalence and resistance. This phase is therefore highly dependent on available and committed parents and supportive therapists (Lock & Le Grange, 2012). **Phase 2** is viewed as transitional, during which treatment is geared toward supporting parents as they gradually shift responsibilities for meals back to the YP. Still treatment in this phase is very much ED-symptom focused, and navigating this phase involves a very gradual process with continual and active parental support. In general, FBT-AN does not recommend starting Phase 2 before the YP is at 90% of ideal weight (Lock & Le Grange, 2012). With **Phase 3**, there is a greater focus on the YP managing their own meals with less directive support. Additionally, there is an increased emphasis on achieving a healthier identity, together with the family returning to a more normal living situation. In this phase, one also addresses how to prevent the return of AN behaviors as a way of coping when facing challenges in an increasingly autonomous daily life. In this phase, developmental and social issues are usually focused upon, and conversations can revisit themes and issues deliberately postponed in Phases 1 and 2, when weight restoration and meal management were main priorities. Moving beyond Phase 3, it is possible that parents and the YP require further support and therapy, and thus referred, or therapy continues. Based on the high risk of relapse following treatment (Khalsa et al., 2017), it is typically not recommended to prematurely end treatment, although the YP and family may have reached a point where the ED has less influence (Eisler et al., 2016; Lock & Le Grange, 2012).

Transitioning between phases is within this context highly contingent upon how collaborations unfold. Weight restoration, the frequency and intensity of ED behaviors and level of responsibility the YP can handle for meal management are usually markers for transitioning to a new phase. Progress is therefore associated with weight gain and the increased responsibility for meals, together with minimizing other ED behaviors as purging and/or excessive exercise (Forsberg & Lock, 2015). Not surprising, research has shown that transitioning through the FBT phases and moving beyond Phase 1 can become challenging for many YPs and their families (Conti et al., 2017; Lavender, 2020; Lock & Le Grange, 2019; Wufong et al., 2019). “Standard FBT” is usually provided within a year and consists of approximately 20 sessions (Wallis et al., 2018).

What characterizes the evidence base for a family-based treatment approach?

By 2015, 12 randomized trials including different therapy models for adolescent AN had been completed in outpatient treatment settings (Zipfel et al., 2015). In total, these trials included 1060 patients with adolescent AN aged 19 years of age or younger (Lock, 2015). Most of these trials investigated either FBT-AN (Lock & Le Grange, 2012) or FT-AN (Eisler et al., 2016).

An updated review of outpatient psychological treatments for child- and adolescent EDs included studies of family therapy, individual therapy, CBT, interpersonal psychotherapy, cognitive training, and DBT (Lock, 2015). The author, who is one of the leading figures in developing outpatient FBT, concluded that ED-focused FBT, either FBT-AN (Lock & Le Grange, 2012) and/or FT-AN (Eisler et al., 2016) had a well-established evidence base that satisfied review criteria Level 1 (Lock, 2015). Further, the review showed that SyFT (Agras et al., 2014) and AFT (Fitzpatrick et al., 2010), both tailored toward AN, have a probable effect (Level 2). Enhanced CBT (Dalle Grave et al., 2013) and cognitive training (Lock et al., 2013) demonstrated uncertain effect (Level 4, experimental). Findings of this review (Lock, 2015) along with a previous review of RCTs (Keel & Haedt, 2008), are thus reflected in the Norwegian treatment guidelines that recommend an ED-focused FBT approach be provided to children and adolescents with any ED (Helsedirektoratet, 2017).

Furthermore, research has shown improved remission rates at 6- and 12-months follow-up when comparing FBT-AN with individually-oriented AFT (Couturier et al., 2013). Of importance, YPs receiving FBT-AN experience a faster increase in weight and fewer admissions as compared with other treatments (Couturier et al., 2013). The significance of rapid refeeding to facilitate weight gain has also been supported by research showing that a weight gain of > 2.3 kg within four weeks predicts a better outcome (Doyle et al., 2010; Le Grange et al., 2014; Madden et al., 2015). Reassuringly, research has also demonstrated that for those who fail to achieve this amount of weight gain within the first four weeks of therapy can achieve corresponding long-term outcome by intensifying meal support after week four by adding extra sessions targeting parental meal support (Lock et al., 2015).

While both FBT-AN and FT-AN are conjoint treatments, research has also shown promising results even when therapists offer family therapy separately, as in providing separate sessions for parents and adolescents (Eisler et al., 2000; Le Grange et al., 1992). Authors have also demonstrated equally good outcome with PFT, where therapeutic sessions are offered to parents only, while the YP has only brief conversations with staff as compared with standard conjoint FBT-AN (Le Grange et al., 2016). Although research is scarce, authors have also suggested that MFT can be of aid in facilitating better treatment outcomes (Baumas et al., 2021; Gelin et al., 2016). MFT shares many theoretical and therapeutic features with outpatient FBT and is usually provided as an adjunctive intervention. Thus, drawing conclusions about the unique benefits of MFT is methodologically challenging. In a recent review of both qualitative and quantitative studies, authors suggest that MFT may be beneficial in promoting weight gain in underweight patients and in improving ED symptoms. Additionally, participation in MFT is associated with improvements in family factors, although findings are mixed (Baudinet et al., 2021).

Despite its promise, the evidence-base of a FBT approach is under debate. Within the ED field, there is little controversy regarding the importance of involving family, especially parents, in outpatient treatment of adolescent AN (le Grange et al., 2010). Still, the evidence-base of FBT is under some debate. Some have suggested its reputation is overrated (Strober, 2014) and research utilizing different outcome criteria has demonstrated the potential of inflating FBT's promise, if using more lenient criteria as outlined above under "defining recovery" (Le Grange et al., 2019). Some authors have called for a better integration of family-based and individual approaches (Ganci et al., 2021; Medway & Rhodes, 2016). In more recent studies, authors central to developing both FBT-AN and FT-AN also recognize that FBT needs to be further improved, and potentially modified to aid those who do not recover after receiving standard treatment (Lock, 2018; Lock & Le Grange, 2019).

In a recent comprehensive review of 25 treatment trials involving a family therapy approach, authors concluded that the evidence-base for a family-based approach is at best, limited. Further, the authors concluded that although there is some low-quality evidence suggesting a family therapy approach could be more effective compared to "treatment-as-usual" in the short-term, it is not possible to demonstrate the superiority of one type of family therapy over another. Lastly, they emphasized that most studies have a potential risk of bias, which limits the clinical implications of conclusions (Fisher et al., 2019). In sum, this review could be interpreted as shining light on the uncertainties pertaining to the question "what is the best available evidence?" for clinicians working within the adolescent ED field. Based on this review, some have questioned whether to revise treatment guidelines that so clearly advocate a family-therapeutic approach (Woo, 2020). Recent qualitative research exploring the subjective perspectives of persons with a lived experience of FBT, has also shown that FBT is not a treatment modality favored by all YPs and parents. Authors have emphasized that continued investigation of non-successful treatment represents an important understudied area that warrants more research (Conti et al., 2017; Lavender, 2020; Medway & Rhodes, 2016; Wufong et al., 2019).

Another controversial issue regarding the evidence-base of FBT is the inevitably complex relationship between therapist adherence to a specific treatment manual and outcome (Dimitropoulos et al., 2020). To date, research has not demonstrated a very clear or conclusive relationship between manual adherence and outcome in psychotherapy research (Miller & Binder, 2002; Perepletchikova & Kazdin, 2005). In clinical FBT trials, adherence to the manual is required, and therapists typically receive expert supervision to avoid therapist drift from the treatment manual. Recently authors have questioned whether the prevention of drift, which usually is considered important within the context of a RCT involving a manualized approach (Waller & Turner, 2016), is unwarranted. Instead, some have underscored the importance of tailoring treatment to the individual persons, the family, the idiographic symptom presentation, and the uniquely evolving processes during therapeutic encounters (Robertson & Thornton, 2021). Thus, the necessity of strict manual adherence during therapy is questioned, along with *how* adherence to manuals is taught and supervised, as firmly adhering to the manual is no guarantee for a favorable outcome. At large, this line of reasoning indicates the need for greater emphasis on developing clinician's skills in negotiating the therapeutic alliance and a better consideration of common psychotherapy factors in FBT training and supervision (Robertson & Thornton, 2021). Being mindful on balancing the manualized format with a more person-centered and tailored approach could therefore be of importance to enhance outcome when N = 1 (Fruggeri, 2011).

Calling for more efficient treatments within different levels of care

Despite the promise of outpatient FBT, substantial work is needed to improve treatment outcome for all EDs (Treasure et al., 2020). There is also a need to develop a better understanding of what works for whom (Brockmeyer et al., 2017; van Furth et al., 2016) and importantly, to advance treatments across all levels of care (Anderson et al., 2017).

In a recent systematic review of inpatient psychological treatments for child- and adolescent EDs, the authors clearly demonstrated gaps and limitations in our knowledge base (Isserlin et al., 2020). So far, no RCTs have investigated longer-term outcome, and the only conclusion possible to draw from extant research is that most inpatient treatment programs assist in facilitating short-term weight gain (Isserlin et al., 2020). Of relevance for the current thesis, research on the experiences of patients and family members with inpatient treatment is generally lacking. In their review, including 66 studies, the authors concluded that making comparisons between inpatient treatment programs is impossible, due to the vast heterogeneity between studies and the largely low methodological quality of studies (Isserlin et al., 2020). Notably, only three studies used a family-based treatment framework during hospitalization, reflecting the scarcity of inpatient FBT programs. Of these three studies, one was a case study using adjunctive FBT telehealth within an inpatient setting (Goldfield & Boachie, 2003). The second was a case report of a brief family-based intervention during a medical hospitalization (Matthews & Peterson, 2016), and the third was the follow-up study of family-based inpatient treatment upon which this doctoral dissertation was based (Halvorsen et al., 2017).

For intensive day treatments, the state of research is somewhat more promising, especially literature derived from a family-based treatment perspective. A recent scoping review of intensive day treatments for adolescent AN, mostly situated in the US, show that these programs can be a cost-effective alternative to inpatient care, which is promising (Baudinet & Simic, 2021). Two-thirds of 49 studies included in the review reported a family-oriented treatment model. However, research on how the different treatment frameworks influences outcome is still very limited, in addition to little knowledge regarding the subjective perspectives and lived experiences of patients and families.

The long-term benefit of inpatient care is debated

Since adolescents with AN often require inpatient care (Herpertz-Dahlmann, 2021), and given the long history of providing inpatient treatment for AN, it is disturbing that the field is lagging in developing more effective treatment programs (Isserlin et al., 2020). With a peak onset during the adolescence (Nagl et al., 2016), AN often emerges during a vulnerable developmental period for both YPs and their families (Blum et al., 2014; Micali et al., 2013). Hospitalizations can also represent a very challenging event, as the YP is temporarily dislocated from contexts where normal development takes place (Offord et al., 2006). Although likely associated with case severity, research has also shown that hospitalizations are associated with a poorer outcome in the long term (Gowers et al., 2000).

Data to inform clinicians on how to best provide psychological treatment for adolescent AN during inpatient care is limited (Herpertz-Dahlmann, 2021; Isserlin et al., 2020; Vandereycken, 2003). As most inpatient treatment programs predominantly enables short-term weight restoration, rather than improvements in behavioral, psychological, and relational dimensions, it should be no surprise that relapse rates are high, with frequent re-admissions (Khalsa et al., 2017; Strober et al., 1997). Thus, authors have questioned the long-term effectiveness of inpatient admissions (Gowers et al., 2007; Gowers et al., 2000; Meads et al., 2001). Discharge and transitioning between services are known to be challenging for most patients (Lockertsen et al., 2020; Treasure et al., 2005). A recent review of RCTs of aftercare interventions in adult patient populations emphasized that relapse represents a severe problem in AN treatment, and more research is needed in order to develop treatments that better bridge between hospitalizations and outpatient treatments (Giel et al., 2021).

Between the ideal and the real. The ED literature supports the importance of patients and families having easy access to specialized ED treatments at different levels of care (Herpertz-Dahlmann et al., 2021). Researchers advocate the necessity of managing seamless transitions between different levels of care, as this is crucial for relapse-prevention and fostering more lasting change (Anderson et al., 2017; Treasure et al., 2005). Still, the situation for most patients and families is far from the proposed ideal. Evidence-based treatments needs to be better disseminated, accessible, and equitable (Lock & Le Grange, 2019; Loeb & le Grange, 2009). At present, where you live, largely decides which treatment options are available. Even if you and your family live near a specialized eating disorders unit (EDU), access is usually limited and beds are few.

Augmentations of standard outpatient FBT

Efforts to augment standard FBT include MFT (Baudinet et al., 2021), meal training for initial non-responders (Lock et al., 2015), PFT (Hughes et al., 2014), FBT adapted for transition aged youth (Dimitropoulos et al., 2018), integrating FBT with elements from DBT (Salbach-Andrae et al., 2008), attachment-based family therapy (Wagner et al., 2016), and cognitive remediation therapy (Lock et al., 2018), along with variations of internet-assisted FBT (Couturier et al., 2022; Darcy & Lock, 2017). Another way of augmenting family-based treatment for AN, is seen in the efforts of strengthening the family-based treatment approach in higher levels of care.

Strengthening the family therapy focus during admissions. New ways of strengthening the focus on family therapy during hospitalizations have been suggested as a fruitful way of advancing inpatient care (Hoste, 2015; Murray et al., 2015). This line of work has predominantly been informed by emerging evidence favoring outpatient FBT for adolescent AN, as outlined in the current thesis. Thus, efforts to integrate FBT core principles into higher levels of care are justified by the dominant narrative of viewing family therapy and/or FBT “best practice” for adolescents with AN (Derenne, 2019; Hilbert et al., 2017; Lock & Le Grange, 2019).

Yet limited, today we are seeing the efforts of incorporating the core features of outpatient FBT into inpatient treatment programs at different treatment facilities in different countries. Family-based admissions in specialized EDUs, which is a novel way of integrating a FBT approach, is used in Scandinavia at the regional EDU in Oslo (Halvorsen et al., 2017), in Tromsø, and in Stockholm (Fjelkegård et al., 2020) and Lund (Wallin & Holmer, 2021). Outside Scandinavia there are also some examples where treatment services have implemented intensified FBT-informed programs within inpatient care, for example, in the US where researchers have described an intensive one-week program (Marzola et al., 2015; Rockwell et al., 2011) and a family-based partial hospitalization program (Hoste, 2015; Rienecke & Richmond, 2018). FBT-informed admissions are also available in Canada (Spettigue et al., 2019), and in Australia, researchers have reported from an intensive two-week family inpatient program that aligns with outpatient FBT principles (Fink et al., 2017; Wallis et al., 2013).

Dilemmas with incorporating key features of a treatment originating in a very different treatment setting. Research on FBT-informed treatments within higher levels of care is still limited. This work is therefore predominantly based on assumptions and less supported by empirical research. Authors theorizing about the potential of adapting key features of a treatment designed for the outpatient setting have warned of several dilemmas, because an inpatient treatment setting represents a very different treatment context (Hoste, 2015; Murray et al., 2015). Still, authors advocate for the promise of strengthening a family-therapeutic emphasis in higher levels of care, and assume that the core features of outpatient FBT, as outlined above, can be well-suited as a guiding framework within inpatient settings (Halvorsen et al., 2017; Hoste, 2015; Murray et al., 2015; Spettigue et al., 2019).

Research on adapting FBT into higher levels of care settings

Internationally and historically, few specialized treatment facilities have experience with delivering family-based inpatient treatment or FBT-informed inpatient care (Isserlin et al., 2020; Wallin & Holmer, 2021). Whether this is due to culture, economy, theoretical considerations and/or treatment preferences, remains unknown (Vandereycken, 2003). Although few studies exist, the ED literature has shown promising findings from inpatient treatments that aligns with the core features of outpatient FBT. This literature will be briefly summarized below. As this research mainly uses quantitative methods, relevant qualitative research is outlined in a separate section.

In Norway, prior to the follow-up study at RASP (Halvorsen et al., 2017), a larger outcome study of children and adolescents treated for AN was undertaken (Halvorsen et al., 2004). In this study, the YPs were admitted to a medical unit together with their caretakers during their treatment. The multi-disciplinary teams that delivered treatment consisted of experienced family therapists working in ways we today would describe as aligning with the core features of outpatient FBT for AN. The clinical teams responsible for treatment during the stay at the medical unit continued to follow up the families after discharge. In this way, treatment intensity was adapted and provided continuity in therapist-family relationships. The outcome for EDs was very promising in this study, as around 80% of participants had no ED diagnosis at follow up. Of note, considerable time had elapsed from end-of- treatment to follow-up assessments, and despite the high ED remission rates, around 40%

had other psychiatric difficulties at follow-up, indicating relatively high morbidity (Halvorsen et al., 2004).

The RASP follow-up study (Halvorsen et al., 2017) demonstrated that most participants (65%) were weight-restored and 59% no longer met full criteria for any ED at follow up after family-based inpatient treatment. Thirty-six percent of the YPs was defined as fully recovered at follow up, on average 4.5 years post discharge. This was a promising finding, considering the sample consisted of YPs with a relatively long illness duration, and a history of comprehensive treatment prior to the family-based admission (Halvorsen et al., 2017). More details on the RASP follow-up study is provided in the Methods section.

In the US, a one-week intensified family-based treatment program consisting of a blend of Maudsley FBT, systemic family therapy, parent coaching, psychoeducation, and a behavioral contract has been described (Rockwell et al., 2011). Although very brief, authors argue that the program has longstanding implications for those taking part. Marzola and colleagues (Marzola et al., 2015) reported outcome from the same site, and showed that 60.8% of former participants achieved a full remission, while 12.2% demonstrated a poor outcome on average 30 months post discharge from the one-week intensive family-based inpatient treatment program.

Hoste (2015) investigated a partial hospitalization program (PHP) in the US that incorporated core features of outpatient FBT into their intensified PHP treatment program. Hoste underscores that even though outpatient FBT cannot be directly replicated at higher levels of care, the core features can be adapted and implemented. In the paper, the author particularly reflects on the challenges with adapting the consultative or non-authoritative stance within a highly structured treatment setting. Clinicians are advised to be creative within their unique contexts to foster parental agency, the hallmark with any FBT approach (Rienecke, 2017). A three-month follow-up from the same site found improvements or stable scores on all measures of ED-symptoms and depression scores between discharge and follow-up (Rienecke & Richmond, 2018). Findings indicated that improvements within the intensified FBT-adapted PHP could withstand the transition after families step down to less intensive outpatient treatments. This is a promising finding, as the months following discharge represent an especially vulnerable time period for relapse (Khalsa et al., 2017).

At the Center of Eating Disorders in Lund Sweden, a psychiatric inpatient treatment delivered within a general psychiatric hospital was compared to family treatment apartments (FTA) (Wallin & Holmer, 2021). The FTA-model was developed in the 1990s and the ED center in Lund has a long tradition of working intensively with families. Treatment in FTA is based on FT-AN as it was originally developed at the Maudsley hospital (Russell et al., 1987). In FTA, the family is admitted together for up to 8 weeks, with frequent use of home leaves to transfer skills learned in FTA. In FTA, parents provide meal support, in contrast to staff, who provide meal support in the general hospital setting.

This is the most important difference between the two treatment situations. Findings showed that re-admissions due to weight loss within the 6 months following discharge were less frequent for patients treated at the FTA. At 14 years post treatment, however, there were no significant differences in ED symptoms between patients treated at the two treatment settings. Despite this finding, authors suggested that providing families with an intensified, short-term treatment setting like FTA could be more efficient than a longer and more resource demanding inpatient care setting, in which parents are provided with fewer skills in meal management. Still, authors stressed that more research is needed to understand the mechanisms of change in FTA. As the follow-up took place long after the end of treatment, most patients could have had numerous treatments in between, potentially influencing outcome and therefore making sound inferences difficult (Wallin & Holmer, 2021).

Another Scandinavian study compared family-based inpatient treatment at Stockholm's Center for Eating Disorders and an EDU in Copenhagen, Denmark, which does not involve the family in treatment. Fewer readmissions and shorter duration of stays occurred at the family-based EDU in Sweden. Taken together, findings suggest that involving the family actively during hospitalizations appear to make changes more lasting (Fjelkegård et al., 2020).

In Sydney Australia, researchers investigated an intensive 2-week hospitalization program based on FBT core principles. The treatment program seemed to provide families struggling with outpatient FBT a better foundation for restarting or continuing outpatient FBT following discharge. Families treated with the intensified admission were equipped with renewed hope and skills in managing the ED (Fink et al., 2017; Wallis et al., 2013).

In Canada, the feasibility of an inpatient treatment program based on outpatient FBT principles was evaluated (Spettigue et al., 2019). This treatment program overlaps considerably with the treatment program offered at RASP in Oslo (Halvorsen et al., 2017), except parents in the Canadian program stayed at home overnight or at a nearby facility, close to the hospital, as compared with RASP/Oslo, where parents have their own family room at the EDU. Improvements in ED symptoms were observed, as well as weight gain and short-term medical and psychological improvements. Findings supported the feasibility of an intensified and adapted FBT program for the inpatient care setting (Spettigue et al., 2019).

Matthews and co-authors (2019) reported outcome from an intensified FBT intervention, where the YPs with AN where hospitalized for medical complications. Findings showed significantly higher weight gain for admissions following the introduction of the new adapted inpatient FBT program, when compared to the original treatment program (Matthews et al., 2019).

In another study, authors described integrating FBT principles into acute inpatient care of adolescents with restrictive EDs at the Boston Children Hospital (Freizinger et al., 2021). Authors outlined the promise of integrating FBT into their treatment program at the medical inpatient unit, as well as describing common challenges with charging parents with increased responsibilities for meal management. Parents typically preferred the treatment team assume responsibility for decision-making and felt anxious about acting in ways that upset their child. Still, authors emphasized that providing parents with intensified support can foster both parental empowerment and instill renewed trust that they were capable of aiding their child towards recovery (Freizinger et al., 2021).

In summary, it is important to highlight that although outpatient FBT has the largest body of evidence (Lock & Le Grange, 2019) and remains the most widely recommended treatment approach for adolescent AN (Hilbert et al., 2017), the family is often not actively engaged in treatments provided at higher levels of care. This is demonstrated in recent reviews of intensified day treatments (Baudinet & Simic, 2021) and inpatient care (Isserlin et al., 2020). Although efforts to strengthen the family-based treatment approach during hospitalization are developing, and usually highly recommended by authors (Halvorsen et al., 2017; Spettigue et al., 2019), research and knowledge is still scarce (Isserlin et al., 2020). Qualitative research of treatment experiences of patients and families within higher level of care settings is even more absent. Research-based knowledge of *how to* optimize inpatient care is thus very limited, which is paradoxical, given that treatment in higher levels of care settings is undoubtedly the most resource demanding of treatments available for EDs. In the US, researchers have estimated the average cost of inpatient ED treatment to be $2267 USD per day (Marzola et al., 2021). As such, we seem to know the least, as viewed from a research-based position, from treatment settings where we tend to utilize the most resources, both human and financial.

Qualitative research - foregrounding subjective meaning and lived experience

Overall, qualitative ED research serves the potential of contributing nuanced insights into subjective meaning-making and lived experience, moving beyond what is possible to obtain by applying quantitative measures. By applying qualitative methods, studies therefore inform and widen our understanding of how different persons perceive and understand different phenomena. Results can both aid treatment development and ultimately contribute to enhancing outcomes (Bezance & Holliday, 2013; Espíndola & Blay, 2009; Medway & Rhodes, 2016; Westwood & Kendal, 2012). Within the ED field, qualitative research has usually investigated treatment experiences from the position of the patient, family members, or health care professionals, with patient perspectives being the most represented in the literature (Gustafsson et al., 2021). Although qualitative research can utilize multiple data sources, most analyze transcripts from personal interviews or data from focus groups.

Scarcity of qualitative research on FBT-informed treatments in higher levels of care

Although qualitative research in the ED field has explored a wide range of topics, research investigating service users' experiences with family-based inpatient treatment or FBT inspired treatments in higher levels of care is generally lacking. This knowledge gap signifies an important backdrop for the current thesis.

In Norway, there exist two master theses reporting qualitative findings emerging from family-based treatment settings in higher levels of care. One is an interview study of participants previously admitted with their parents in a medical child unit during treatment (Andersen, 2008). In this study, the main aim was not to investigate treatment experiences. Rather, the aim was to contribute knowledge of how young adult women with a lived experience of AN described their journey with an ED from adolescence into young adulthood. The other master's thesis investigated a subsample of parents who participated in the follow-up study at RASP (Voldnes, 2017). The treatment program is further outlined in the Methods section. This thesis conducted seven semi-structured interviews of 14 parents following treatment, and the main aim was to explore parents' experiences with taking part in treatment. Main findings demonstrated that being involved in treatment was crucial for feeling safe, important for feeling supported in their role as caregivers, and important for understanding more about the ED and how to cope. Findings also revealed that parents called for more information and knowledge of EDs, both during the admission and from their local treatment facilities (Voldnes, 2017).

To my knowledge, only two qualitative studies exist that explore user experiences with FBT-informed treatments in higher levels of care besides these two master theses from two different Norwegian intensified treatment settings. The first involves a brief, two-week family admission program (FAP), located in Sidney, Australia (Fink et al., 2017), and the second study is situated within a pediatric tertiary treatment setting in Canada. The latter (Coelho et al., 2021) is briefly described below under the subheading "parent perspectives".

The FAP in Australia represents a two-week treatment program, during which families are admitted for intensified, adapted inpatient FBT. One of the main aims of the FAP is to offer families struggling to achieve progress in standard outpatient FBT an intensified treatment program, in order to maximize the benefit of further outpatient FBT following discharge (Fink et al., 2017). In a different paper, the brief FAP is also described as a step-down intervention from regular inpatient treatment (Wallis et al., 2013). The qualitative study, which includes 10 families, report that the brief intensified FAP seem to be of aid in equipping families with enhanced skills, strengthening family relationships, and largely provides families with a new and reunited vantage point for further outpatient FBT (Fink et al., 2017).

Qualitative research, beyond FBT-informed treatments in higher levels of care

Looking past research on FBT-informed treatments in higher levels of care, the ED literature contains numerous studies applying qualitative methods with relevant knowledge to broaden our understanding of several salient topics. For my thesis, I have drawn inspiration from qualitative research covering issues including: a) *being affected by, or living with AN* (Espíndola & Blay, 2009; Malson, 1999; Tierney & Fox, 2010), b*) service users' experiences of being engaged in different treatments in different levels of care* (Bezance & Holliday, 2013; Medway & Rhodes, 2016; Westwood & Kendal, 2012), and c) *user perspectives on the recovery process* (Fogarty & Ramjan, 2016; Hay & Cho, 2013; Hsu et al., 1992; Musolino et al., 2016; Nilsson & Hagglof, 2006).

Of interest, a recent meta-review of 17 qualitative systematic reviews representing 255 studies was published. Predominantly female study participants with AN were included in the original studies. In their meta-review, studies included 1) persons with a lived experience of EDs, 2) caregivers, and 3) health care professionals. Thirteen of the reviews reported on patients' perspectives, five on family members' opinions, and three on health care professionals' views. The thematic analysis, which included 13 of the 17 systematic reviews initially reviewed, captured three overarching themes, 1) *being in control or being controlled*, 2) *balancing physical recovery and psychological needs*, and 3) *trusting relationships* (Gustafsson et al., 2021). These overarching domains, capturing numerous service user's experiences, represent especially salient themes reverberating with many original studies. Adjacent to interpreting and reporting these highly condensed themes, the authors reflected two important tendencies. Namely, that health care professionals seem to value *the biomedical model*, a model underscoring the importance of physical recovery, as especially helpful and significant, whereas persons with a lived experience and their caregivers tends to call for a better *individualized and holistic treatment approach* (Gustafsson et al., 2021).

Three other reviews were especially important as background for the current thesis. These studies reviewed qualitative research of YPs' lived experiences with EDs, treatment, and perspectives on the recovery process (Bezance & Holliday, 2013; Espíndola & Blay, 2009; Westwood & Kendal, 2012). Together with these, another review of high importance reviewed adolescents' experiences with different forms of outpatient family therapy interventions (Medway & Rhodes, 2016). These reviews were included in the above-mentioned meta-review, except the one by Westwood and Kendall (Westwood & Kendal, 2012). The latter reviewed literature (N=11) on adolescent perspectives on different AN treatments. Findings largely resonated with the overarching themes captured in the meta-review (Gustafsson et al., 2021). Three core themes were identified by Westwood and Kendall (2012), including 1) aspects related to control, as AN can both be experienced as a means of gaining control, as well as taking control over the person, 2) the tension and/or dynamics between the physical and psychological domains during treatment, as YPs largely hold a preference for psychological interventions versus experiencing treatment providers' prioritizing the physical dimensions during treatment, and 3) aspects related to the therapeutic alliance that can both benefit and hinder treatment collaborations (Westwood & Kendal, 2012).

Espindola and Blay (2009) performed a meta-synthesis of 24 studies that investigated patients' understanding of their ED, experiences with treatment, and perspectives on recovery. Of particular importance was the experiential dimensions of being affected by an ED, with identity and control as predominant aspects. The meta-analysis also explored how the ED was understood, and how the ED affected daily lives (Espíndola & Blay, 2009). Bezance and Holliday's (2013) meta-synthesis included a re-examination of 11 studies. New core themes were identified through performing a thematic synthesis, and the following overarching themes included a focus on the role of family, peers, and professionals, family therapy, the inpatient setting, and the dichotomy between the physical versus psychological, and conceptualizations of recovery (Bezance & Holliday, 2013).

Particularly relevant, some qualitative research from outpatient treatment settings illustrates adolescents' experiences of family-based interventions for AN. In their review, Medway and Rhodes (2016) included 15 original studies. Three of the original studies focused on user experiences after taking part in a manualized FBT approach (Medway & Rhodes, 2016). Common for the included studies was a focus on the YP and not parents and siblings. The meta-synthesis grouped findings thematically in four key conceptual themes. These included, the YPs ambivalence concerning giving away control during treatment (1). The YPs perspectives reflecting treatment to improve family relationships (2). The YPs views of treatment failing to address underlying issues contributing to the development of AN and/or issues other than the ED, together with the perceived need for an individualized approach (3). Lastly, the YPs perspectives on treatment failing to address certain central family issues, as treatment predominantly addressed surface issues, together with a lack of family engagement and sibling involvement (4). Authors concluded their analyses largely mirrored quantitative research favoring a FBT approach, as well as identifying areas for further treatment improvements when working within a predominant family-based framework. These included addressing different underlying family and individual issues. Authors also stressed that their review identified methodological weaknesses of this literature, which again leaves uncertainties about drawing conclusions in the meta-synthesis (Medway & Rhodes, 2016).

Parent perspectives. At large, parents want to be engaged in treatment and enjoy tailored support, as most parents seem to prefer a holistic and individualized treatment approach (Gustafsson et al., 2021; Herpertz-Dahlmann, 2021). Research investigating parents' experiences of caring for a child with AN, demonstrates high parental self-blame, prevalent feelings of helplessness and social isolation, and elevated emotional and cognitive distress (Fox et al., 2017; Whitney et al., 2005). Accommodating behaviors have been well documented (Goddard et al., 2013; Rhind et al., 2016), as one study vividly reported, a common parental feeling is "…having to tread on eggshells and constantly be vigilant of controlling their own emotional responses to the patient for sheer terror of being met by refusal to eat" (Kyriacou et al., 2009, p. 848).

A recent study explored parental perspectives on their child's ED treatment at a tertiary level of care setting at the time of discharge. Authors constructed five high-level concepts based on their inductive analysis: 1) experience of delays in identifying ED symptoms, 2) challenges with accessing ED services, 3) the right treatment at the right time, 4) emotional impact on parents, and 5) parental expertise and involvement (Coelho et al., 2021). Besides suggesting the importance of early detection and intervention, authors underscore the importance of managing transitions between levels of care and the importance of competent decision making to ensure that YPs receive the most appropriate treatment based on their clinical presentation and needs. The study also aligns with previous research demonstrating high caregiver burden (Stefanini et al., 2019) and that parents largely want to be involved in treatment (Herpertz-Dahlmann, 2021).

Qualitative research has also shown that parents receiving additional parent-to-parent counselling empowered them as caregivers, prevented social isolation and opened a reflexive space for reviewing within-family dynamics (Rhodes et al., 2009). This aligns with parental perspectives after taking part in MFT, demonstrating that parents engaging with other parents and families can be of great support and give rise to new perspectives and insights (Engman-Bredvik et al., 2016).

Sibling perspectives. Siblings of children and adolescents with long-standing illnesses have been found to be at risk for poorer mental health (Vermaes et al., 2012). Limited research exists on how a severe case of AN affects the non-affected sibling or how siblings perceive various aspects with AN treatment. Still, the experience of enhanced family conflict, higher levels of depression, poorer quality of life, psychosocial difficulties, support needs and complications within sibling relationships have been demonstrated in AN (Jungbauer et al., 2016; Latzer et al., 2002; Latzer et al., 2013; van Langenberg et al., 2016). One study demonstrated that siblings often experience their role as protector and/or mediator within the family, and that living with a sibling with AN is associated with considerable emotional distress, as well as more beneficial aspects (Dimitropoulos et al., 2009).

The latter was demonstrated in a recent study showing that although the burden, distress and need for support can be high, siblings living with AN can experience increased knowledge and insight, thus enhancing personal development (Fjermestad et al., 2020).

Siblings have reported that being involved in treatment can improve their understanding of AN, and research demonstrates siblings are supportive of the YP and the family in many ways (van Langenberg et al., 2018). Still, even though outpatient FBT encourages sibling involvement, siblings often attend at a relatively low rate (Hughes et al., 2018). Collectively, literature pertaining to siblings of YP-AN point toward the importance of finding new ways to better improve siblings' involvement and support during treatment (Fjermestad et al., 2020; Jungbauer et al., 2016; van Langenberg et al., 2018).

To sum up, qualitative research investigating patients' and caregivers' treatment experiences have, 1) broadened our understanding of the importance of experiencing control in both living with, and recovering from an ED, 2) enhanced our knowledge of the significance of balancing physical and psychological aspects during treatment, and, 3) shed light on important factors related to the therapeutic alliance. Together with these very broad overarching themes of control, balancing treatment, and aspects with negotiating the alliance, qualitative research has largely demonstrated that YPs-AN and parents seem to prefer treatment being individually adapted and holistic (Gustafsson et al., 2021; Mitrofan et al., 2019; Sibeoni et al., 2020).

Aim of the study

The main aim of this doctoral dissertation is to investigate how patients, parents, and siblings experience family-based inpatient treatment for adolescent AN. Gaining insight into service users' personal experiences with treatment represents a valuable source of knowledge and helps inform future service delivery.

The dissertation takes as a vantage point that,

a) although clinicians working within higher levels of care settings can seek guidance from different treatment modalities, outpatient FBT is the highly recommended treatment approach when a YP has developed AN, and outpatient FBT has the largest body of evidence,

b) clinicians in higher levels of care settings are recommended to better align inpatient care with the core therapeutic features that characterize evidence-based outpatient FBT,

c) there remains limited empirical research to guide clinicians in these efforts,

d) investigating service users' "insider perspectives" from a treatment setting informed by outpatient FBT represents a valuable source of knowledge to supplement and extend the scope of emerging quantitative outcome research,

e) knowledge of service users' subjective experiences with family-based inpatient treatment is lacking.

Theme and aim of the first paper

Strengthening the family-therapeutic focus into higher levels of care has been proposed as promising for those who fail to respond to outpatient treatment. With this study, we aimed to investigate broadly how former adolescent inpatients experienced the family-based inpatient treatment program for adolescent anorexia nervosa.

> To systematically investigate former adolescent inpatients experiences with taking part in a family-based inpatient treatment program.

Theme and aim of the second paper

With this study, we aimed to better understand how young persons with lived experience from a family-based inpatient treatment setting viewed therapeutic aspects related to staff-patient collaboration and staff-related behaviors.

> To systematically investigate how young persons with lived experience from a family-based inpatient treatment experience collaboration with staff, and which staff behavior and skills are valued important.

Theme and aim of the third paper

With this study, we aimed to investigate the perspectives of young persons with a lived experience of AN on factors related to the recovery process. The study focuses on how the perspectives of YPs with lived experience with AN can provide important knowledge about how to improve and better tailor family-based treatment.

> To systematically investigate which factors young persons with lived experience from a family-based inpatient treatment at a specialized eating disorder unit report as important for recovery.

Theme and aim of fourth paper

With this study, we aimed to extend prior research utilizing the young patients' perspectives by applying a multi-perspectival approach while including parents, siblings, and former patients in the same analysis. The overarching aim was to investigate family members' perspectives following a family-based inpatient treatment program for adolescent anorexia nervosa and to discuss clinical implications for treatment providers.

> To systematically investigate the multiple user perspectives within a family (parents, siblings and patients) following admission to a family-based inpatient treatment program at a specialized EDU for adolescents with AN.

Material and methods

This thesis forms part of a larger naturalistic research project, “The Follow-up Study – ED Outcome and Family Members’ Experiences 1-7 Years after Family-Based Inpatient Treatment”. From the outset, the follow-up study aimed to investigate different aspects related to family-based inpatient treatment for adolescent AN by employing both quantitative and qualitative methods. Thus far, different sub-studies have reported on ED outcomes (Halvorsen et al., 2017), physical restraint during inpatient treatment of adolescent AN (Blikshavn et al., 2020) treatment satisfaction (Halvorsen & Ro, 2019), siblings’ perspectives on living with a sibling with AN (Fjermestad et al., 2020), and the subjective experiences of YPs and family members following family-based inpatient treatment. The latter encompasses the original research for this thesis (Nilsen et al., 2019a, 2019b, 2020; Nilsen et al., 2021). In addition, one master’s thesis on parental experiences with family-based inpatient treatment has been conducted (Voldnes, 2017).

In the following section, I first present the dissertation’s research design, before describing perspectives on sampling procedures and reflecting upon the decisions faced in the different sub-studies. Next, I reflect ethical considerations, describe the research participants and outline the inpatient treatment program. Finally, I summarize the methods used, including reflecting on saturation, safeguarding quality – together with an extended account of researcher reflexivity. Although some authors prefer to include a specific *methodological considerations* section in the discussion section, I have chosen to include relevant considerations regarding methodological decision-making as the story unfolds throughout the methods section. This choice mirrors my wish to preserve textual coherence.

Research design

This qualitative research project is characterized by a predominantly descriptive research design (Creswell & Poth, 2018; Magilvy & Thomas, 2009). A descriptive design is often valued when the research topic echoes an understudied area, and when the aim is to provide nuanced descriptions of similarities and differences in subjective experience and meaning, as compared to generating theoretical or conceptual insights (Doyle et al., 2020). Choosing a predominantly descriptive design enables different possibilities for analyzing interview data. As reported in the individual papers, a version of thematic analysis (TA) has been the guiding analytic framework in this thesis. This particular approach to TA was originally developed by Braun and Clarke (Braun & Clarke, 2006) and further developed in consecutive papers (Braun & Clarke, 2019, 2021a, 2022).

TA is often misconstrued as a solely descriptive approach (Braun & Clarke, 2021b). Aligning with the authors, I too prefer refraining from viewing description and interpretation as “positioned as separate and distinct activities" (Braun & Clarke, 2021b, p. 339). For me, this wider view resonates with my preferred analytic stance, and is why I portray the research design as *predominantly* descriptive. While analyzing interview data within a principally descriptive research design, I thus acknowledge that I inevitably use my own subjectivity, creativity, and interpretive skills. I therefore recognize that even though my main aim is to "give voice" to – as *describing* – the service users unique subjective views, positions and meaning, without too much interpretation, I ultimately tell *my story* about data.

Sample procedure and recruiting participants to take part

All patients and family members taking part in family-based inpatient treatment at the adolescent EDU between May of 2008 and June 2014 were asked to participate in the follow-up study. Data collection was completed in 2015. Originally, it was estimated that about 55 patients, 90 parents and 40 siblings were eligible for participation. Parents and/or stepparents were invited. Siblings who were at least six years old during the admission and older than eight years at follow up were also invited to take part in the follow up interview. Another criterion for siblings was that they were engaged in treatment during the admission. Family members who only took part in occasional conversations at the EDU, but who were not admitted, were not included in the study.

Eligible participants were sent an information letter (see appendix for details) and consent form with a decline option. This letter was sent with a prepaid envelope to return to the EDU. If no response was received, one of the team members followed up by telephone to ensure information was received, and addressed questions or concerns. Patients and family members who consented received a questionnaire by mail about one week prior to the in-person interviews. Siblings above the age of twelve were also asked to fill out a questionnaire. The questionnaires were administered to gather information for use in quantitative studies. Patients and siblings were interviewed individually. Most of the parents were interviewed as a couple. Information received from one family member was not disclosed to other family members. Details on participants and interviews are found below.

Decision-making concerning sample procedures and the development of the 4 different sub-studies – A dynamic and gradually developing process

Determining sample sizes for the different studies has been a dynamic and gradually evolving process, which often is the case in qualitative research (Levitt et al., 2018). Different sampling strategies were considered prior to deciding to include all available participants (N = 37) in Papers 1-3 and the eight complete families in Paper 4. It was first after I had spent considerable time immersing in the whole data set that the contours of the different sub-studies became clearer. Interestingly, the review process also influenced this decision-making, after submitting a first draft of Paper 1. Here, valuable feedback from the reviewers facilitated discussions within the research team. This process ultimately guided the decision of separating one – at the time, a very complex study – into two separate sub-studies (Paper 1 and 2). During this process, the idea of conceptualizing Paper 3 as a distinct original project with unique aims and research questions gradually developed. Thus, the work of developing, framing and conducting the different sub-studies was less of a straight-forward process, than reading the individual papers might give an impression of (Braun & Clarke, 2019).

The original plan for Paper 4 was outlined at the outset. Still, the actual work with this sub-study was only initiated once Papers 1-3 were conducted by utilizing interview data from the YPs. From the beginning, I wanted to include a project investigating user feedback from a family system approach, mirroring what eventually became the multi-perspective analysis in Paper 4. This study was also characterized by initially trying out different sample strategies, including a different analytic framework as reported in the paper. Here too, the decision was made to include a complete data set utilizing all available families in the data corpus. As for the other papers, this was a choice driven by the wish to maximize diversity in lived experience and perspectives on treatment. The analytic framework TA (Braun & Clarke, 2006) also informed my choice to maximize diversity by including all available participants. TA is particularly suitable when the aim is to capture breadth and diversity in identifying themes across cases in relatively large samples, and when the aim is to generate meaningful knowledge with clear implications for practice (Braun & Clarke, 2021a). TA is also viewed suitable when data are collected independent from the analytic development, which also resonates with the current research (Braun & Clarke, 2021a, p. 43). TA is further outlined below.

Ethical considerations

The study was approved by the regional ethics committee (REK2014/2223). Participation required written informed consent. One participant was under 16 years at follow up, and consent was obtained by parents, along with assent from the YP. This aligns with Norwegian legislation that states YPs between 16 and 18 years are legally able to provide consent themselves if research does not involve surgical procedures and/or medication. All participants were informed that if their participation indicated the need for additional health or mental health services, interviewers would provide advice on how to reach out to relevant services, and even offer a written referral if needed. Participants were also assured that if study participation triggered concerns or difficulties during interviews, the project leader or one of the team members would schedule an appointment to accommodate individual needs.

During recruitment, participants were assured that participation was voluntary and choosing not to take part or withdrawing the consent at any time would not influence future assistance from the EDU. Still, the chance of participants feeling pressured to take part cannot be ruled out. However, we believe communication during the process of recruiting participants had little negative impact on the current study. At the outset, the research team determined there were no serious ethical dilemmas in asking former patients and family members about their current situation and experiences with prior treatment, if we safeguarded the above-mentioned issues. Trusting that the interview situation posed minimal threat to the person's well-being and integrity was aided by the project leader's prior experience with a similar follow-up project (Halvorsen et al., 2004). Here, participants largely appreciated the opportunity to talk about their current situation and share prior treatment experiences. Relevant ethical and methodological considerations are discussed in the individual papers' limitation sections.

One other ethical consideration, briefly touched upon in Paper 4, is that we did not provide participants with the opportunity to give feedback on their participation, beyond inviting informal feedback at the end of each individual interview sessions. In other words, we did not ask for user feedback during the process of data analysis and writing up the different papers. Together with potential methodological issues, this is important ethically, as participants may have felt misinterpreted or misunderstood, without the opportunity to provide further feedback and/or make corrections of potential misunderstandings. Although anecdotally, on occasions, I have had informal conversations about the research project with some of the study participants, in addition to sharing findings with persons with lived experience in formal settings. Without exception, these conversations have resonated with participants, and others, recognizing this research as highly relevant and importantly, meaningful. In general, findings shared have reverberated with their own views and experiences. Still, having had the chance to start all over, this is one of the issues I probably would have preferred to solve in a different manner.

Participants in Papers 1, 2 and 3

As participants in Papers 1, 2 and 3 utilized the same subset of participants, they are described together in the first section. The next section is reserved for participants in Paper 4. Since the eight YP-AN included in Paper 4 are also included in the first three studies, the section below focuses predominantly on parents and siblings. Approximately three-quarters of the participants had at least one inpatient admission at their local hospital prior to their admission to RASP, and some of the participants had more than one previous inpatient admission.

All former patients (N = 57) who received inpatient family-based treatment for AN during the period May 2008 – June 2014 were successfully contacted. Sixty-five per cent, 33 females and 4 males consented to participate in the study. Of importance, there were no significant differences between the 37 participants and 20 non-participants, on demographic or clinical variables during the admission (Halvorsen et al., 2017). One patient dropped out from treatment. This was a non-participant. In the event that a participant had more than one admission to the EDU, the focus of the follow-up interview was the initial family-based admission. The inpatient admission was based on parental consent for all of the patients under 16 years of age (N = 19), while 14 (78%) of the patients over 16 years were treated voluntarily and four (22%) compulsory. Duration of ED prior to the admission was on average 2.7 years (range; 0.5–6.0, *SD* = 1.8), and the mean age at admission was 15.8 years (range; 12.4–19.5, *SD* = 1.8). Length of stay was on average 20.8 weeks (range; 3–58, *SD* = 13.5), including planned leaves from the ward, which was an important part of treatment. None of the participants dropped out of treatment. The mean number of years from discharge to the follow-up interview was 4.5 years (range; 1.3–7.0, *SD* = 1.7). The mean age at follow-up was 20.2 years (range; 15.8–25.3, *SD* = 2.6). Sixty-two percent (N = 23) reported they had experienced no hospitalizations after the family-based admission. Thirty-eight percent (N = 14) had received additional inpatient treatment during the follow-up period, either at the EDU or elsewhere.

Recovery status at follow up. There was no mortality at follow up. Body mass index (BMI, kg/m2) at follow-up was either measured at the follow-up interview (N = 16), or was based on self-reported weight and height. BMI percentiles for age and sex were calculated using a Norwegian version of a weight-for-height ratio calculator based on reference data from Child Growth Foundation, United Kingdom (Cole et al., 1995). Based upon data from the outcome study by Halvorsen and colleagues (2017), we know that the majority of participants (65%) had achieved normal body weight at the time of the follow-up interviews (Halvorsen et al., 2017). The authors had defined “weight recovered” as reaching BMI ≥ 18.5. “Fully recovered” was defined as normalized eating attitudes and behaviors as indicated by a EDE-Q global score ≤ 2.5, plus no episodes of binge eating or purging/other compensatory behaviors over the last three months, in addition to BMI ≥ 18.5. There were 36% of participants classified as “fully recovered” (i.e., BMI ≥ 18.5, EDE-Q global score ≤ 2.5, and no binge eating/purging behaviors the last 3 months). The mean EDE-Q global score for the total group was 2.2 (±1.5) and the mean scores on the Clinical Impairment Assessment (CIA; Bohn et al., 2008) was 15.9 (±11.7). With reference to the CIA, a clinical threshold of < 16.0 has been consistently found to optimally distinguish caseness based on ED-related impairment (Bohn et al., 2008; Reas et al., 2016). Using the diagnostic items of the Eating Disorder Examination 16.0 interview (EDE; Fairburn et al., 2008), 59% percent (N = 22) no longer met full DSM-V criteria for any ED at follow-up, 22% met criteria for AN (N = 8), 5% for BN (N = 2), and 14% (N = 5) unspecified ED, or DSM-5 other specified feeding or eating disorder (OSFED). Forty-three percent (N = 16) had one or more comorbid psychiatric diagnoses at follow up, as assessed by The Mini International Neuropsychiatric Interview version 6.0 (MINI; Sheehan et al., 1998). All except four participants had received further ED treatment following discharge, and 14 (38%) of the participants had been re-hospitalized, including seven cases with more than one readmission.

On function. Although the data are limited, 25 (68%) participants were students at follow up, seven of the participants were employed (4 in skilled work, 3 in unskilled work), and five reported no current work or studies due to their current health problems. During the last month prior to the follow-up interview, 19 (51%) of the participants reported they were working or studying full time, and nine (24%) part-time, which indicates that more than 50 % were engaged in work or studies, as self-reported.

On progress during the admission. Regarding changes in psychological functioning or other parameters during treatment, data is only available for weight gain. Weight gain increased, on average 7.6 kg (± 4.3 kg) during admission, and the mean BMI-percentile at discharge (21.4 ± 17.8) was in the normal range (i.e., >12, which corresponds to approximately BMI 18.5 in adults) (Halvorsen et al., 2017).

Participants in paper 4

Eight former inpatients and their family members were included in this sub-study (8 former patients, 14 parents, and 10 siblings). This subsample was purposively derived from the complete data set of thirty-seven inpatients. As briefly discussed above, we decided on selecting these eight families because they represented families for which we had interview data from patients, as well as siblings and parents. This strategy mirrored our aim to investigate user perspectives from multiple positions within a single family and to enable within and between family comparisons. Again, maximizing diversity in experiences was a guiding principle for sampling.

For Paper 4, mean age at admission was 15 years (range: 12–18) and mean age at follow up was 19 years (range: 16–21). Mean length of stay was 21.4 weeks (range: 8–58). All patients had an admission diagnosis of AN. No statistically significant differences existed between the 8 participants and the 29 non-participating patients for the following variables: age at admission, duration of ED before admission, length of stay, weight and BMI percentile at admission and discharge, time elapsed between discharge and follow up and EDE-Q global score at follow up. During the follow-up interviews, 5 of the former patients did not meet the criteria for any DSM-5 ED diagnosis. In seven of the eight families, the parents were married. Six of the parent interviews were conducted with both parents together; two of the interviews were conducted only with the mother. Siblings' mean age at admission was 11 years (range: 6–16) and mean age at follow up was 15.4 years (range: 11.9–23). None of the siblings reported any previous treatment encounters beyond visitations during prior hospitalization of their sibling. Only one of the siblings had previously attended a family session at the local outpatient clinic.

Interview guides

The interview guides were developed by the team when planning the study. This effort was in line with a strong interest in obtaining feedback from patients and family members regarding a wide range of questions concerning their treatment experiences and lived experiences with AN. Although the interview guides were developed prior to starting my PhD position, I took part in this collaborative work. My contribution was particularly influenced by my previous work in developing a post-admission interview guide for parents. A work driven by my interest in ensuring and learning from user feedback. Of note, the interview guides were not developed with any specific analytic framework in mind.

Separate interview guides were developed for patients, parents, and siblings. Although different, the questions were based on the same timeline and organized according to the phase prior to the admission, the admission, and the post admission phase. The interview guides were piloted with the research team and items revised accordingly to reach a consensus (see appendix for interview guides). The research team consisted of experienced ED clinicians, yet the formal expertise in performing qualitative research was limited. The potential limitations of this is reflected in the individual papers.

Structured diagnostic interview. Prior to interviewing patients about their treatment experiences, a psychologist or a psychiatrist administered a structured diagnostic interview. This structured interview consisted of diagnostic items of the EDE Interview (Fairburn et al., 2008) and the MINI interview (Sheehan et al., 1998). These assessments were included for the outcome study as quantitative measures (Halvorsen et al., 2017). The EDE and MINI thus generated data for a different research purpose than the current study. The data from these structured diagnostic interviews were published previously (Halvorsen et al., 2017) and summarized above, under participants.

Treatment setting: from individually based care to family-based inpatient treatment

A brief note on terminology

Starting in May of 2008, the adolescent EDU offers a treatment usually labeled “family admissions.” Although family members are admitted together with the YP-AN, the term “family admission” requires clarification. As parents often took turns staying at the EDU and siblings rarely stayed throughout the admission, the entire family were rarely present for the duration of inpatient care in the current study. Thus, I decided to use the terms “family-based inpatient treatment program” and/or “family-based admission” interchangeably in this doctoral dissertation, when referring to the treatment program.

Describing treatment as an “inpatient treatment program” is also debatable, as the term “program” can imply a manualized, or formalized treatment protocol. In our situation, however, the term “treatment program” does not refer to a manual-based treatment program. Although treatment is viewed greatly influenced by manualized FBT, the EDU did not purport to directly implement an outpatient treatment manual. In regards to the correspondence between the outpatient and inpatient setting, it is reasonable to claim that the main focus of inpatient family-based treatment largely corresponds to phase one in outpatient FBT-AN (Hoste, 2015; Lock & Le Grange, 2012; Murray et al., 2015). The “default” priority during inpatient admissions is to support parents in managing meals and encouraging weight gain, which are the hallmarks of FBT phase one.

Restructuring treatment to provide a family-based treatment approach

In 2008, the adolescent inpatient EDU was restructured to board families. The EDU has a maximum of six beds for admitting YPs-AN together with family members. This means that few beds are available and earmarked for complex and severe cases. Referrals come from local specialized mental health services in a very large catchment area that covers about half of the Norwegian population. The main admission criterion is that patients must have undergone extensive treatment within the local specialized services without success. This includes prior inpatient and outpatient treatments, as well as family-based interventions at their local services, without sufficient progress. The waiting period for an admission can be long. For some families, the wait time is 6 months or more after the EDU has accepted the referral. How frequent patients and families engage with the EDU in the pre-admission phase varies from case to case, as this phase is not standardized.

Since no formal written description of the inpatient treatment program is available, this description is strongly informed by my own work experience at the EDU. I was employed as clinical psychologist between the years 2006-2010 and again, between the years 2014-2016. In the section below on *researcher reflexivity*, I reflect further on this dual role of conducting research at the site where I previously worked as a clinician. In addition, the following description is informed by numerous conversations with clinicians working at the EDU. Of special relevance is the close collaboration with my co-author, Dr. Inger Halvorsen, particularly during 2007-2010. Halvorsen was central in the effort to restructure the inpatient treatment program at RASP, and to initiate the research project to investigate outcome. The decision to restructure treatment and adopt a family-based inpatient treatment approach was inspired by several sources, as, 1) the evidence from research on outpatient FBT, 2) the desire to avoid disrupting family relationships during admissions and to foster more durable changes, and 3) to conform to the legal situation in Norway, where children have a legal right to be accommodated by a parent during hospitalization.

Inviting the whole family to take part

Although not defined as a “family unit”, the EDU has since 2008 prioritized admitting the family for the duration of the inpatient admission, as this approach is seen as important in making a difference for families over the long term. Still, the practical challenges in admitting the entire family is challenging, as families face several other obligations to manage. Although siblings were always welcomed to take part in the admission, most families arranged for siblings to remain at home during most of the hospital stay. Siblings could still attend family therapy sessions and family meals at any time. Besides an occasional group session led by a senior nurse or clinical psychologist, siblings were not offered any specific type of treatment intervention. Despite a few exceptions, parents typically traded off when staying at the EDU, as most siblings remained at home. During the hospital admission, every family were provided a family room, and typically, the YPs also had their own private room. When at the EDU, siblings could either stay overnight with their parents or together with their sibling.

***Assessments*.** Prior to hospitalization, decisions by the treatment team were based upon the written referral and an initial assessment with the YP, their family and the referral system. If necessary, additional meetings were scheduled to complete the assessment. Formal psychological or family-relational assessments conducted at the EDU prior to the admission were rarely used. Following a formal treatment offer, the pre-admission phase started. The pre-admission phase typically included at least two meetings with the family in order to start forming an alliance, prepare for the admission, and to form a tentative treatment plan. This phase could again vary considerably from case to case.

From predominantly caring for the patient, to supporting parents to care for their loved ones

As there was no available empirically supported treatment guideline or formal recommendations on how to optimize the inpatient treatment context, the efforts of restructuring treatment was inevitably both pioneering and experimental. In addition to the emerging literature supporting a family-based treatment approach and the clinicians’ own experiences, preferences and expertise, one particular inspirational source was the work project leader PhD Inger Halvorsen had conducted in southern Norway a decade earlier. Dr. Halvorsen conducted a research project on a family-based treatment collaboration between a specialized outpatient clinic and the local medical child department with promising results (Halvorsen et al., 2004). Relocating to Oslo and starting to work at the EDU in 2007, Dr. Halvorsen brought both her clinical expertise with ED treatment, systemic practice and family therapy, in addition to her research interest. To prepare, Dr. Halvorsen started educating and supervising staff on adapting an enhanced family therapy focus, together with other senior colleagues at the EDU. One major and immediate change was that staff now better enlisted the support of parents in caring for their loved ones, as compared to directly working with the adolescent patient. This was a huge change for many staff members, as one can imagine.

Empowering parents. Charging parents with increased responsibilities at the EDU

The greatest shift involved the presence of parents and family members at the EDU. The focus on supporting parental authority was most clearly expressed by assisting parents to manage the regular meals on the ward and at home during planned leaves. In addition to helping parents become confident in knowing what their child needed to eat in order to restore a healthy weight, parents were supported in providing emotional support for their child. In contrast to outpatient FBT, however, the treatment team retained the final responsibility for meal plans during most admissions. That said, decision-making was done in close collaboration with parents, and depending on age and progress, the YP was involved during the weekly treatment meetings as appropriate. During later phases of hospitalization and prior to discharge, the adolescent was encouraged to assume greater responsibility for meal planning, with continued parental supervision in most cases. This process of increased responsibility for meals handed over to the YP-AN could be viewed as a gradual process, mirroring the phased logic concerning meal management embedded in outpatient FBT (Eisler et al., 2016; Lock & Le Grange, 2012).

Prior to 2008, all patients had weekly treatment meetings with their multidisciplinary team. Now, these meetings included the family, and parents played a greater role in decision-making. Although staff still had a central role in evaluating and revising treatment plans, staff more often explored potential solutions to various challenges or dilemmas together with parents and the YP before revising the treatment plan. The traditional inpatient focus on ensuring adequate weight gain and medical monitoring for underweight patients was gradually integrated into the family-based treatment. For most cases, a minimum weight gain of 1 kg per week was recommended. This mirrored non-negotiable components in line with most inpatient treatment programs for adolescent AN enabling weight gain (Isserlin et al., 2020).

During the admission, parents were provided with frequent parental counseling. Sessions were planned and held regularly, and often, included staff working shifts on the ward. Families had family therapy sessions twice a week on average. Some of the patients were also offered individual sessions. The provision of supplementary individual sessions for YPs was arranged in collaboration with the adolescent and parents. At discharge, all patients and families were referred to their local outpatient clinic for further therapy and support, and sometimes, in lasting collaboration with the EDU's treatment team as part of aftercare.

The family meal as the critical therapeutic scene. Educating and supporting parents taking charge of the meals at the EDU. The single-most visible change in addition to the presence of family members involved how the four daily meals were organized and managed. Parents were now gradually put in charge of meal management, with staff assuming an indirect position of supporting parents. In outpatient FBT, family meal management is a frequently addressed topic in family sessions throughout treatment, and a family meal session is also a specific intervention in FBT-AN session two (Lock & Le Grange, 2012). During admissions, the regular meals offer a therapeutic context in which parents can work to develop ways to better manage the difficult meals, several times a day, every day, every week. Thus, the family meals could be viewed to represent the most essential component of treatment for ensuring sustained systemic changes that prevent relapse following discharge.

Parental psychoeducation and help to strengthen parental meal management skills form an integral part of treatment. This was not offered to parents in a standardized way except on some occasions, where the EDU provided a weekly course for parents inspired by the new Maudsley approach (Goodier et al., 2014; Treasure et al., 2007). Educating parents was instead mostly embedded in the day-to-day therapeutic activities and conversations, including regular sessions with staff working in the milieu and in regular family therapy sessions or separate sessions for parents. Additionally, there were typically several opportunities for ad hoc meetings with staff during the day, where parents could get support and be educated on how to provide care for their loved one. Staff working shifts had daily scheduled conversations with both parents and the YP about preparing meals (i.e., addressing roles, responsibilities and providing efficient support) and for continually evaluating the ongoing processes. Often these conversations included psychoeducation in situ by enabling tailored problem-solving of concrete dilemmas (i.e., meal management) under supervision of experienced staff members, enabling learning by doing and reviewing.

Predominantly aiming to align inpatient care with the first phase of outpatient FBT

The family-based inpatient treatment program is usually described as corresponding to the first phase of outpatient FBT. The main aim during an admission was usually to support and equip parents with sufficient skills and confidence to manage subsequent progress at home. As recovery is most often a long journey, the overarching goal was thus not full ED symptom remission or recovery at discharge. Frequently, the EDU would aim to keep the patient until normal weight was obtained, as this is a recognized parameter that can prevent rapid relapse, although this was not always the situation (Halvorsen et al., 2017). Determining which corresponding outpatient FBT phase the adolescents and their families had obtained at the time of discharge from the EDU, or at any given point during the admission, is difficult to evaluate. Still, it is reasonable to claim that most participants were likely in a treatment phase corresponding to Phase 1 in outpatient FBT. As for others, it would be more accurate to say they were transitioning into Phase 2, with a few adolescents/families even potentially progressing further. Still, this is impossible to determine precisely in this study.

Providing supplementary individual sessions for the YP-AN

As the focus of the inpatient program was centered on family therapy, and the milieu therapy was predominantly guided by a stance of supporting parents in supporting their child, there was no specific individual therapy offered, such as supplementary CBT (Dalle Grave et al., 2013) and/or AFT (Fitzpatrick et al., 2010). Adolescents did not participate in systematic group therapy. Still, most of the YPs-AN were provided with the opportunity to speak one-on-one with a therapist if the YP and/or the parents, or even the treatment team deemed this as fruitful. In these instances, YPs were provided with supplementary individual sessions. Supplementary means this was principally provided as supportive and not intended to conflict with the predominant family-based treatment approach. The decision on whether the YP was offered individual sessions was pragmatically arranged in collaboration with the family and the YP.

Activities and school

Structured activities for the patients have been few and not systematically integrated into the treatment program. On some occasions, there have been activities in the EDUs living room such as movie nights or an occasional outing to an amusement park. There were no formalized restrictions on YPs interacting with peers during the stay. Since it was not mandatory for family members to be present continuously and none or very few of the patients had staff present all the time, the adolescents could thus engage in informal dialogues with others during the day, both alone and together with family members. As such, during a regular day or average week, there would be many potential opportunities and occasions to interact and exchange experiences, ideas and opinions. The EDU provides a school service for the YPs during the admission, as well as for younger siblings. Teachers often participated in the weekly team meetings and are viewed as an important resource and part of the multidisciplinary team.

Qualitative data analysis

> For us, qualitative research is about meaning and meaning-making, and viewing these as always context-bound, positioned and situated, and qualitative data analysis is about telling "stories", about interpreting, and creating, not discovering and finding the "truth" that is either "out-there" and findable from, or buried deep within, the data. For us, the final analysis is the product of deep and prolonged data immersion, thoughtfulness and reflection, something that is active and generative (Braun & Clarke, 2019, p. 591).

In this section, I expand upon what is written about analyzing data in the dissertation's different papers. In the following paragraphs, I outline the analytic framework guiding data analyses across studies, briefly reflect on saturation and expand on ensuring quality and researcher reflexivity.

Thematic analysis as the guiding analytic framework

> Our reflexive approach involves six – recursive – phases of: familiarization; coding; generating initial themes; reviewing and developing themes; refining, defining and naming themes; and writing up (Braun & Clarke, 2021a, on their contemporary *reflexive* TA approach, p. 39).

Braun and Clark's original version of TA (Braun & Clarke, 2006) has gone through different developments since their seminal paper from 2006. Today, the authors refer to their TA approach as reflexive TA (Braun & Clarke, 2019, 2021a, 2021b, 2022). They renamed their approach to emphasize the highly constructive and situated nature of data analysis, together with the "importance of the researcher's subjectivity as analytic resource" (Braun & Clarke, 2021b, p. 330). In their updated version of TA, *researcher subjectivity* is thus at the fore (Braun & Clarke, 2019, 2021a).

Recognizing there are different approaches to conducting TA and considerable overlap between their version of TA with other analytical frameworks, as qualitative content analysis (Vaismoradi et al., 2013), interpretative phenomenological analysis (Smith, 2019), grounded theory (Charmaz & Thornberg, 2021), and pattern-based discourse analysis (Braun & Clarke, 2013), the authors claim there are three different approaches to TA (Braun & Clarke, 2021a). These include a) *coding reliability approaches*, which often utilizes multiple coders to ensure consensus through establishing inter-rater reliability, b) *reflexive approaches*, as representing their contemporary approach to TA – known for foregrounding researcher subjectivity and reflexivity, and c) *codebook approaches*, where structured coding is applied (Braun & Clarke, 2021a).

Today, I believe Braun and Clarke's updated version of TA – as reflexive TA – resonates with how I prefer to view my predominant analytic stance. Looking back, I believe reflexive TA echoes with how I have engaged with data throughout the different sub-studies. Specifically, their perspectives corresponds with my own recognition of researcher subjectivity in generating findings, together with the importance of providing transparency on researcher reflexivity, and enabling readers to engage in evaluating the trustworthiness of the research. My preferred stance of analyzing data also mirrors reflexive TA's emphasis on coding, as being "open and organic, with no use of any coding framework", as compared with a codebook approach to TA (Braun & Clarke, 2021b, p. 334) .

> The coding process is unstructured and organic, with the potential for codes to evolve to capture the researcher's deepening understanding of the data. Coding is recognized as an inherently subjective process, one that requires a reflexive researcher – who strives to reflect on their assumptions and how these might shape and delimit their coding (Braun & Clarke, 2021a, p. 39).

Braun and Clarke's version of TA represents a pragmatic and theoretically flexible approach (Braun & Clarke, 2006, 2019). I believe this is especially suitable for the current study, as we did not aim to analyze data through a specific theoretical lens. This does not mean theory is not relevant or has not mattered for the different analyses. Still, the theoretical flexibility recognizing TA, mirrors an absence of *inbuilt* guiding theory (Braun & Clarke, 2021a).

Braun and Clarke's version of TA is sometimes misunderstood as atheoretical, indicating that theory or theories do not matter, as if analysis is possibly performed in a "theoretical vacuum" (Braun & Clarke, 2021b, p. 331). This is not the case, nor is it the case in the current research. As researchers, we always analyze data while being influenced by conscious or unconscious assumptions and/or our interests in the topics under investigation. Therefore, what in the end constitutes meaningful knowledge is highly reliant on the researcher's subjectivity and positions.

Reflecting on saturation

> It is nigh on impossible to define what will count as saturation in advance of analysis, because we do not know what our analysis will be, until we do it (Braun & Clarke, 2021d, p. 210).

Saturation is regarded as a methodological principle in qualitative research, and the underlying logic is related to making "a predictive statement about the unobserved based on the observed" (Saunders et al., 2018, p. 1893). Often, saturation is related to the process of making decisions on what constitutes sufficient data in a particular study and historically, the term has been associated with determining sample sizes in theory-building approaches such as grounded theory (Pandit, 1996). In the current study, saturation was not used as a guiding principle for determining sample sizes. Rather, we pragmatically decided to include all available participants in order to maximize diversity in viewpoints, without theorizing about saturation. Our reasoning around saturation and sample size was also fueled by assuming that "the depth of data likely generated from each participant or data item" may be limited, at least partly, if choosing a different strategy that led to smaller sample sizes. Hence, an initial evaluation of data quality while familiarizing myself with the data supported the decision to maximize diversity (Braun & Clarke, 2021a). This approach toward sample size, I believe, resonates with the overarching aim of facilitating nuanced descriptions of differences and similarities in perspectives and meaning, as compared with aiding theory building, where questions pertaining saturation could have a different significance (Saunders et al., 2018).

Beyond determining sample size, saturation is related to the analytic process, as in determining when one has reached the point of information redundancy. Information redundancy is reached when no new information is expected to make a difference in enhancing the analysis (Braun & Clarke, 2021d). In the current study, this way of viewing saturation, sometimes framed as inductive thematic saturation (Saunders et al., 2018), was inspirational in the process of ending the different analyses. Still, this was not adhered to strictly as a criterion, as my stance towards data or thematic saturation was driven by acknowledging the potential for new meaning to develop *if* the analytic process continued. This is a stance reverberating Braun and Clarke's recent writings questioning the usefulness of data saturation (Braun & Clarke, 2021d).

Ensuring quality

Qualitative inquiries are very much reliant on the analyst's mind and decision-making (Sandelowski, 2015). Qualitative research has therefore frequently been criticized as failing in establishing scientific rigor and trustworthiness (Kvale, 1994). At the heart of evaluating the quality of qualitative research – essentially whether it is good enough – is examining the performance of research. As research is both a situated and a performed practice, highly influenced by the researcher's subjectivity, it is therefore crucial to give readers an honest account of how research was done, and why in this way? To safeguard qualitative research practice, different quality criteria have been developed (Lincoln & Guba, 1985, 1986; Mruck & Breuer, 2003; Tracy, 2010).

Safeguarding quality in the current research has reverberated around ensuring data analysis being performed in a sufficient rigorous and trustworthy way. As data was collected in 2015, I therefore used considerable time on listening on audio recordings, transcribing interviews and hence familiarizing and immersing with data, in order to develop and refine research aims and research questions for the different sub-studies. Additionally, considerable work was used on deciding upon the research design, sampling strategies and deciding which analytic framework would best fit data and overall research aims.

Different strategies for ensuring quality in TA are summarized by Braun & Clarke in Chapter 9 in their latest book, which also introduced an updated version of TA, reflected above (Braun & Clarke, 2021c). These different ways of safeguarding quality while performing reflexive TA resonates with previous writings (Braun & Clarke, 2006, 2021a, 2021b, 2021d, 2022), and have served as a map guiding my own research process in aiming to ensure and maintain quality. Strategies included, 1) preventing a premature closure of the analysis, 2) keeping a reflexive journal, 3) engaging in conversations with others about data analysis, 4) allowing time for analytic insights to fully develop, 5) working with an experienced supervisor, mentor or co-researcher, 6) making sure themes are themes, and naming them carefully, 7) drawing inspiration from excellent examples of published research, and, 8) demonstrating quality through an electronic or paper trail (Braun & Clarke, 2021c).

In the following paragraphs, I outline relevant topics regarding quality, starting out with *ensuring rigor and trustworthiness*, followed by *ensuring generalizability and usefulness*. Lastly, I end the section with reflecting further on *researcher reflexivity*. As issues captured in these three domains overlap, they are best considered together.

Ensuring rigor and trustworthiness. In the current study, I have strived to ensure scientific rigor and trustworthiness by spending considerable time on reflexively immersing with the data. Also, I have deliberately worked toward refraining from prematurely closing the theme development. By reflexively immersing with data, I mean prioritizing reading transcripts numerous times, listening to original recordings, reading and re-reading, and deliberately moving the analysis very gradually forward in an iterative, critical and self-reflexive way. By critical, this means that I have worked very hard to prevent the risk of simply searching for ideas or generating themes based upon my own prejudices, assumptions and/or preferred clinical positions. Viewing researcher subjectivity as a resource, and recognizing qualitative analysis as interpretative and generative (Braun & Clarke, 2019, 2021a), I have, congruent with the research aims and the predominantly descriptive design, attempted to safeguard against generating themes that stretch the data too much. Critical points regarding my views on *researcher reflexivity* are outlined below, along with a description of different risks or pitfalls relevant for the current work.

Starting out, co-authors read chosen interview transcripts in order to familiarize themselves with data. Still, the concrete work of analyzing the data for the different sub-studies has been led by me, as first author, throughout the process. This choice to not collaboratively analyze data, which is more common in coding reliability and/or codebook approaches to TA (Braun & Clarke, 2019, 2021a), mirrors the latest version of TA, where the authors emphasize that the researcher's subjectivity is so vital to reflexive TA, that "a research team is not required nor even desirable for quality" (Braun & Clarke, 2021b, p. 333). From this viewpoint, involving a team to perform inter-rater reliability implies a positivist stance not compatible with a reflexive TA stance, foregrounding researcher subjectivity as a vital resource (Braun & Clarke, 2021a, 2021b). In the current study, as is also acknowledged by the co-authors, I have therefore assumed responsibility for conducting and completing the data analysis. Still, this process has been continually aided by regular supervision and frequent discussions with the co-authors. In the different papers, this collaborative stance has been characterized by team members performing the role of a "critical friend" during analysis (Smith & Sparkes, 2006). By collaborative stance, I mean that at every step, when I or one of my collaborators have felt I am stretching the data *too* much, either by moving beyond "what is probably conveyed in data" or over-interpreting or reading-in ideas or concepts that are probably not contained within the data, I have initiated the process of going back to raw data. This means that I have rejected preliminary or suggested themes several times. Supporting this dynamic process included keeping a research diary. Writing a research diary – as making reflexive notes to track and communicate developments in thinking and feeling – has supported the generative work of analyzing data and served as a resource for supervision sessions and discussions within the research team (Braun & Clarke, 2021c).

Ensuring generalizability and usefulness. The current study is situated within a specific treatment setting not easily compared with others. Thus, I do not claim to develop knowledge that has direct generalizability to different settings and other patient populations. More so, it has been an ambition to contribute with clinically relevant knowledge, or knowledge reverberating high inspirational utility. Hence, our position towards generalizability echoes generating situated knowledge positing a potential transfer value, for clinicians working within different intensified treatment settings (Maxwell & Chmiel, 2014). Overall, as the study reports from an understudied treatment setting, I believe the research can prove particularly useful for, 1) treatment providers working to optimize inpatient ED treatment, 2) future patients and families, and 3) generating new ideas for future research.

The study contributes clinically relevant "insider perspectives" from an inpatient treatment setting where there to date exists no agreed-upon guidelines for delivering treatment. Hence, the study is viewed as useful to inform the work of optimizing adolescent AN inpatient care in a broad sense. Linked to clinical relevance, I believe findings within and across studies contributes with knowledge of direct relevance to ongoing discussions of how to best manage the many difficult dilemmas associated with adolescent AN inpatient care (Hoste, 2015; Isserlin et al., 2020; Murray et al., 2017; Murray et al., 2015). I also believe the study has the potential to support the development of treatments in line with preferences of service users. This is viewed important, both as research has demonstrated that service users want a holistic and better individualized approach (Gustafsson et al., 2021; Herpertz-Dahlmann, 2021) and because emphasizing the clients subjective perspectives aligns with an evidence-based practice framework (Peterson et al., 2016).

Throughout the process of working with the thesis, it has been central to safeguard the clinical relevance of this study. This has been a significant priority from the outset. The main inspiration for doing the qualitative part of the follow-up study was clinicians' interest and belief in the value of systematically generating user feedback, as this could have direct clinical utility in furthering treatment development. Safeguarding transferability, ensuring usefulness and clinical relevance have thus been concerns within the research team. Regular dialogues with the research team has supported this work. Collaborating with a team of experienced clinicians with expertise from intensified treatment settings has ensured frequent discussions pertaining the research's value and relevance, throughout the process. Together with numerous within-team discussions, this work has also been enhanced by engaging in dialogues outside the research team. For instance, it has been valuable to present preliminary findings and share aspects of the research process at seminars with ED professionals and persons with a lived experience. Additionally, this study has been presented at national and international conferences, which again has supported the ongoing research process and strengthened the quality.

Generally, I believe that parts of this thesis, or in its entirety, could reverberate a transfer value for clinicians working in similar clinical settings, or in treatment contexts who are considering developing their treatment program to include a family-based focus. Findings or themes throughout the study could therefore be judged as potentially relevant or useful within different clinical contexts by the reader – an approach to generalization often recognized as a case-to-case transferability (Maxwell & Chmiel, 2014; Smaling, 2003). It is thus my hope that the extended summary, where I contextualize the research, outline central aspects of the treatment program, expand upon the guiding analytical framework, and reflect further on researcher reflexivity, further aids the reader in critically evaluating whether findings can have a transfer value to their unique clinical context.

Researcher reflexivity

> Researchers using reflexive TA inductively need to identify, and ideally articulate in their reporting, the theoretical assumptions informing their analysis (Braun & Clarke, 2021b, p. 331).

I end the methods section by expanding on aspects related to researcher reflexivity. This topic, which received less focus in the individual papers, is vital for the knowledge developed and importantly, the reader's ability to evaluate the quality of the research performed (Maxwell & Chmiel, 2014). I share my reflections concerning *five domains.* The content captured in the different domains overlap, and sometimes resonate with what is shared above, especially paragraphs covering *ensuring rigor and trustworthiness*, and *ensuring generalizability and usefulness*. Still, this section is included to provide further insight into how *I* as a researcher reflect the inescapable; how aspects within myself and the different contexts that I inhabit and partly co-create, affects the research process. The questions captured within the different domains have accompanied me "as questions of concern" since starting out as a PhD candidate in the autumn of 2017. A specific risk related to each theme is formulated below (1-5). These risks could be viewed as resonating with the common threats to validity proposed by Maxwell in qualitative research, namely, researcher bias and reactivity (Maxwell, 2013).

> Why is it necessary to talk about ourselves and our presuppositions, choices, experiences, and actions during the research process in a sufficiently precise way so that it allows others to follow what we mean and did? It is necessary because without such reflection the outcomes of the research process are regarded as "characteristics of objects," as "existing realities," despite their constructed nature that originates in the various choices and decisions researchers undertake during the process of researching (Mruck & Breuer, 2003, p. 192).

1: Doing qualitative research is a creative and constructive endeavor.

The risk of constructing findings predominantly based upon my own preconceptions

It is not unusual to come across descriptions as “finding x emerged through the analysis”. Still, findings in this context are inevitably generated and shaped by actively engaging both intellectually and emotionally with data. From the outset, I thus utilize myself as a resource – as an active instrument in interpreting others’ stories about something. From taking part in developing the study, constructing interview schedules, conducting interviews, performing the analysis, to the process of writing up the individual papers, I play an active part in making decisions on how to frame a story about what I consider reflects the data.

The likelihood of creating findings that stem as much from the analyst’s own mind and prejudices as grounded within data is therefore especially important to continually consider (Maxwell, 2013). This kind of researcher bias is particularly crucial to reflect upon when research is fueled by a descriptive and inductive analytic stance, aiming to “give voice” to the service users’ subjective experiences, as the current research. Managing this balance have been a recurring concern and has been detailed above under *ensuring rigor and trustworthiness*.

Specific strategies undertaken to safeguard against this risk included *preventing premature closure* of the iterative analytic process by allowing sufficient time to develop insights, *journaling* – as in tracking my thinking and questioning, and *engaging in frequent conversations with supervisors and others* about the data and the analytic process.

2: Doing research situated at the EDU where I previously worked as a clinician

The risk of generalizing too much from my prior work experience at the EDU, as uncritically idealizing my own “insider knowledge”

Resonating with the above, is a different aspect of researcher bias, and relates to the fact that I have prior work experience at the EDU. My clinical work experience relates to three different phases. Firstly, I worked part time as a milieu therapist between the years 2004-2006. Then I worked at the EDU during two periods as a psychologist, firstly between the years 2006-2010 and secondly between the years 2014-2016. As the EDU decided to change the treatment program to provide family-based inpatient treatment from May of 2008, I was thus one of the staff members working at the EDU while the restructuring occurred. Thus, I have work experience from the EDU both before and after reorganizing inpatient treatment. This also means that I have been part of the multidisciplinary treatment teams for a few of the YPs and their families taking part in the study, specifically during the years 2008-2010.

Having previous work experience at the EDU could be both methodologically advantageous as well as potentially disadvantageous by posing a threat to scientific rigor (Dwyer & Buckle, 2009). Looking back, I hope this “fact” has predominantly given me a) a beneficial vantage point of having unique “insider knowledge” from the treatment setting where the research took place and b) promoted critical self-reflexivity, a stance relevant in all research endeavors (Moore, 2013). I hope that I have avoided the pitfall of generalizing or imposed too much based on my own prior clinical work experience, therapeutic preferences, prejudices, and clinical stances when interpreting the data. At the same time, I hope I have not blocked out my own potentially valuable clinical experiences and expertise as a valuable resource in conducting this study.

Specific strategies undertaken to safeguard against the risk of uncritically generalizing from my previous work experience included continually reflecting and reviewing the risks of inferring from my therapeutic presuppositions by engaging in frequent dialogues and discussions with supervisors and co-authors. Largely, I believe this vigilance strengthened the overall trustworthiness in the current research. For each step in every analysis, I have critically re-evaluated theme developments numerous times, by going back to the raw data. Critically scrutinizing whether “this finding” is sufficiently grounded within the data, or whether it was predominantly generated by my creative brain, to simplify, has served as a guideline throughout the work of analyzing data.

3: Treatment diversity, and the influences of my own preferred clinical positions

The risk of either consciously or unconsciously wanting to confirm a preferred therapeutic practice

By conducting research at the EDU where I previously worked as a clinician, I inhabit a dual role. I therefore need to critically reflect upon the potential bias introduced by consciously or unconsciously wanting to confirm a certain clinical approach. One potential pitfall is uncritically contributing evidence to validate the potential promise of a family-based inpatient treatment approach. As I participated, and hence invested, in restructuring the inpatient treatment program in 2008, I could therefore risk consciously or unconsciously searching for meaning and perspectives to confirm this preferred practice. At the same time, I could risk leaving out or toning down traces of contradictory views in the data, or findings critical of the preferred or chosen treatment modality.

Another related and potential bias lays in the opposite direction. In other words, there is a risk in excessively highlighting data that seemingly contradicts the preferred family-based treatment framework, in order to avoid the appearance of uncritically seeking evidence to confirm this therapeutic approach. By wishing to demonstrate a critical and reflexive stance, I could therefore risk exaggerating the importance or salience of contradictory perspectives. Keeping this juxtaposition or dynamic in mind has been a focus throughout the work.

Strategies undertaken to safeguard against this risk included allowing sufficient time to reflect on my clinical stances, and critically review how I, as a therapist, could come to influence data analysis and the stories told. This has been supported by journaling and engaging in numerous talks with supervisors and others. Additionally, the recognition that engaging in qualitative research is *not* about confirming a specific way of working has aided the process. Another important aspect includes reflecting upon the context of this research and allowing myself sufficient freedom to be data-driven, even if data contradicts the preferred way of providing treatment at the EDU.

Reflecting back on myself as a psychotherapist and reexamining my treatment preferences, I recognize I prefer to remain open for tailoring treatments toward the unique presentations recognizing each case (Cecchin et al., 1992). As a therapist, I can seek out inspiration from different ED-specific and non-specific treatment traditions. Although a FBT approach to treating adolescents with AN is recommended by most treatment guidelines, family therapy or family-based interventions are by no means a treatment panacea (Le Grange et al., 2019; Le Grange & Lock, 2014). Largely, I view the adolescent ED field as having numerous uncertainties, especially when cases are complex and severe, as is the case for the current research. Generally, I prefer to consider myself as a clinician frequently visiting different "schools of therapy," while deliberately refraining from getting married to *one* specific treatment model. My preferred position could thus be viewed as a multi-modal stance, recognizing the need to be equipped with a wide range of ways of understanding and intervening (Asen, 2004).

For me, this means I like to seek inspiration and guidance from different traditions, both within and outside the ED field, from contemporary psychodynamic traditions, psychotherapy research, cognitive theory, to family therapy and systemic practice. This diversity in interests, I believe, has been highlighted by my previous writings, as I have written on different topics including the importance of the therapeutic alliance when working with adolescents (Nilsen, 2013), countertransference (Nilsen, 2014) and mentalization-based treatment when conducting multi-family group therapy (Nilsen & Skårderud, 2012).

Within the context of ensuring that research is trustworthy, I do believe that my diverse experience and expertise, my broad knowledge of different treatments – from individual to systemic frameworks – together with my experiences in being a systemic supervisor and teaching systemic practice, represent an advantage. Particularly when the aim is to describe user experiences within a theoretically flexible analytic framework, and prevent the analysis from being unconsciously "skewed" towards favoring a specific treatment approach. Still, I realize I have played an active part in the construction of findings, and I do recognize that my preferred clinical stances are mirrored in some of the findings. The latter is still not an argument against trustworthiness within this research tradition. Quite the contrary, it could be argued that *because* I know the field and the specific treatment context well, trustworthiness and the relevance of this research is enhanced (Tracy, 2010).

4: The inpatient treatment setting and the choice of deliberately giving priority to persons with a lived experience

The risk of uncritically idealizing user experiences as positing a knowledge source more valuable than other sources of knowledge

Inpatient care represents a highly complex treatment situation. Multiple professionals are involved, a plethora of diverse opinions exists, and there are, to date, no authoritative consensual evidence-based guidelines to support care (Anderson et al., 2017; Herpertz-Dahlmann, 2021). By doing research within a specific higher level of care setting, where I previously have worked as a clinician, my vantage point as a researcher is, as described above, not to seek or confirm or even necessarily support a specific mode of practice. This, I believe, is key for me to reflect upon. Qualitative research, I believe, has the potential of favoring a particular story. Although not claiming neutrality, I am primarily motivated by the opportunity to give priority to persons with lived experience – regardless of whether the findings support the EDUs preferred treatment practices or not.

Safeguarding against the risks of uncritically idealizing the knowledge derived from user experiences, has been a constant concern. Strategies undertaken to safeguard against this risk include, as noted above, engaging in conversations with supervisors, journaling and promoting a tentative stance toward how this knowledge can be of use, as in maintaining a critical and reflexive stance toward transferability. While deliberately foregrounding user experiences as a vital source of knowledge, I also acknowledge the risk of a confirmation bias, as in searching for data consistent with the desire to tailor future treatments to resonate better with service user's views and perspectives. Although some of the findings do reverberate my own preferences as a clinician, particularly in Paper 2 regarding the importance of minding the adolescent within family-based care, I do believe this finding is reflected in data, not simply constructed from my prejudiced views.

5: Research as a collaborative endeavor – still, the chief responsibility of analyzing data and ensuring quality had to be mine

Who is in charge? The risk of power dynamics within the team of co-authors influencing research

In the current study, all stages of the research process, from brainstorming and formulating initial research ideas with the research team, to the process of finalizing the specific research papers and navigating the peer review process, were performed by human beings. Inevitably these persons, performing different roles and responsibilities, positing different stances, subjectivities, and both conscious and unconscious preferences or prejudices, do influence the research process and even the findings and the stories told.

Research is never performed in a vacuum, and it is neither something I do, or did, solely on my own. Although I am the first and corresponding author, this research has from the outset been a collaborative endeavor. This again inevitably influences the research findings in different ways, often difficult to grasp. Also particularly relevant, is that when I started doing research full time, data had been collected. Thus, the story about this research began even before I entered the scene. It is likely that another researcher would have provided a somewhat different story than mine. As a team of clinicians was responsible for conducting the interviews, data has been collected and influenced by several sources. This has been briefly reflected in the different papers' limitation sections and is a topic discussed during several team meetings throughout the work.

An important strategy undertaken to safeguard against this risk included reflecting and agreeing upon roles and responsibilities upfront within the research team. This means that starting out, my supervisors and I agreed that "however we set up the different analysis," this will be a constructive and creative endeavor where I must take the lead, implicating that different ways of organizing our collaborations would have influenced the processes differently.

Results – summary of main results

In this chapter, I will briefly summarize the main results of the four papers included in this thesis.

Paper 1

The specific aim in this paper was to investigate how former patients with lived experience from a family-based inpatient treatment program experienced treatment. Interviews with thirty-seven inpatients diagnosed with AN were examined. The accounts were analyzed utilizing an inductive thematic analytic approach. The analysis yielded 4 main themes, constituted by in all 8 subthemes. Main themes were *1) Enabling new ways of understanding and relating, 2) Enhancing or maintaining negative power dynamics, 3) Vulnerable transitions, and 4) Sibling relationships and different ways of involvement.* With its "insider focus," this study contributes with knowledge on how family-based inpatient treatment is perceived from a user perspective. The study has value for both advancing the development of family-based inpatient treatment, and by adding patient perspectives to the ongoing effort of providing family-based approaches at higher levels of care.

Paper 2

The purpose of the second paper was to provide knowledge of how young persons with lived experience from a family-based inpatient treatment setting viewed therapeutic aspects related to staff-patient collaboration and staff-related behaviors. This was deemed important because during family-based inpatient treatment, collaborative efforts are largely directed toward the parents of the adolescent. Consequently, the therapeutic focus on the young person is more of an indirect one. Thirty-seven semi-structured interviews of former adolescent inpatients were analyzed inductively by applying a thematic analytic framework. Findings revealed that former inpatients prefer tailored treatment and a collaborative approach. Eight subthemes constituting two main themes were constructed: *1) There are no ready-made solutions. Staff should facilitate collaboration by tailoring treatment to the young person's perspectives, and 2) Emphasizing skills that matter. Staff should display a non-judgmental stance, educate patients, stimulate motivation, enable activities and prevent iatrogenic effects during the stay*. The study contributes with important user perspectives on treatment collaborations and tailoring treatments.

Paper 3

This study aimed to investigate which factors young persons with a lived experience of AN and different treatments consider important for the recovery process. All participants had been provided with a family-based inpatient treatment program inspired by the core features of outpatient family-based treatment. As family-based treatments largely prioritize collaborating with the parents, understanding the young persons' views on recovery becomes important, as this may facilitate the therapeutic alliance and aid therapeutic processes. All 37 participants presented with an extensive treatment history, including outpatient and inpatient treatment for AN. Interview transcripts were analyzed by applying a predominantly inductive thematic approach to generate themes and patterns across participants. The qualitative analysis generated a thematic structure entailing three levels. The superordinate theme, *Recovery is a long and winding journey: recognizing the need for support and highlighting the need for action,* captured three main themes, including *1) Realizing you have a problem, 2) Being involved in important relationships, and 3) Giving treatment a real chance.* This paper is relevant to clinicians working within predominantly family-based frameworks in which collaborations with parents are prioritized.

Paper 4

The main objective of this paper was to extend our prior research on adolescents' perspectives following treatment by allowing within and between family comparisons. In this study, we provided a multi-perspectival approach extending our knowledge beyond the single-position approach previously applied. A subsample of eight families taking part in a naturalistic outcome study at a specialized eating disorder unit participated in the study (8 patients, 14 parents, and 10 siblings). As with the previous studies, the thematic analyses were inductive, predominantly descriptive, and guided by a multi-perspective framework. Five main themes were constructed: *1: Expectations and evaluation of needs. Entering treatment from different vantage points, 2: Interactions with peers during the admission as highly beneficial or problematic, 3: Perspectives on staff expertise and the eating disorder unit's structure, 4: Influencing within family relationships in different ways, and 5: Being admitted is at best only half the job: reflections on leaving the eating disorder unit*.

Discussion

The overarching aim of the current study was to develop knowledge based on investigating service users' experiences with taking part in family-based inpatient treatment for adolescent AN. It is assumed this knowledge could aid the ongoing work of optimizing adolescent AN inpatient care and serve as inspiration for clinicians providing AN treatment within different intensified care settings. Results are presented in four papers. Paper 1 investigates YPs views of taking part in family-based inpatient treatment. Paper 2 explores YPs views on treatment collaborations and their perspectives on staff skills and expertise. Paper 3 investigates YPs views on what they perceive as key factors in recovering from the ED, and Paper 4 explores a subset of eight families' experiences with family-based inpatient treatment. A more detailed discussion of the findings from the four studies and the methodological limitations are outlined in the different papers.

The following discussion section is organized into four parts:

A. **Firstly**, the current qualitative study is briefly contextualized with the quantitative outcome study (Halvorsen et al., 2017). This is relevant, as the naturalistic outcome study utilized the same sample of participants as Papers 1-3, and because the qualitative study aims to add nuance to and widen the scope of the quantitative outcome research.

B. **Secondly**, overall patterns within and across the study's different papers are reflected upon.

C. **Thirdly**, and this represents the discussion section's main part, the discussion is organized around *five thematic domains* of findings within and across papers. These thematic domains reflect issues viewed as essential considerations for treatment providers. Potential *treatment implications* are reflected throughout this section, and for some thematic domains, specific suggestions are outlined.

D. **Lastly**, the discussion section ends with sharing ideas for future research.

A. Empirical contribution: adding nuance to the RASP naturalistic outcome study by using qualitative methods to investigate user experiences

In the quantitative outcome study (Halvorsen et al., 2017), authors demonstrated that weight status and ED outcome at 1 to 7 years following family-based admissions, were relatively comparable with outpatient FBT outcome studies utilizing strict recovery criteria (Lock et al., 2010; Murray et al., 2019). The authors concluded that findings were promising and that providing a family-based inpatient treatment approach might be considered beneficial for YPs who required intensified care after previous treatment efforts failed (Halvorsen et al., 2017). Still, authors were humble in their conclusions. They largely emphasized that findings are preliminary, and stressed that further research is warranted. Additional knowledge is therefore called for, both to understand better how we best can manage the complex inpatient setting to aid sustained changes (Isserlin et al., 2020), and how we best can adapt the core features of outpatient FBT into a very different treatment setting (Herpertz-Dahlmann, 2021; Hoste, 2015; Murray et al., 2015).

For the current qualitative study, we can only speculate as to *if* and *how* the family-based admission influenced recovery status at follow up, especially as the naturalistic outcome study had no comparison condition. Additionally, considerable time had passed between discharge and follow-up, and the majority of participants had received further treatment following discharge. The current qualitative study was conceived and designed with these limitations in mind. Investigating user experiences was valued as vital to add nuance to and widen the scope of the quantitative research. The main aim was therefore to generate new situated knowledge based upon interviews with persons with lived experience, in order to aid the treatment development at both the EDU and elsewhere. Explorative descriptive qualitative research is especially useful when knowledge and research evidence is scarce.

B. Patterns within and across papers

Collectively, the findings in this study suggest the presence of two parallel, yet somewhat divergent, patterns when analyzing participant perspectives and experiences with family-based inpatient treatment. In particular, these two patterns were observed in Papers 1, 2 and 4, which most directly reported on the inpatient experiences of YPs and their family members. These patterns can be viewed as reverberating *two different stories*, one reflecting a predominantly “promising story”, and one a more “concerning story”.

The “promising story” reflects common themes found within and across papers in which family-based inpatient treatment was viewed as a unique and intensified treatment setting providing families with new opportunities to reunite and collaborate in ways that foster change. Aligning with this story, treatment was largely appreciated as beneficial, and hence, supports “the promising story” of a family-based inpatient treatment approach. The more “concerning story” echoes patterns within and between papers reverberating that this approach to providing inpatient treatment could also contribute to maintaining negative family dynamics, fragmentize families, disengage young patients and family members, and ultimately treatment unintentionally nurtured the ED, potentially hindering positive changes for the YP and the family.

Thus, on one hand, we have findings that supported the assumption that family-based inpatient treatment represents a promising way of providing inpatient care. This is a story echoing the conclusions in the quantitative outcome study (Halvorsen et al., 2017), and a story largely mirroring encouraging research from the brief family admission program in Sydney Australia (Fink et al., 2017; Wallis et al., 2013) and elsewhere (Marzola et al., 2015; Rienecke & Richmond, 2018; Rockwell et al., 2011; Spettigue et al., 2019). Interestingly, this story also aligns with the prime narrative of family therapy being the preferred treatment framework for adolescents who develop AN, and that this treatment approach should be strengthened across all levels of care (Murray et al., 2015).

On the other hand, findings within and across studies could be viewed as representing *food-for-thought* on scrutinizing *how* treatment can be further optimized, and importantly, preventing bad situations from getting worse during an admission. This story reflects previous qualitative research demonstrating how challenging an event a hospital admission can be for patients (Offord et al., 2006). It also echoes research on user perspectives calling for better family engagement in treatment and the importance of a more flexible and tailored approach (Gustafsson et al., 2021; Herpertz-Dahlmann, 2021; Medway & Rhodes, 2016). The “concerning story” is thus congruent with previous research on user perspectives calling for a greater emphasis on the individual person, and the specific and unique issues afflicting the family. Underlying family dynamics can fly under the radar, even in specialized care, along with treatment failing to address other important issues than the ED or ED-specific symptoms. Findings reverberating this more “concerning story” also reflect past qualitative research questioning if adolescent AN treatment creates sufficient space for individual therapeutic work within a predominant family-based treatment framework (Bezance & Holliday, 2013; Medway & Rhodes, 2016).

Also, findings reported in Paper 3 suggest that although former inpatients largely recognize support from others as crucial, they particularly emphasize their own determination and self-responsibility as vital for improvement. This stance of the YPs acknowledging their own agency or self as salient for fostering change becomes relevant to consider within a predominantly family-based treatment framework, known for prioritizing parental empowerment and support.

C. Five thematic domains essential to consider

In this section, findings within and across studies are further reflected. The section is organized within five thematic domains. For each domain, a specific question viewed as essential to consider has been outlined:

1 Engaging the entire family during admissions. Questioning the family-based foundation of the treatment program

2 Engaging the YP-AN during treatment. Questioning if treatment can become too oriented towards parents

3 Engaging the YP and family prior to the admission. Questioning the utilization of the pre-admission phase

4 Enabling sustained transitions. Questioning discharge planning and collaborations with the referral system

5 Strengthening relevant competencies within treatment teams. Questioning how recruitment, education and supervision is managed

1 Engaging the entire family during admissions. Questioning the family-based foundation of the treatment program

Our research suggested that participants viewed treatment as enabling families to join forces and work together in ways that strengthened within-family relationships and parental authority (Papers 1 and 4), which is encouraging. Still, it is important to consider the foundation of family-based treatment if important parts of the family system are frequently absent from the EDU, as was the case for most participants. In Paper 4, some of the siblings voiced the potential of increased family fragmentation, consequential of how the admission was organized.

The importance of engaging the whole family has since long been a favored stance in FBT for EDs (Eisler et al., 2015; Whitney & Eisler, 2005). Still, even in outpatient FBT-AN, a treatment model that emphasizes engaging both the parents and siblings in treatment, research indicates that regular attendance by all family members is challenging in practice. Particularly siblings have low rates of attendance, whereas mothers attend sessions most frequently (Hughes et al., 2015).

In Paper 4, the process of deciding upon a subsample of families revealed that we had interview data from few entire families (Nilsen et al., 2021). This could partly be due to some families with young children, and that although siblings may have stayed on the ward, they did not participate in the study because of their young age. Another aspect worth considering is that some siblings could have participated in family therapy sessions and thus engaged in treatment, but still did not partake in the study because they did not stay on the unit. Nevertheless, I believe the availability of complete data from relatively few families could mirror the rarity of admitting whole families for the duration of the stay during the period 2008-2014.

The EDU's preferred practice of enabling parents to make decisions regarding the extent of sibling involvement, I believe, can contribute to strengthening parental empowerment and decision-making. Still, this can also have a potential downside, as the full potential of the family-based admission may be compromised when siblings are not fully involved. When parents usually decides that siblings remain at home during admissions, parents themselves must take turns at being at the unit. Thus, this way of organizing an admission can make it especially challenging for the family to consolidate resources when working together from day-to-day. In my clinical experience at the EDU, I do remember frequent discussions between colleagues and within treatment teams, as contra-factual thinking of "how treatment *could* have been," *if* we had succeeded in boarding the entire family for the duration of the stay. Thus, retrospectively assuming that the therapeutic potential could have been enhanced in promoting sustained changes *if* the whole family had been present for most of the stay.

Our research (Papers 1 and 4) demonstrated that for some of the young patients, the treatment setting could represent a context potentially nurturing the ED. By engaging in peer interactions not properly managed by staff or parents, young patients *can* learn from peers by either observing, or by sharing or picking up ED behaviors from conversations with fellow inpatients (Vandereycken, 2011). Although these inter-personal dynamics may be difficult to completely prevent, they are important to consider. Thus, how clinical teams and families address and manage such frequently occurring dynamics in day-to-day care becomes essential. Although we can only speculate, a greater presence of family members, including siblings and both parents when available, could help maintain a better focus on the specific family, and their unique family dynamics, during admissions. Boarding the whole family could therefore facilitate the prevention of potentially destructive peer dynamics, increase the likelihood of sustained family relational changes, together with increasing the prospect of enabling shorter stays.

2 Engaging the YP-AN during treatment. Questioning if treatment can become too oriented towards parents

When the aim is to strengthen the family therapeutic focus during admissions, outpatient FBT is usually the treatment framework recommended to incorporate (Hoste, 2015; Murray et al., 2015). This approach is especially known for prioritizing the parental alliance, and thus, holds a more indirect therapeutic stance toward the YP with AN. Due to the roles and responsibilities ascribed to the parental system, FBT is therefore often described as a parental empowerment model (Forsberg & Lock, 2015). In addition to parental empowerment, one of the other key features of FBT is the conceptualization of AN using a narrative language (Lock & Le Grange, 2012). By strategically externalizing the ED and viewing AN as temporarily capturing the YPs mindset and behaviors, the YPs internal motivation becomes a less necessary requirement in order to promote therapeutic change. Although externalization of the ED is relevant for the duration of FBT, it is especially important at the beginning. As AN is theorized to prevent the YP in managing independently on their own, swiftly facilitating parental engagement by charging parents with increased responsibilities becomes crucial.

When incorporating the key features of outpatient FBT into the inpatient setting, the first step is therefore to restructure treatment to become a context in which parents are empowered. Staff thus needs to continually keep this stance in mind, in addition to integrating the other core features into their therapeutic practice. Considering the specific treatment setting within which this research was situated, i.e., a specialized EDU where the YPs and families have experienced several failed treatment attempts prior to the admission, it becomes pertinent to ask *if* there could be a risk of orienting treatment too much toward the parental system. As many of the patients also have had considerable family-based treatments prior to the admission without experiencing sustained changes, it becomes relevant to ask whether they now need “more of the same.” Do they need an intensified family-based treatment approach, or do they need something different?

The current research is not able to answer these important questions. Still, the study shed light on the importance of considering this issue, particularly in higher levels of care settings where cases are severe and complex, and importantly, for individuals whose prior treatments have also been guided by a family-based treatment focus.

Paper 2 demonstrated that YPs strongly favor a collaborative and tailored treatment approach (Nilsen et al., 2019b). Importantly, participants emphasize the necessity of clinicians being curious about their own viewpoints and perspectives during treatment. They largely speak in favor of clinicians being able to approach them as a unique person, as well as having an ED, and refrain from meeting them in ready-made ways, as there is no one-size-fits-all treatment. Informed by our interpretations of their feedback, we should therefore ask whether treatment sufficiently enables engaging the YPs during admissions. Collectively, the findings suggest that many patients, in retrospect, reflected upon the need for more personalized and tailored treatment toward their unique history, situation, and person. This is a stance reflecting previous qualitative research (Gustafsson et al., 2021) and echoes an evidence-based practice framework, where clinicians are encouraged to balance their clinical expertise with the best available research-based evidence, *and* persons’ own views, values, and perspectives (Peterson et al., 2016).

Findings from Paper 3 suggested the importance of strengthening YPs’ treatment engagement and commitment (Nilsen et al., 2020). This study accentuated the significance of participants’ beliefs in their own agency and highlighted self-responsibility for promoting change. As treatment unfolds, there is usually a fine line in negotiating the therapeutic alliance. On one side, treatment often needs to focus on non-negotiable treatment goals promoting improvements in physical health. At the same time, staff needs to incorporate and invest in the person's subjective perspectives and psychological needs (Geller & Srikameswaran, 2015). As frequently demonstrated, patients of all ages often present with ambivalence, fluctuating and even low readiness, together with a relatively low commitment to change (Abbate-Daga et al., 2013; Vitousek et al., 1998).

To what extent is the YPs' agency, motivation and treatment engagement managed within a predominantly family-based treatment framework that prioritizes the parental alliance? This I believe is important to examine, especially within treatment settings favoring a family-based treatment framework. This, I believe, becomes even more important to review in higher level of care settings where patients largely enter treatment with several previous failed treatment attempts, including prior family-based treatment (Halvorsen et al., 2017) and when the child often is of an older age (Dimitropoulos et al., 2015).

In a similar vein, findings from Paper 1 showed that some of the participants preferred a somewhat different treatment approach. Although not discrediting a family therapeutic emphasis per se, they suggested that admitting the entire family should not be the only option (Nilsen et al., 2019a). These are findings leaving us to speculate as to whether a slightly different way of organizing treatment could have better fostered change. We might speculate whether a different way of providing care *could* have better enabled treatment engagement and/or minimized conflict and resistance – at least for some. Additionally, Paper 2 shed light on how participants experienced the balance between a treatment with a predominant focus on ED symptoms as compared to a more holistic focus on them as a person. Quite a few participants expressed these concerns, as feeling being labeled "as yet another anorexic" (Nilsen et al., 2019b) – which raises the question of how externalization of the ED was managed, a hallmark with any FBT approach (Rienecke, 2017). Externalizing the ED as an illness "as if" separate from the person, could be especially challenging if the YP disagrees or find it hard to accept such a perspective, and externalization needs to be managed with wisdom (Voswinkel et al., 2021).

Although features of the therapeutic alliance and ED outcomes are presumably linked, these complex relationships are not clearly understood (Graves et al., 2017). Research has shown that the parental emphasis in outpatient FBT is mirrored in alliance evaluations, as it is usual to observe higher scores of parental alliance as compared with the YPs evaluations (Rienecke, Richmond, et al., 2016). There is also some preliminary evidence proposing the therapeutic alliance and outcome is differentially related for parents and the YPs (Rienecke, Richmond, et al., 2016). While parental alliance has been associated with weight restoration and treatment retention (Ellison et al., 2012; Isserlin & Couturier, 2012; Pereira et al., 2006), the YPs alliance has been associated with psychological measures (Isserlin & Couturier, 2012; Rienecke, Richmond, et al., 2016). The latter, I believe, could again suggest the value of an increased emphasis of how we manage negotiating the therapeutic alliance with the YPs during admissions, as research show that achieving positive sustained changes on psychological measures is especially lacking after inpatient care (Isserlin et al., 2020). Thus, managing an optimal balance between treatment recommendations as in prioritizing the parental alliance, and simultaneously engaging the YP becomes vital (Medway & Rhodes, 2016).

Consistent with this thinking, some authors have recently questioned whether a predominantly parent-oriented treatment framework as standard FBT is sufficiently able to engage the YP in treatment. This issue is being examined by ongoing work to develop an adapted FBT version for transitional-aged youths, allowing a greater focus of collaborating one-to-one with the YPs between the ages of 16-25. This is viewed crucial, as the authors view standard outpatient FBT as not always developmentally appropriate for older adolescents (Dimitropoulos et al., 2015). An increased emphasis on the YPs mind and behaviors is also reflected by ongoing work to advance adolescent-focused treatment for adolescents with AN (Fitzpatrick et al., 2010; Lock et al., 2010). Additionally, CBT is being developed specifically for adolescents as an alternative to FBT (Dalle Grave et al., 2013; Dalle Grave et al., 2014; Le Grange et al., 2020). In another recent paper, authors have investigated the potential of better integrating the key features of FBT with more individually-oriented approaches, to better align treatment with the YPs vulnerabilities and needs. A work that could have inspirational value for treatment providers at higher levels of care, aiming to foster better treatment engagement and collaborations with the YPs (Ganci et al., 2021).

3 Engaging the YP and the family prior to the admission. Questioning the utilization of the pre-admission phase

In the long run, hospitalizations are associated with a poorer outcome (Gowers et al., 2000). In one recent review the authors questioned the prospect of achieving sustained psychological changes during hospitalizations (Isserlin et al., 2020). Admittance to a specialized EDU is therefore no guarantee for a favorable outcome. As the long-term effect of hospital admissions is under debate, it is important to provide nuanced and knowledge-based information on the potentials of inpatient care. Despite this realism, it is crucial to install hope and emphasize that an admission represents a unique opportunity – *a potential context* – for working together to aid sustained changes. Assuming that the probable success of an admission is at least partly conditional on how treatment is planned and prepared, it becomes essential to critically review how the pre-admission phase is utilized.

Every admission to the EDU is preceded by a pre-admission phase. Usually, this phase runs from accepting the referral up until the date of the admission. Congruent with prior research (Anderson et al., 2017; Lockertsen et al., 2020; Treasure et al., 2005) Paper 1 suggests that individuals with a lived experience typically perceive the transition between services as a vulnerable period (Nilsen et al., 2019a). Undoubtable, hospitalization is a major life event, and findings in Paper 4 demonstrate that family members usually enter treatment with a variety of expectations (Nilsen et al., 2021). Entering treatment within a tertiary treatment facility, the YPs and family members take along their diverse treatment experiences. Common for most is that previous treatments have failed to promote sustained changes. Feelings of disempowerment, helplessness, self-blame, the experience of living in a continual crisis, together with a potentially limited trust in treatment, could all contribute to family members having different expectations of what is needed or desired from the services.

Largely, findings within and across papers suggest that treatment providers should critically reflect upon how admissions are planned and prepared. A more in-depth analysis of the perceived needs, prior treatment experiences and expectations concerning the upcoming admission may promote a more optimal vantage point for the admission. Additionally, our findings support the relevance of considering conducting formal assessments and exploring the possible benefit of providing tailored interventions prior to the admission.

In what follows, I briefly reflect upon different suggestions for assessment, the use of case formulations, and pre-admission interventions, as inspired by the current research and by the literature. The rationale for offering pre-admission interventions is motivated by the belief that investing more resources in pre-admission collaborations could help prepare YPs and families prior to entering a complex treatment setting, in addition to creating the context to initiate change processes prior to the admission.

Enhancing the pre-admission phase – assessments, case formulation and interventions to consider

Assessments. Standardized psychological assessments are rarely performed at the EDU prior to the admission. Instead, the decision whether to offer treatment or not is based upon the written referral, the referral systems evaluations and background assessments, and importantly; conversations with the YP, family and the referral system. This, I believe is not necessarily negative or a missed opportunity, yet more formal assessments during the pre-admission phase are worth considering, as the use of different assessment tools could aid in understanding the specific “case” and the unique family’s situation, and aid the development of a better tailored treatment plan.

More formal assessments to assist treatment planning could, together with suitable ED questionnaires and/or structured interviews of the YPs, include assessing parental accommodating behaviours (Sepulveda et al., 2009), self-efficacy (Byrne et al., 2015; Rhodes et al., 2005; Robinson et al., 2013) and expressed emotions (Le Grange et al., 2011; Rienecke, 2018) – factors associated with treatment outcomes. Additionally, assessment of meal management is likely relevant to evaluate more systematically *prior* to an admission, beyond inviting informal verbal feedback from the families. This could be arranged by inviting the family to one or more pre-admission meals. Meals could reflect the family meal session in outpatient FBT (Lock & Le Grange, 2012), be observed by staff and filmed to enable post-session feedback and reflections. The purpose would be to obtain a baseline of current meal management to help better tailor meal support from the outset, in addition to catalysing change processes prior to the admission. Additionally, this would also be an opportunity to determine whether one or both parents would benefit from therapeutic support for their own personal or inter-personal difficulties, which may potentially interfere with treatment.

Collaborative case formulation. Although informal case formulations are part of a treatment team's preparation work, this is not performed in a systematic way. Thus, another way of maximizing the pre-admission phase is by working collaboratively with the family in developing an initial systemic case formulation prior to the admission. This work should be arranged with the individual family and in collaboration with the referral system, who has usually supported the family for a considerable time.

Consistent with a recent paper on case formulations in ED focused family therapy by Baudinet and colleagues (2021), this work could address how different persons in the family conceptualize the ED and view factors related to the ED. This involves exploring different views on the potential predisposing, precipitating, presenting, protective, and perpetuating factors, with the aim of guiding the treatment team toward developing a tentative plan, with specific domains to target in therapy (Baudinet et al., 2021). This work would help to develop a mutual and more nuanced understanding of the emergence and maintenance of the ED within the unique family setting. Working collaboratively at the pre-admission phase could also strengthen the alliance and assist goal setting for the upcoming admission. Focusing on other key issues alongside the ED, such as family resources, protective factors, interests, future dreams, and family member's preferences for potential solutions could also broaden the lens beyond addressing ED symptoms. Addressing non-ED topics that often "fly under the radar," is often lacking in family therapy treatments, but desired by persons with lived experience (Gustafsson et al., 2021; Medway & Rhodes, 2016).

When adapted to a higher level of care setting, case formulation work could be two-fold. Firstly, this could encompass focusing on a systemic and broad understanding of the ED and the unique family situation as outlined above, and secondly, by emphasizing the upcoming admission by outlining concrete treatment goals, addressing roles, responsibilities and different needs of support. This case formulation could be incorporated into treatment plans and continuously updated during treatment. Finally, the formulation could ideally serve as a *potential bridge* post-discharge, when an updated version is handed over to the team responsible for following up the family after discharge.

Psychoeducation and/or skills-based program for parents. Usually, considerable time passes between the EDU accepting the referral and the actual admission. Outcome could thus potentially benefit from offering a tailored pre-admission intervention for parents. At pre-admission, EDUs aiming to strengthen the family focus might consider developing and implementing a parental educational program, adapted to the specific inpatient treatment setting. This type of program could seek inspiration from the new Maudsley Model (Franta et al., 2018; Philipp et al., 2021) emphasizing psychoeducation, caring styles and responses to the ED, and/or seek guidance from the literature on ED-specific family therapy at-large, in addition to providing information and transparency on the upcoming treatment program. Such an intervention could also include inviting a family previously admitted to the EDU to share their experiences and take part in discussions in a peer support format. A tailored parent program offered at pre-admission could be delivered either in a group format or individually. Sessions could consist of elements of psychoeducation, sharing information, invited discussions, reflections, and even role-play, to enable work on specific parental skills, such as meal support, or minding their child through emotion-focused work (Robinson et al., 2015). A structured program could also aid parents in managing their expectations, together with supporting them in developing skills and knowledge, which are highly relevant for the admission. Pre-admission workshops for parents could also be delivered online.

Pre-admission sessions targeting the YPs' treatment engagement. In addition to pre-admission sessions for parents, the EDU and other family-based treatments adapted for higher levels of care could consider developing a supplementary pre-treatment program for the YP-AN. Perhaps counterintuitive, as FBT is predominantly oriented toward empowering parents. Still, I believe this is especially relevant to consider when the YP has experienced several failed treatment attempts, including prior unsuccessful family-based interventions. It is even more important to consider if the YP present with treatment ambivalence and low readiness for change. Such a program could focus on providing information regarding the treatment program and seek to improve their knowledge of EDs in a supportive and non-judgemental way. It could include tailored psychoeducation, with conversations designed to explore and foster treatment engagement, or it could be less structured, inviting the YPs to talk freely about what they have on their mind. If structured, this pre-admission program could be grounded within a FBT framework by explaining the treatment rationale of inpatient FBT, and by supporting the YPs to become more accepting of their parents' increased responsibilities during the upcoming admission. In addition, the clinical team could consider incorporating elements from motivational interviewing (Treasure & Ward, 1997), motivational enhancement therapy (Feld et al., 2001; Ziser et al., 2021), providing literature and/or self-help (Cardi et al., 2020; Cardi et al., 2015), or prescribing written tasks, such as writing a letter to the ED or articulating arguments for or against change. As all interventions, these elements must be used with wisdom and adapted to the age and needs of the YP.

Sessions for siblings and/or including the wider family. Inspired by the literature on siblings (Medway & Rhodes, 2016; van Langenberg et al., 2018) and findings in the current study (Nilsen et al., 2019a; Nilsen et al., 2021), the EDU could consider pre-admission sessions for siblings and/or including the wider family. Offering siblings pre-admission sessions could provide them with better information, give them a chance to speak and ask questions to a trained team-member, and provide the opportunity to explore their perspectives on roles and responsibilities. We could also assume that caring better for siblings, could strengthen the family-based focus during admissions.

Inviting the wider family to a family network meeting could also enable sharing information about the ED and treatment, initiate dialogue, invite questions, and facilitate discussions that collectively, have the potential to engage other important persons in the family's network to participate in treatment, and thereby enable much-needed support for parents and the nuclear family. Inspired by an open dialogue practice, such gatherings of the wider family network could enable new and different stories to emerge (Botha, 2015). A potential consequence of including the wider family is to also counter typical family dynamics when a child has severe AN, including isolation, hopelessness and caregiver burden (Eisler, 2005; Whitney & Eisler, 2005).

4 Enabling sustained transitions. Questioning discharge planning and collaborations with the referral system

Relapse is common, even in recovered patients (Berends et al., 2016) and research has frequently demonstrated that the phase following discharge represents a high-risk situation (Khalsa et al., 2017). Findings from the current research also indicate that discharge represents a vulnerable transitional phase (Papers 1 and 4). Most clinicians working within inpatient services would agree upon the necessity of fostering sustained changes. Although staff aspire to provide patients and families with quality care and enable seamless and sustainable transitions, the reality is that discharging a patient or a family can be very challenging. This attributes to challenges with the ED and ED treatment itself and institutional or system barriers (Anderson et al., 2017). System barriers can also contribute to prolonged stays and rapid relapse following discharge (Treasure et al., 2005). Ideally, optimal discharge planning likely begins with the pre-admission phase. During the initial collaborative work of developing individualized treatment goals based on pre-treatment assessments, the case formulation, and assessing the needs of the YP, family and the referral system – discharge should also be discussed.

During the initial treatment planning, the treatment team should therefore be transparent on the forthcoming admission representing a *potential* and *temporary base* for working together for change. Throughout the admission, the team should emphasize the importance of managing and negotiating treatment collaborations, both with the YP, family and the referral system. This stance of acknowledging the temporality in higher levels of care is vital and underscores the time-limited nature of the admission within the treatment trajectory. Ultimately, the goal in higher levels of care is to enable families to step down in treatment as soon as feasible, and to continue care at a lower level. I therefore believe it is important at inpatient EDUs to strategically develop treatment plans with realistic and attainable goals, evaluate treatment continually and ensure collaborations with the referral system during the duration of the admission. The latter entails the importance of tentatively deciding upon "what happens after treatment" (Khalsa et al., 2017) before the admission starts, with flexibility throughout the course of treatment.

Findings in the current study indicated that both parents and patients could experience discharge negatively. The current study also suggested the importance of managing situations where YPs and/or families experience a lack of trust in the original referral system, yet are expected to re-enter treatment at their local treatment facility post discharge. Clinical teams at tertiary treatment facilities should consider sending weekly or bi-weekly reports to the referral system, together with ensuring ways to organize collaborative meetings during the admission. This is important to prevent discharge being experienced as poorly prepared and disruptive. Ideally, a tentative follow-up plan should be made in collaboration from the outset and negotiated throughout treatment.

Although relapse is common, relatively little research has systematically investigated developing post-discharge interventions (Giel et al., 2021). Usually, EDUs provide some form of after-care, as staff taking part in follow-up meetings and/or being available for telephone consultations if needed. Still, it is usual that treatment is transferred back to a very different setting post discharge, especially when the EDU covers a large catchment area, as was the case in the current study. As tertiary treatment facilities always operate within larger treatment systems, considering how the treatment setting manages its position within the larger treatment system thus becomes vital to consider, together with carefully reviewing how after-care and transitions are managed.

5 Strengthening relevant competencies within treatment teams. Questioning how recruitment, education and supervision is managed

> The therapist could be considered the lost variable of treatment research. More attention needs to be directed at understanding how the how therapists actually work in everyday clinical settings, and helping them to learn new ways of better using their strengths and improving their weaknesses (Clinton, 2010, p. 8).

Family-based inpatient treatment is a very complex treatment setting. Although only Paper 2 (Nilsen et al., 2019b) reports findings that directly highlight the importance of staff skills and expertise, I believe that overall, the current research underscores the importance that individual clinicians and treatment teams display competencies and skills across several domains in order to provide high quality care, as viewed from the service user's perspectives. As competence is not static, clinicians and treatment teams therefore need to stay atop of emerging knowledge, both within the ED field, including research investigating user experiences, and outside the ED-field. Thus, clinicians need to strengthen what could be framed as both their *internal* or ED-specific competencies, and *external* competencies, e.g., knowledge grounded in psychotherapy research, developmental psychology, neuroscience, and other relevant knowledge domains, including interventive skills from different treatment modalities.

Clinical expertise is a core feature of evidence-based practice (Peterson et al., 2016). There are different frameworks regarding how to develop clinical expertise. One framework of note when working within a complex treatment context such as the inpatient setting, is the pragmatic framework outlined by the Italian professor Laura Fruggeri (Fruggeri, 2011). This framework, which describes different levels of psychotherapeutic competence, represents a critical perspective on working with treatment manuals within systemic and family therapeutic treatment contexts. Positioning her framework as a critical approach towards manuals, this framework could be of high relevance for clinicians working within a hospital setting aiming to incorporate key features of a family-based treatment manual. In her model, in which she does recognize the value of treatment manuals, especially for cultivating what she describes as *technical* competence, Fruggeri underlines the importance of clinicians also embodying *institutional*, *reflexive* and *relational* competences, when engaging in therapeutic collaborations with families (Fruggeri, 2011).

Fruggeri's emphasis on the importance of staff cultivating different psychotherapeutic competences alongside manual-based and technical skills, resonates with a recent paper that questioned manual adherence when working with treatment manuals. As Fruggeri (2011), these authors (Robertson & Thornton, 2021) acknowledge that manuals can have many benefits. Still, they call for a greater focus on developing what Fruggeri characterizes as institutional, reflexive, and relational competencies, as there is little evidence of a sound relationship between strict manual adherence and treatment outcome. As the potential benefit of a manual is always influenced by the uniquely evolving therapeutic relationship, and embedded within unique clinical contexts, the authors recommend we critically question the focus on strict manual adherence in both ED training and supervision. In addition, clinicians would also benefit from considering treatment factors found valuable *beyond* the specific manual (Robertson & Thornton, 2021). Further, the authors suggest an enhanced emphasis in both education and supervision on *how* clinicians manage tailoring treatment to the individual patient in real-world settings, *how* they manage the emergence of complex therapeutic alliances and *how* they engage clients in collaborative work and foster readiness, beyond adhering to the specific manual (Robertson & Thornton, 2021).

These viewpoints also resonates with contemporary psychotherapy research that focuses to a greater extent on the therapist's contribution to treatment outcome (Heinonen & Nissen-Lie, 2020). Reverberating with Fruggeri's relational and reflexive competency domains (Fruggeri, 2011), both *facilitative interpersonal skills* (Anderson et al., 2009) and cultivating *professional self-doubt* (Nissen-Lie et al., 2017) have been identified as salient therapist factors associated with more favorable treatment outcomes – and should therefore be considered crucial for both training and supervision. Not as in competition with, but as adjacent to fostering technical competencies in more manual-specific skills.

Inspired by the user feedback provided throughout the current study, together with relevant discussions in the psychotherapy literature briefly reflected above, I suggest the EDU and different treatment facilities providing inpatient adolescent AN treatment review how they manage important domains as recruiting staff, education, supervision and skills-based practice more thoroughly. Although not mandatory, I also suggest reflecting upon whether education, supervision and skills-based training for employees could benefit from working within a specific framework of cultivating clinical competence, such as Fruggeri's pragmatic framework, for example (Fruggeri, 2011). Being guided by a framework or a model of cultivating different competencies could enhance clarity, provide coherence and better secure the type of training and supervision that enables moving beyond the specific skills endorsed by the contemporary favored treatment approach.

Specific domains to consider

Recruiting staff. When an EDU or other higher level of care setting opt to strengthen the family-based treatment approach, it is wise to recruit staff with expertise in both general child and adolescent psychiatry and systemic practice and family therapy. It is also an advantage to have psychiatrists and psychologists at the EDU with expertise in systemic practice, in addition to clinical experience from other psychiatric illnesses, as these professions typically lead multidisciplinary teams and hence, are typically responsible for decision-making. Recruiting staff with expertise and work experience from both general psychiatry and family therapy is of importance, as cases are complex with significant comorbidity.

Providing education. An EDU offering specialized family-based treatment could probably benefit from providing an ongoing education program for staff. This would be relevant for new employees being introduced to the preferred treatment modality in addition to continued education for staff working at the treatment center to broaden their skills and expertise. In addition to enriching knowledge of systemic thinking and skills in family-based interventions, this program could also benefit from educating staff about comorbid conditions, and incorporating knowledge from psychotherapy research that emphasizes the necessity of developing interpersonal skills and cultivating self-reflexivity. This program could be led by a team of senior staff or by hiring expertise from outside the EDU. As suggested, such a program could benefit from focusing on both core interventive skills and stimulating reflexivity on different levels of competencies (Fruggeri, 2011).

Supervision and emphasizing skills-based training. Even experienced clinicians need supervision. Supervision could be managed in a group format on a regular basis and offered individually when necessary. Supervision would benefit from aligning with the preferred treatment modality and reflect the demands of working with complex cases, with an overarching aim of fostering a safe treatment environment for both staff and clients. Supervision should enable staff to share challenging clinical examples, foster transparency and self-reflexivity, and learning from practice. Sessions should be separated from cathartic debrief and include role-play and interpersonal activities reflecting day-to-day dilemmas to strengthen skills-based training. To secure personal and professional development one could consider ongoing supervision being guided by either deliberate practice (Rousmaniere, 2017) or personal practice (Bennett-Levy, 2019; Bennett-Levy & Finlay-Jones, 2018) frameworks, in order to facilitate both intellectual and emotional reflexivity and concrete skills-based training.

Staff members and treatment teams could, for example, identify relevant skills to cultivate. Individual staff members could develop personal plans for skills development based on specific domains, and receive feedback from group members and supervisors. Targeted skills would vary from person to person. This could include staff training on how to empower parents during a difficult meal setting, where parents articulate hopelessness and prefer that staff assume responsibility. It could be working with engaging the YP within a family-based treatment program without taking the parental role, addressing treatment resistance with curiosity and empathy, and/or developing skills in communicating how hunger affects the brain, to name a few examples.

D. Ideas for future research

Strengths and weaknesses pertaining the dissertation's different original studies are reflected in the different papers (Halvorsen et al., 2017; Nilsen et al., 2019a, 2019b, 2020; Nilsen et al., 2021). Perspectives on limitations related to the current study is also reflected throughout the method and discussion section. Below I suggest different projects, all aiming to push our knowledge further, of how to optimize the inpatient treatment setting for YPs and families in need of intensified treatment. These suggestions are inspired by both my own research, limitations pertaining the current research, and more in general, the lack of sound empirically based knowledge of how to optimize adolescent AN inpatient care.

Outline a description of the treatment program. Moving forward, it would be advisable to outline a more formal description of the inpatient treatment program at the EDU. This would be beneficial for both research and clinical purposes, and should be framed as a flexible protocol or treatment guide, allowing tailoring treatments toward the unique presentations and needs. This work could be carried out by a collaborative team of clinicians with work experience at the EDU, and be informed by reviewing relevant literature, including research from the follow-up study (Blikshavn et al., 2020; Fjermestad et al., 2020; Halvorsen et al., 2017; Halvorsen & Ro, 2019; Nilsen et al., 2019a, 2019b, 2020; Nilsen et al., 2021). To supplement this endeavor, one could also explore relevant topics to include by interviewing staff at the EDU, either in-person and/or focus groups by interviewing treatment teams. Additionally, one could also consider a small-scale field work project, investigating treatment "as it unfolds" in real time for a designated time period.

A written and easily accessible description of treatment could be of value for staff education and serve as a formal reference when the EDU makes corrections and implements new treatment features in the future. Ensuring the treatment program is more accessible could also aid treatment development at the EDU and stimulate developments across treatment facilities. Outlining a flexible manual, while balancing the aims embedded in the treatment program together with describing clinical dilemmas from day-to-day practice with suggested solutions, would likely be an inspirational resource for the adolescent ED field. To ensure user perspectives, previously admitted family members could be invited to form a reference group.

Investigate the feasibility of different pre-admission interventions. To enhance our knowledge of whether greater preparation for the upcoming admission could improve outcome involves conducting research to evaluate the feasibility of some of the suggested pre-admission strategies. This could involve investigating 1) the feasibility of a tailored program for parents, including skills-based training, 2) pre-admission interventions for the young patients, and 3) pre-admission network meetings including larger family networks. Yet another relevant pre-admission intervention to explore is the implementation of a pre-admission meal-training program for families, inspired by the family meal session in outpatient FBT. Providing structured pre-admission meal sessions could be of benefit for the upcoming admission, as families will be better attuned to the predominant treatment focus during the admission and the clinical team could better assess the family's meal management and support needs. This work could focus on roles and responsibilities during meals and include emotional coaching and tailored support aligning with the preferred treatment focus. In some instances, this intervention could also facilitate change processes that makes the admission redundant.

Another future research direction involves investigating whether implementing formal assessments at pre-admission and the use of a systemic case formulation prior to the admission can make a difference for quality of care. The potential effects of and experiences with such an approach could be evaluated by interviewing staff, families and the referral systems. When investigating the different pre-admission interventions, a mixed-methods design could be advisable, in order to generate both quantitative and qualitative data.

Interview study of experienced ED clinicians. Another research avenue to determine the optimal way of adapting the core features of FBT into intensified treatment settings is to conduct a qualitative study to interview experienced ED clinicians. In such a study, interviewing clinicians about their decision-making and problem solving of perceived salient dilemmas could be the emphasis. Exploring clinicians' lived experiences with FBT adaptations in higher levels of care, investigating their opinions, meaning making and perceived dilemmas, could be of value for furthering our knowledge of *how* to optimize inpatient care. This work could also focus on addressing perceived facilitators and barriers and invite reflections on what clinicians feel characterizes optimal inpatient care. This research could generate knowledge to inform the writing of consensus-based guidelines for adolescent AN inpatient care. Interviews could be conducted with clinicians working at the EDU and elsewhere, as well as staff working abroad in similar settings. To supplement research focusing on clinicians' perspectives, one could also consider investigating recurrent dilemmas with adapting FBT core features from different service user perspectives.

Investigate how providing an education program with supervision affects clinicians' self-efficacy, job satisfaction and perceived competence. As reflected upon above, the EDU could consider developing a tailored education program for staff. Together with providing general knowledge of EDs, treatment and common comorbid conditions, the program should emphasize managing outpatient FBT core features within an inpatient setting. This education program should also aim fostering interventive skills and therapeutic stances that moves beyond standard FBT, as cases are complex, and staff needs to be equipped with multiple competencies and interventive skills. The program could therefore, in addition to emphasizing FBT interventions; aim to strengthen staff skills and competency in systemic thinking and self-reflexivity. The program could also benefit from incorporating features from other treatment modalities, such as DBT, CBT, emotion-focused strategies, together with providing knowledge of common factors research. The impact and perceived utility of the program could be investigated by conducting a mixed-methods study combining quantitative measures with focus group interviews and/or in-person interviews. Results should feed back into developing the program.

Conducting a pilot study investigating how well-prepared and time-limited admissions impact outcome and user experiences. In this pilot study, three or four of the six beds could be reserved for a highly structured, well-prepared and more time-limited inpatient FBT approach (i.e., maximum 8 weeks, where the whole nuclear family is preferably boarded for at least the first 4 weeks). The other two or three beds would then be reserved for longer-term admissions (up to 4 months or longer) for highly complex or severe cases. By this restructuring, the EDU could a) potentially serve more patients/families in the catchment area, and b) investigate how briefer and highly focused admissions are compared with prior “treatment as usual”. Here, too, we could imagine a mixed-methods study, evaluating both quantitative outcome and user feedback, including feedback from the referral systems on how they perceive this type of differentiated support from the EDU.

Developing an ED-family-based inpatient treatment-specific feedback system. Inspired by the current research and psychotherapy research advocating feedback-informed approaches, it could be advisable to develop a questionnaire or another system of obtaining feedback to track user experiences systematically *during* treatment. Currently, patients and families are invited to retrospectively share feedback during a post-admission interview 6 months after the end of treatment. A new approach could be implemented *as treatment proceeds* to provide clinicians with feedback of how treatment is perceived and experienced. Ideally, such an instrument should address user perspectives on core features of inpatient treatment, including an evaluation of the alliance. The feedback system should have unique modules for each family member and include a multi-disciplinary team version.

Implementing an aftercare intervention and evaluate its potential impact on managing sustained transitions. Regarding the vulnerable phase after discharge, the EDU could consider piloting a structured aftercare intervention and conduct research on its feasibility. The intervention should allow sufficient flexibility to accommodate different needs, and ideally, it should be well integrated with the team responsible for following up the family after discharge. An aftercare intervention could include post-discharge "booster sessions" with the YP and their family, along with the team responsible for follow-up. The intervention could also include a relapse prevention module utilizing written self-help materials inspired by skills exercised during the admission. A main aim could be investigating whether providing a tailored aftercare intervention contributes to promoting better sustained changes, to prevent relapse and the need of re-admissions.

Conclusion

To our knowledge, this is the first investigation of the experiences of YPs with AN and their families with being admitted to a family-based inpatient program with a length of stay beyond two weeks. With its "insider focus," this study contributes to the literature by providing knowledge of how critical aspects of family-based inpatient treatment for adolescent AN are experienced from different user perspectives. Findings inform ongoing practice, and the themes developed in the different papers represent "food for thought" for clinicians engaged in these efforts. Overall, the study has the potential value of advancing treatment developments by adding important user perspectives, which are marginalized voices in most outcome research.

On one hand, findings largely support emerging quantitative research, which suggests that providing a family-based inpatient treatment approach could be a promising way of delivering adolescent AN inpatient care. On the other hand, the study widens the scope of quantitative outcome research by adding nuance to the many complexities associated with providing family-based inpatient care. Throughout, findings demonstrate there are no ready-made solutions, and clinicians therefore need to sensibly tailor treatment despite the structured setting. In order to facilitate treatment collaborations and enable sustained changes, treatment and transitions need to be carefully planned and prepared. Sibling involvement needs to be carefully weighed, and staff needs to strive for a balance between supporting parent empowerment *and* engaging the adolescent during treatment. Another important issue involves securing a balance between focusing on alleviating somatic concerns during treatment and addressing the psychological needs of the YP. In general, the study underscores the variety of skills and breadth of clinical expertise that clinicians should posit. Additionally, the study demonstrates that although YPs with a lived experience of AN who received family-based inpatient treatment largely recognize the need for support from others, including family and professionals, they especially emphasize their self-responsibility and own determination in order to get better. These are findings inspiring us to further reflect on how we can better engage YPs during predominantly family-based treatment.

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Minding the adolescent in family-based inpatient treatment for anorexia nervosa: a qualitative study of former inpatients' views on treatment collaboration and staff behaviors

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Abstract

Background: For some young persons diagnosed with anorexia nervosa, treatment will inevitably involve phases where hospitalization is required. Inspired by the encouraging evidence-base for outpatient family-based treatment for adolescent anorexia nervosa, clinicians and program developers have started to incorporate outpatient family-based treatment principles into higher levels of care. During family-based inpatient treatment, collaborative efforts are largely directed toward the parents of the adolescent. Consequently, the therapeutic focus on the young person is more of an indirect one. With this study we aimed to understand how young persons with lived experience from a family-based inpatient treatment setting, where the adolescents were admitted together with their parents, viewed therapeutic aspects related to staff-patient collaboration and staff-related behaviors.

Methods: Thirty-seven semi-structured interviews of former adolescent inpatients were conducted. Participants' post-treatment reflections were inductively analyzed by applying a thematic analytic framework.

Results: Based upon user perspectives from a treatment setting highly influenced by a family therapeutic approach, findings revealed that former inpatients prefer tailored treatment and a collaborative approach. Eight subthemes constituting two main themes emerged: 1) *There are no ready-made solutions. Staff should facilitate collaboration by tailoring treatment toward the young person's perspectives, and 2) Emphasizing skills that matter. Staff should display a non-judgmental stance, educate patients, stimulate motivation, enable activities and prevent iatrogenic effects during the stay.*

Conclusions: This study adds valuable user perspectives to the ongoing work with adapting family-based frameworks into higher levels of care. Clinicians could benefit from viewing their practice from the standpoint of the young person's post-treatment reflections. From their unique perspectives as having lived experience and hence, "insider knowledge" with a specific treatment situation, clinicians are reminded of the importance of being mindful on the young persons' views.

Keywords: Anorexia nervosa, Adolescent, Family-based treatment, Hospitalization, Qualitative research

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Background

Engaging the young person with anorexia nervosa (AN) in therapy is typically challenged by the disorder's characteristic ego-syntonic symptom quality and fluctuating motivation for change [1, 2]. As patients often attribute positive values to illness behaviors, it is not surprising that clinicians can find it demanding to uphold a health promoting therapeutic relationship with adolescents with AN [3, 4]. For adolescents with AN, a family therapeutic approach is usually recommended [5]. Even in a well-established evidence-based treatment such as outpatient family-based treatment (FBT) [6], creating and managing fruitful working relationships has been found difficult [7–9].

For some young patients diagnosed with AN, treatment will inevitably involve phases where hospitalization is required. Motivated by the encouraging evidence for outpatient FBT [10], clinicians and program developers have started to incorporate FBT principles into higher levels of care [11–14]. Although these developments could be a promising step for those in need of hospitalization, more research is needed on how to tailor and adapt family-based interventions into inpatient care [15, 16].

Creating and managing a collaborative therapeutic relationship has frequently been positively associated with psychotherapy outcome [17]. This relationship (i.e., the alliance) has been pan-theoretically conceptualized as consisting of three intertwined domains; therapeutic goals, tasks and the affective bond [18]. Within this framework, the quality of the alliance is related to the degree the patient and therapist (i.e., staff) are able to collaborate on therapeutic tasks and goals, as well as the quality of the affective bond [19]. This interpersonal process of co-constructive collaboration is thus embedded in the alliance construct. As a common factor, negotiating the alliance, or collaborating within each of these three domains, lies at the heart of all psychotherapeutic conversations. This relationship has usually been investigated within the therapist–patient dyad and involving adult patients [17, 20]. For adolescents diagnosed with AN, it is both appropriate and necessary to go beyond the therapeutic dyad and involve the whole family in treatment [6, 21]. Hence, in family-based treatments for AN, the emergence of co-existing and multiple working alliances implies further complexity for both creating and managing collaborative relationships.

The parental working alliance is inevitably prioritized during the first phase of FBT. In FBT, parents are charged with the responsibility of managing refeeding and weight restoration. The therapeutic effort converges toward aiding parents to manage this increased responsibility [6]. This more or less all-encompassing emphasis on parents is correspondingly pursued when FBT-principles are adapted to an inpatient setting [12]. Engaging the adolescent in conversations on personal and adolescent-related issues, which may need to be addressed therapeutically, is postponed to the last phase (i.e., toward end of treatment, when weight is restored and the adolescent is able to take back control of eating). Hence, the focus on the adolescent during the initial phases of family-based treatment is toned down.

Although presumably important within a family-based treatment framework, the relationships between aspects associated with the therapeutic alliance and ED outcome are not yet clearly understood [22]. Still, research has shown that the strong parental emphasis embedded in outpatient FBT is mirrored in alliance evaluations, as it is usual to observe higher scores of parental alliance, when compared with the young persons' scores [23]. There is also some preliminary evidence suggesting that the therapeutic alliance is differentially associated with outcome for parents and the young person [23]. Parental alliance has been associated with weight restoration and treatment retention [24–26], whereas the young persons' alliance has been associated with psychological measures [23, 24].

Qualitative research on patients' treatment experiences can both aid treatment development and aid clinicians to tailor interventions [27, 28]. Qualitative research has shown that patients with AN typically prefer treatment to be a joint and collaborative effort and favor therapists who are supportive, non-judgmental, active (i.e., taking initiative), respectful and caring [29–32]. Overall, qualitative research on patient preferences seem to converge toward patients favoring therapists that are skilled in ED management, and able to utilize a wide range of behaviors (i.e., displaying both acknowledged therapeutic stances and capable of multiple ways of intervening), when engaging patients in therapy [30, 32]. Reassuringly, young patients taking part in outpatient family-based treatment seem to appreciate the increased parental responsibility, externalization of the ED and that treatment enables lower degrees of within-family criticism. Still, this research has also shown that in hindsight, adolescents prefer greater involvement in family-based treatment, as important issues are perceived as being neglected [33]. Although quantitative studies of the relationship between therapeutic alliance and ED outcome show mixed results [22, 34], findings suggest that the quality of the therapeutic relationship can be of extra importance for younger patients. In fact, various aspects of the therapeutic alliance have shown stronger relations to outcome for younger versus older patients [22].

The present study was conducted within a family-based treatment context where adolescents are admitted together with parents, and, if appropriate, siblings. Our study aligns with previous qualitative research which has called for additional research to address the perspectives and viewpoints of young AN patients involved in family-based treatment [28, 33]. Our overarching aim was to investigate post-treatment reflections following discharge from a treatment program which, corresponding to family-based treatment, emphasized parents. Specifically, the research questions were a) how do the participants with lived experience from a family-based inpatient treatment experience collaboration with staff, and b) which staff behavior and skills are valued and/or considered important. By prioritizing the young person's "insider knowledge" with a family-based inpatient program, we aimed to inform ongoing discussions on how to optimize the inpatient setting for those in need of family-based treatment for AN at higher levels of care.

Methods

This is a qualitative study that forms part of a larger research project with a naturalistic design aimed at investigating the outcome of inpatient family-based treatment within a tertiary ED inpatient unit for adolescents [11].

Participants

Thirty-seven (64%) of 58 invited former inpatients (33 females/4 males), provided written consent to participate in this sub-study. For the sole participant under the age of 16 (i.e., age of consent) at follow up, parental consent was also provided. There were no significant differences on clinical and demographic variables when comparing participants with non-participants [11]. All had a primary diagnosis of AN, and were admitted together with family members between 2008 and 2014. Prior to the family-based admission, all participants had received outpatient treatment at their local child and adolescent clinic. Approximately three-quarters previously had at least one inpatient admission to their local hospital. Duration of ED prior to the family admission (FA) was on average 2.7 years (range; 0.5–6.0, *SD* = 1.8). Mean age at admission was 15.8 years (range; 12.4–19.5, *SD* = 1.8). The majority (33/37) were admitted voluntarily. Mean length of stay was 20.8 weeks (range; 3–58, *SD* = 13.5), including planned leaves from the ward as part of the treatment program. All families agreed to stay at the hospital with their child during the hospitalization. The mean number of years after discharge to the follow-up interview was 4.5 years (range; 1.3–7.0, *SD* = 1.7). The mean age at follow up was 20.2 years (range; 15.8–25.3, *SD* = 2.6). Thirty-eight percent had received additional inpatient treatment during the follow-up period. At follow up, the majority (65%) had achieved normal body weight, as defined by attaining a BMI ≥18.5 [11]. The mean body weight improved during admissions (7.6 ± 4.3 kg), and the mean BMI-percentile at discharge (21.4 ± 17.8) was in the normal range (i.e., > 12, which corresponds to approximately BMI 18.5 in adults).

Twenty two (59%) participants did not meet the criteria for any DSM-V ED-diagnosis, 8 met criteria for AN, 2 for BN and 5 for OSFED. ED diagnoses at follow-up were determined by using the diagnostic items of the Eating Disorder Examination 16.0 [11, 35].

Treatment setting

Throughout family-based inpatient treatment, staff actively promotes collaboration with parents. Consequently, the therapeutic focus on the young patient is more of an indirect one. Without adhering to manualized FBT, the guiding treatment principles were inspired by outpatient FBT [6, 11]. The overall treatment focus for the majority of participants corresponds to the first phase in outpatient FBT. The main treatment program features included giving parents increased responsibility for managing meals and weight restoration, externalizing the ED and adhering to a non-blaming and non-etiological stance. The main programming consisted of family therapy, supplementary individual therapy and milieu therapy with the overarching aim of supporting parents to support their child during the stay.

Up to five families were hospitalized at the same time. Although all members of staff assisted families, each patient and family were allocated a multidisciplinary team during the duration of stay. The nucleus of this team consisted of a child- and adolescent psychiatrist working closely with a clinical psychologist, and two or three nurses. The team and family members could consult a clinical nutritionist as needed. Families were typically offered family therapy sessions at least twice a week. Some patients were offered supportive individual therapy in addition to family therapy, and this was arranged in collaboration with the adolescent and parents. Nursing staff had daily scheduled conversations with both parents and the young person, for preparing meals and evaluating the ongoing process, together with spontaneous ad hoc sessions as needed during the day. Patients and parents took part in the weekly treatment meetings. At discharge, all patients and families were referred back to their local clinic for further outpatient treatment.

Recruitment and data collection

Ethics approval for this study was obtained from the Regional Committee for Medical Research ethics, South East Norway [REK2014/2223]. Thirty-seven participants took part in a semi-structured interview which was administered by a senior researcher, two clinical psychologists, one psychiatrist or a psychiatric nurse. Four of the interviewers had been directly involved in the provision of treatment. Twenty-six of the interviews were conducted on-site at the hospital, seven at the participant's home, three by telephone, and one in-person elsewhere. All interviews (including telephone interviews) were audiotaped and transcribed verbatim. The qualitative interviews lasted between 30 and 100 min.

Interview guide

The semi-structured interview guide was originally developed to investigate participants' post-treatment reflections on a range of issues, and not specifically designed for the sole purpose of this study's research questions. The interview was structured into three sections: pre-admission, during admission, and post-admission experiences. Main questions used for the present study included, "Looking back, how was the admission for you?" "How did you experience the support from the staff?" "Do you have any ideas on wanting anything to be different during the family-based admission?" and "What should treatment providers emphasize in their work with adolescents with an eating disorder?"

Qualitative data analysis

All 37 participants were included in the qualitative thematic analysis to allow as much diversity in views as possible. Transcripts were analyzed according to six phases outlined by Braun and Clark [36]. The analysis was mainly informed by an inductive and semantic approach. Inductively analyzing the transcripts meant that we aimed at staying sufficiently long with the raw material to "truly" grasp the meaning of the accounts. Applying a semantic approach implied that the explicit and surface meanings were primarily considered, rather than inferring beyond the content conveyed in the accounts, as would be the case with a more interpretative, implicit approach [36].

First, the first author read all the transcripts several times. To increase familiarity with the material, three of the co-authors read randomly selected interviews. The first author was responsible for coding, identifying and developing the main themes and adjacent subthemes. The analysis was conducted in close collaboration with two of the co-authors (HWO and TWH). Following multiple team discussions, the theme structure was reviewed and discussed, and during the process there were several modifications to achieve a final consensus between all collaborators (i.e., JVN, TWH & HWO) on how the specific labels and structure could best reflect the raw material. Before completion, the first author read all transcripts to ensure that the themes captured the material in a reasonable way. The QSR International's Nvivo11 Software was used in the initial phase of coding [37].

Results

The thematic analysis yielded 2 main themes and 8 adjacent subthemes (see Table 1) as presented below. Subthemes are illustrated by quotes. The source of each quote is indicated by the participant's research ID number. Quotes are directly translated from Norwegian to English with only minor revisions to enhance readability.

Main theme 1: there are no ready-made solutions. Staff should facilitate collaboration by tailoring treatment toward the young person's perspectives

The majority of the participants emphasized that treatment must be a collaborative and reciprocal endeavor. Several suggested that treatment teams should aim for developing a novel or unique treatment for each patient and "not do the same thing over again." Quite a few participants reflected that a more adolescent-oriented approach was needed, and that health care professionals should be mindful of individual differences in needs and vulnerabilities, with flexibility in potential solutions. Many emphasized that treatment teams should integrate the views of the young person into decisions, allowing for a more shared and dynamic decision-making process. The subthemes portray the aspects of collaboration which were valued as especially important.

Subtheme 1: It's not always best to go by the book

Participants stressed that treatment should be tailored to fit the individual, family, and their unique situation. Some called for more comprehensive assessment of their specific needs and vulnerabilities prior to the start of treatment. Several reflected that they felt the treatment approach or dominant structures were too predetermined:

> *P: … individuality … ehm … yes … be aware that they are different patients … different disorders … and different illness histories … maybe not just do the same thing over and over again … that it is not always … it's not always best to go by the book … [P60].*

Table 1 Minding the adolescent in family-based inpatient treatment

Main theme 1: There are no ready-made solutions. Staff should facilitate collaboration by tailoring treatment toward the young person's perspectives	Subtheme 1: It's not always best to go by the book (*N* = 25) Subtheme 2: Managing the balance between the symptoms and the person (*N* = 18) Subtheme 3: Managing the balance between flexibility and firmness (*N* = 25)
Main theme 2: Emphasizing skills that matter. Staff should display a non-judgmental stance, educate patients, stimulate motivation, enable activities and prevent iatrogenic effects during the stay	Subtheme 1: Beware of stereotypes and prejudice: cultivating respect and curiosity (*N* = 24) Subtheme 2: Exploring and working with personal goals: strengthening the young person's own motivation for recovery (*N* = 20) Subtheme 3: Providing information and transferring knowledge in meaningful ways (*N* = 15) Subtheme 4: Enabling a shift of focus by providing activities (*N* = 14) Subtheme 5: Addressing and working with covert ED-behaviors at the ward: be attentive and preventive (*N* = 13)

Numbers in parenthesis (N) equals the number of participants' sharing accounts within each subtheme

… and others, that treatment has to be wisely adapted, since treatment is not “one-size” fits all:

> *P: There is no one way of having an eating disorder. There are as many eating disorders as there are persons suffering from them, so you can never have a book for how you manage “Eve 14 and her anorexia” … there is no … it’s not like that … [P15].*

Subtheme 2: managing the balance between the symptoms and the person

Several of the participants reflected on the importance of not losing sight of the person behind the symptomatic behaviors. Several emphasized the importance of striking a balance between focusing on the person versus the ED, and echoed the potential negative consequences of an unbalanced approach (i.e., too symptom oriented). Even though the vast majority acknowledged the necessity of weight restoration and managing somatic complications during treatment, many had views similar to P56:

> *P: I wish that, at least in certain phases of treatment … that there could have been more focus on me, who I was, and not just how the ED influenced me. I was in pretty bad shape when I was admitted and it became easy, in a way, to not see me … one only saw what was driving me. That was also a frustration I had back then, because I was really suffering and the ED became, in a way, my survival technique and that they in a way just took that from me, without giving me the chance to get better. That was very painful … and … that … yes … I did gain weight during that admission, but I didn’t feel that I had really improved, thinking differently, when I was discharged … [P56].*

Others shared views in line with P10:

> *P: I often felt like a number, from week to week … that in a way … it was the number on the scale that decided how it went that week … and that this didn’t relate to how I felt … and when you, or the staff, was most happy … because I had gained … that was the most difficult part for me … [P10].*

Subtheme 3: managing the balance between flexibility and firmness

Several participants shared their perspectives on rules and routines encountered in the highly structured inpatient setting. Taken together, this subtheme conveys a need to manage the inpatient structure in a more collaborative way to match the perceived needs and vulnerabilities of the individual. Many of the participants preferred that rules be negotiable to a certain extent. Quite a few reflected on the difficulties of adhering to strict rules that did not seem to fit their perceived needs at the time. For instance, being required to participate in mandatory group resting time after meals could be viewed as unnecessary for those without problems sitting still or purging, and possibly promote disengagement or resistance to treatment. However, some participants favored rules, as rules were viewed as necessary and therefore valued:

> *P: That I wasn’t allowed to negotiate then … That it was … That I couldn’t do. That was a good thing, because then I gave up on that, and … even if it sounds a bit silly; that you should eat every last bit of that yoghurt … it was … making me safe … […] … Ehm … that it was … ehm, that it was … ehm … strict … that was at least making me secure … [P34].*

Whereas others advocated for a more flexible and individualized approach:

> *P: I think the rules should be more individually adjusted, so if you don’t have a certain problem, you don’t need to face the same rules as those who in fact struggle with it … [P51].*

Main theme 2: emphasizing skills that matter. Staff should display a non-judgmental stance, educate patients, stimulate motivation, enable activities and prevent iatrogenic effects during the stay

The second main theme captured 1) the acknowledgement by participants that AN treatment is a highly complex and difficult endeavor, and that 2) staff needs multiple skills within different domains to engage the young person in treatment. While the first main theme captured the participants’ call for modifications and individual tailoring of treatment, the second theme pertained to preferred staff characteristics and skills.

Subtheme 1: beware of stereotypes and prejudice: cultivating respect and curiosity

Participants emphasized the importance of friendliness and kindness. Some emphasized that years of medical education and extensive clinical experience did not matter if staff did not treat the young person with respect and curiosity. Some remarked that they easily noticed whether staff members were emotionally invested in their jobs, and preferred staff that were highly invested in their work and “not just doing their job to get their salary.” Respect, genuine curiosity, and a non-judgmental stance were all highlighted as important professional characteristics. Some emphasized that they were usually treated with respect and curiosity during their admission, which had boosted treatment involvement.

> *P: They were considerate, respected me for who I was. They were attentive, that was of importance too, and I felt in different ways that they understood me, and that I … like, opened up and in ways observed, noticed their reactions. And then I felt even more secure … and, that I could open up even more and more. That I remember as a good thing … [P23].*

Others, however, reflected upon having the opposite experience, being perceived as “yet another anorexic” and stereotyped in generalisms. Quite a few participants cautioned staff against being too “know-it-all”. Participants underscored the importance of staff displaying a genuine interest in getting to know them as people, and understanding the influence the illness had upon their lives, without too much preconception.

> *P: … they said things that maybe … as if they knew … said things in ways that sounded like they in a way knew things better than me … and that … They couldn’t know how I felt and how things were for me … And some were maybe generalizing a bit, on how the ED was … because that is individual, for everybody … [P56].*

Subtheme 2: exploring and working with personal goals: strengthening the young person’s own motivation for recovery

Working with the young person’s own motivation for change was emphasized. Participants acknowledged this was a demanding undertaking, as many recalled being highly indecisive and some even resisting treatment during the admission. However, several participants viewed personal readiness and commitment to change as the most important aspect of recovery, thereby deserving greater attention during treatment. Many participants shared views such as “you have to want to change yourself, to make change happen” or “it was when I decided to change myself that change really started to happen”. Collaboratively exploring and setting personal future-oriented goals were emphasized as important mechanisms to enhance treatment engagement and provide meaningful goals. In hindsight, several acknowledged that identifying personal reasons to recover was a crucial component in the recovery process:

> *P: … that [motivation] is the most crucial aspect, right? in the treatment of eating disorders … so … that is the most important … when motivation emerges you have to do anything to maintain it … because it is so crucial and rare … that is what makes eating disorders so difficult to treat … that it is the only disorder you don’t want to get free from … that’s why motivation is so important when talking about treatment … [P60].*

Subtheme 3: providing information and transferring knowledge in meaningful ways

Participants emphasized that staff should be highly skilled in providing information and transferring knowledge, for example, on the various somatic and psychological aspects of starvation, purging and excessive exercise. Reflecting back, however, participants acknowledged this might be difficult to accomplish immediately upon admission, as the young person may have little interest, or regard this information as irrelevant during early phases of treatment:

> *P: It would have been useful with more information on the physical consequences by being underweight over time, and on how physical and mental states influence each other. Because that is really something I’ve had to discover myself. I don’t think I really got any information … [P10].*

Others reflected on the necessity of advice or information being delivered in a constructive and collaborative manner, not just stated repeatedly as factual information to be trusted:

> *P: … You have to make them think … not just tell them to … for example; “you have to eat so and so much” … it wouldn’t be of any help … maybe there and then … but in the end you have to work on the mental part … make them to work on the psychological issues first … that was at least what I did … and after a while the other things will find its way … it is important to find the drive … to answer the questions of “why … should I do this, why should I eat more … why should I gain weight” … and [help them] transcend the fear we all have, of getting fat … and all that … [P22].*

Subtheme 4: enabling a shift of focus by providing activities

Several highlighted the importance of initiating a variety of activities to engage young patients and shift the focus away from a potentially highly monotonous treatment environment. Shifting focus by providing extracurricular activities also accommodated other important aspects of their daily lives. Some encouraged staff to feel “freer” when engaging the young patient, and not be too afraid to assume the parents' roles and responsibilities. Rather than requesting activities for the family to do together during the admission, participants appreciated staff-led initiatives, as the feeling of boredom during treatment can represent a vulnerable situation.

> *P: Once we went to an amusement park … and we got to live more as normal human beings … [P33].*

Several called for activities beyond the ED-focused treatment schedule, and emphasized the importance of variety:

> *P: It was very quiet here. It was helpful when I could go out and go for a walk and things like that … It easily becomes boring when you're admitted … so I think … It was a small activity room here … but things were very little organized around that … […] so maybe a bit more drive from the staff too … to ask whether we should do things … [P31].*

Subtheme 5: addressing and working with covert ED-behaviors at the ward: be attentive and preventive

Some emphasized that illness behaviors were both maintained and exacerbated within the context of the treatment unit, even during family-based admissions. Examples of illness behaviors included self-induced vomiting, excessive exercise, water loading pre-weighing, and attaching objects to the body to increase weight. Some participants felt that these behaviors were poorly addressed during treatment, and some reported learning new ED-behaviors while hospitalized. Reflecting back, participants emphasized that staff must be knowledgeable about the manifestations of the illness, in addition to potential ways to conceal illness behaviors during hospitalization. Some warned staff to not be too naïve or inattentive to the evident self-destructive forces that can drive a young person with AN during hospitalization:

> *P: If I hadn't had the shirt on, then I couldn't have put the weight belt on, and maybe they would have discovered that my bladder was completely full … ehm … I think at most I drank 4 l of water … [P32].*

Participants underscored that staff should be aware of, thereby potentially preventing, various illness maintaining behaviors such as water loading, attaching weights, purging, and excessive exercise to burn calories at night or in a private room:

> *P: Look more after patients when they are at the loo … mhm … and don't allow too much solitary time in their room. I was running around continually, to burn calories. It was very exhausting, yet I felt I just had to … [P63].*

Discussion

This qualitative study investigated the viewpoints of former adolescent inpatients admitted to a family-based inpatient treatment program. Knowledge of how young patients with AN generally experience and perceive various aspects of treatment and staff-related behavior is scarce [28]. Knowledge is especially lacking regarding young patients' experiences within a family-based treatment approach for AN at higher levels of care [33].

The participants' reflections revealed that involvement and collaboration are highly valued, along with efforts to individually tailor treatment. They also recognized that staff requires diverse skills to facilitate engagement in treatment. With some exceptions, few viewed treatment as a reciprocal and collaborative experience. Improved collaboration was desired to achieve better balance between the ED versus the person, and to provide sufficient flexibility when negotiating the rules and structures, thereby individually tailoring treatment. Reflecting back on staff-related behaviors, the participants emphasized the importance of showing genuine interest in the young person, rather than an enhanced focus on family processes. Other desired staff-related skills and characteristics included having a non-judgmental stance, educating patients, enhancing motivation, providing activities and preventing iatrogenic effects during the stay.

Findings pertaining to the importance of facilitating a good therapeutic collaboration align with psychotherapy literature documenting the co-constructive nature of therapeutic processes and the importance of negotiating the therapeutic alliance in therapeutic encounters [20, 38]. However, quantitative research investigating the intricate bidirectional relationship between measures of the therapeutic alliance and treatment outcome in ED treatment has shown varied results. Alliance research has suggested that early symptom improvement fosters a positive influence on the alliance in ED treatment, and that the therapeutic relationship can be of extra importance for younger patients, as studies show stronger relations between alliance and outcome for younger versus older patients [22]. Our findings extend prior qualitative research which has shown that patients with EDs often value aspects associated with the therapeutic alliance, preferring treatment as a joint and collaborative effort, as demonstrated in main theme 1 [29–32].

Taken together, our findings shed light on managing complexities, and might suggest the need for a greater degree of tailoring and differentiation when providing family-based inpatient treatment, as there is no treatment program that fits all. Our findings suggest we critically examine whether the inpatient context, with common rules and structures, offers sufficient tailoring to the individual family and young person, an intended hallmark with outpatient family-based therapy [6, 21]. Managing the balance between set structures and sufficient flexibility during hospital admissions is a complex endeavor [28, 39, 40].

The emerging literature on feedback-informed treatment may prove an inspirational source to encourage feedback from young persons during treatment. Ideally, inviting feedback could improve aspects of the working alliance and thus, enhance the feeling of working together during treatment [41, 42]. Still, this is an intricate balance, as we can imagine that invitations to negotiate “the non-negotiables” (i.e., negotiate fixed rules and structures associated with inpatient treatment) may be problematic and in the worst case, fuel the ED (i.e., allowing too much negotiation could prove to be a pitfall). Nevertheless, reconsidering the “non-negotiables” might be more of a question of how, rather than if, we should negotiate with younger persons during family-based admissions to achieve better collaboration.

The second main theme implied that health care professionals and multidisciplinary teams should cultivate diverse therapeutic skills within several domains. With the exception of knowledge related to illness manifestations and concealment of ED behaviors, which was considered important to prevent iatrogenic effects during the stay, all other preferred skills aligned with the psychotherapy literature’s common factors across treatment modalities. One such pan-theoretic domain was motivational enhancement [1, 43–45]. Another involved enhancing knowledge by educating patients regarding the illness, as well as initiating activities to allow opportunities to shift focus during the admission. Looking back, participants seemed to indicate increased desire for staff to take initiative to engage the adolescent despite the family-based focus of treatment, enabling more direct interaction with patients themselves. Additionally, several participants underlined the importance of respect and curiosity, which are acknowledged therapeutic stances. This is in line with the recommended non-judgmental stance characteristic of outpatient FBT [6, 46]. Importantly, at higher levels of care, patients have typically undergone several treatment efforts without experiencing sufficient improvement. Patients may initiate treatment with a lack of trust in the treatment services and presumably, a reinforced view of seeing themselves as a failure [47]. This warrants health care professionals to be especially mindful of how they interact with patients [30, 31, 34]. Interestingly, several of the participants retrospectively reported staff were too lackadaisical or inattentive in recognizing covert ED behaviors, whereas greater awareness could be preventive in the long run [48]. Some patients seem to retrospectively wished behaviors such as water loading or privately excessive exercising in their room had been detected. These reflections underscore that living with AN is not a condition the young person, at least retrospectively, desired. In hindsight, with greater maturity and on average, less afflicted by the ED, findings suggested that the majority called for a greater interest in their own personal views during treatment. The post-treatment interviews seemed to afford the opportunity for participants to caution health care professionals of the potential pitfalls of generalizing too much from theory or previous treatment successes. People are different, and hence, they need individually tailored interventions that accommodate unique qualities and needs.

How exactly increased collaboration with adolescent patients who are ill enough to need hospitalization would look like, is difficult to determine, and represents questions we would like to pursue further. We principally think there is a potential for increasing collaboration with the young patient through all stages of treatment, and that individual variations in severity and impairment along different variables can make arguments for a greater differentiation and a more tailored or personalized treatment during admissions.

Strengths and limitations

Several strengths and limitations of the study deserve mention. Including all available participants in the analysis ($N = 37$) is considered a strength. Still, potential selection bias cannot be ruled out, as 58 participants were invited to participate. One obvious limitation is the retrospective nature of interviews. The time between hospitalization and the follow-up interview were considerable in length, and thus subject to recall or memory biases. However, a delay between discharge and follow-up may have allowed the participants’ time to reflect sufficiently upon their experiences, and provide greater nuance and self-reflection less affected by events and emotions immediately upon discharge. As the majority of the participants received treatment between discharge and follow-up, we cannot rule out that post-treatment views concerning the family-based admission were influenced by later treatment experiences.

Another limitation is that four of the interviewers were involved in both development and general provision of treatment at the unit, as well as specifically involved in the treatment of some of the participants. This represents a source of bias in the data collection. However, two out of three responsible for analyzing data had no previous work experience at the unit.

The inpatient program and health care setting in Norway enabled the opportunity to provide extended family admissions within a hospital setting, which may limit generalizability to other health care systems. Despite this, we would argue that the study and the findings have proper transferability value [49]. Overall, we would argue that the findings make a contribution to the current literature by improving our knowledge related to patients' views on important aspects of adolescent AN treatment at higher levels of care. The findings may have implications for treatment development, training and supervision. We believe that the current study can be of relevance for health care professionals and treatment providers offering, or planning to provide, family-based treatment at higher levels of care, both within the ED field and for other psychiatric conditions.

Conclusion

By investigating former patients' perspectives pertaining to collaboration and preferred staff behaviors and skills, this study adds to the ongoing work of optimizing the inpatient context for adolescents in need of AN treatment on higher levels of care. Based upon user perspectives from a treatment setting highly influenced by a family therapeutic approach, findings revealed that former inpatients prefer tailored treatment and a collaborative approach. Staff members working within a family-based framework should be equipped with multiple skills and expertise, and clinicians' knowledge base should not be restricted to family therapy alone. From their unique perspectives as having lived experience and hence, "insider knowledge" with a specific treatment situation, clinicians are reminded of the importance of being mindful on the young persons' views. Especially, participants raise our awareness of the importance of how we balance between the person and the symptoms, how we balance firmness and flexibility, and overall, how we balance between focusing on the parents and the young person during inpatient family-based treatment for AN.

Abbreviations

AN: Anorexia nervosa; ED: Eating disorder; FBT: Family-based treatment

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Authors' contributions

All listed authors were involved in designing the current study. Together with JVN, IH made a substantial contribution to developing the interview guide, and IH conducted the majority of interviews and supervised the data collection. All authors familiarized themselves with the data set by reading complete transcribed interviews. JVN transcribed the majority of the transcripts, proofread the whole data set and read and re-read the whole data corpus several times. Developing theme structure, analyzing and interpreting the data material was a collaborative effort between JVN and TWH and HWO, with JVN leading the process. JVN wrote the first draft of the manuscript. HWO have supervised the whole process and together with ØR and TWH made substantial contributions to the final paper. All listed authors are accountable for all aspects of the work, including issues related to accuracy and integrity. All authors read and approved the final version of the manuscript.

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Availability of data and materials

The dataset collected and analyzed during the current study are not publicly available as this could compromise participant privacy. The corresponding author can be contacted with questions considering the dataset.

Ethics approval and consent to participate

Ethics approval was granted by the Regional Committee for Medical Research ethics, South East Norway [REK2014/2223]. All participants gave their written consent to participate.

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no competing interests.

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RESEARCH ARTICLE Open Access

External support and personal agency - young persons' reports on recovery after family-based inpatient treatment for anorexia nervosa: a qualitative descriptive study

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Abstract

Background: Recommended treatment for adolescent anorexia nervosa (AN) is usually family-based and an overarching treatment aim is to empower the parents to manage the difficult meals and aid their child toward recovery. While family-based treatment prioritize collaborating with the parents, understanding the young persons' views on recovery is also important. Understanding the young person's views and ideas is relevant as this may facilitate the therapeutic alliance and thus aid the therapeutic process. The purpose of the present study was to investigate the reflections of young persons with a lived experience of anorexia nervosa, and what factors they consider important for the recovery process. All participants had been provided with a family-based inpatient treatment program, a program inspired by the core features of outpatient family-based treatment.

Methods: Participants ($n = 37$) presented with an extensive treatment history, including outpatient and inpatient treatment for AN. Interview transcripts were analyzed by applying a predominantly inductive thematic approach to generate themes across participants.

Results: The qualitative analysis generated a thematic structure entailing three levels. The superordinate theme, "Recovery is a long and winding journey: recognizing the need for support and highlighting the need for action", captured three main themes, "Realizing you have a problem", "Being involved in important relationships", and "Giving treatment a real chance".

Conclusions: Our results demonstrated that although young persons with a lived experience of anorexia nervosa recognized the importance of support from others, they placed a distinctive emphasis on self-responsibility and determination. We recommend clinicians working within the recommended family-based treatment frameworks be curious about young patient's subjective perspectives of the recovery process, as connecting with their views can potentially strengthen therapeutic relationships and facilitate change.

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Plain English summary: Recommended treatment for adolescent anorexia nervosa is usually family-based. These recommendations are supported by decades of research. In family-based treatment the overarching aim is to empower the young person's parents to manage and take charge of the difficult situation caused by the eating disorder. As recommended family-based treatments usually prioritize collaborating with the parents, it is important to be curious on the adolescents own views of what is regarded as important for the recovery process. The present study offers insights into factors considered important to the recovery process by young persons with lived experience of AN. Although voicing the importance of enlisting support from families, friends, and loved ones, the young participants distinctly emphasized their own responsibility, motivation and self-determination as critical factors for recovery. Inspired by our findings, we recommend that clinicians address the young patient's own preferred ideas for recovery during treatment.

Keywords: Eating disorders, Anorexia nervosa, Recovery, Adolescent, Qualitative research, User perspectives

Background

Recovery from anorexia nervosa (AN) is not universally defined in the literature [1], and quantitative research has demonstrated that recovery rates vary exceedingly depending on the definition used [2, 3]. Moreover, recovery can be approached from several positions, as treatment providers, researchers and people with a lived experience may support different definitions. An alternative to the prevailing symptom-oriented recovery emphasis is recovery perceived from the position of people with a lived experience, emphasizing personal opinion and subjective meaning making [4].

Regardless of how one defines recovery from AN [5, 6], an interest in understanding what young persons with a lived experience perceive as important ingredients in the recovery process is important. Connecting with the patients' own beliefs, values and preferences is considered essential for the design and delivery of evidence-based practice for eating disorders [7]. Using their clinical expertise, clinicians working with adolescents and families need to continually and wisely balance the best available research evidence and the treatment preferences of the patient and their family [8].

Research investigating patient's or former patient's perspectives on recovery has usually addressed this by asking adults or young adults to share their views [4]. This research has generally demonstrated that the journey toward restoring health could best be viewed as an intricate interplay between multiple factors [4, 9–11]. The importance of the person's own willpower, motivation and agency on the one hand, and the significance of meaningful and supportive relationships on the other, has been highlighted in several studies [9, 12–15]. Together with these individual and interpersonal features, mastering daily life in general (such as coping with education, work, and being engaged in other meaningful activities) has been underlined as a crucial requirement for recovery [9, 12, 16]. Another recurrent theme has been the importance of treatment in general, and the significance of being actively involved to achieve progress [4]. In order to experience improvement, it seems the person has to develop ways to truly distance oneself from the eating disorder, both by actively taking charge of the recovery process (i.e., striving for a different ideal), and ultimately attaining a different identity in order to become fully recovered [9, 10, 13, 17]. Overall, qualitative findings shed light on the complex interplay between individual, relational and contextual factors when the journey toward recovery is perceived from the patients' perspectives [4, 18–21]. Research investigating patient perspectives on recovery from the perspective of the young patient, literature is more limited [22]. In a review from 2015 that aimed to explore and synthesize the process of recovery from AN, the authors included only one study that involved young people (i.e., under 18) [4]. Even in this qualitative study over half of the participants were adults [17].

When a young person is suffering from AN, a family-based treatment approach is usually recommended [23]. Family therapy and family-based treatments have a long history in the treatment of adolescent AN [24, 25]. One possible consequence of emphasizing the family and parental role in obtaining recovery is less clinician investment in working directly with the young person afflicted with the ED [20, 26]. In manualized family-based treatment for AN the parental emphasis is especially clear, as the overall therapeutic aim in the critical first phase of treatment is to charge the parents with the responsibility for refeeding and weight restoration. Consequently, the main therapeutic task becomes to empower the parents to manage this responsibility [27]. In such a family-based framework, enhancing the young person's intrinsic motivation, promoting the adolescent's responsibility for change, and working with adolescent-related issues, both within and outside the family, is usually toned down or postponed to the end of treatment [27, 28]. Although a predominantly family-based treatment approach is frequently portrayed in the literature as supported by promising research evidence [3, 29], researchers have started to question the evidence-base [30–32], describing its outcome in clinical trials as modest at best [3, 32] with some arguing that despite its promise, treatment needs to be augmented and better tailored to improve outcome [33, 34].

One way of augmenting the family-based treatment approach for adolescent AN is seen in the ongoing effort of enabling an enhanced family therapeutic focus at higher levels of care [35]. Although situated in various local treatment contexts, common features for these efforts is the overarching goal of aligning the intensified treatment (i.e., day-, residential- and inpatient treatment) with the core features associated with outpatient family based treatment [36–38]. Although such adaptations should be investigated further, preliminary outcome research show that this can be a promising way of providing treatment at higher levels of care for those who fail to respond to outpatient treatment [36, 37, 39].

Understanding better how young persons' with lived experiences reflect upon important factors for recovery can provide additional knowledge, and help ascertain whether patient preferences and views align with the recommended treatment focus [20, 28]. Although the intricate relationship between the therapeutic alliance and ED outcome is not clearly understood [40] we do believe that managing a balance between treatment recommendations and the young person's preferences is vital, as discrepancies can challenge therapeutic relationships and enhance conflicts. There is a paucity of research investigating the young person's beliefs about what is considered important for recovery. As such, the present study can contribute with knowledge relevant for the ongoing effort of augmenting practices to tailor treatment to those failing to respond to the recommended first-line treatments for adolescent AN [34].

Research that focuses on the perspectives of young persons with lived experience with AN can provide important knowledge about how to improve and better tailor family-based treatment. With the present study, we aimed to investigate the perspectives of young persons with a lived experience of AN on factors related to the recovery process. By being situated within a higher level of care setting highly influenced by a family-therapeutic treatment approach, the present study can bring forth facets of recovery from a specific treatment context not included in previous research. The research question was, "what do adolescents with a lived experience of anorexia nervosa, who have taken part in a family-based inpatient treatment program at a specialized eating disorder unit, report as important factors for recovery?"

Methods

Context

This qualitative descriptive study formed part of a larger research project which aimed to investigate naturalistic ED outcome of family-based inpatient treatment for AN [36], treatment satisfaction [41], and the experiences of family members following family-based inpatient treatment [42]. Thirty-seven (64%) of 58 former inpatients (33 females/4 males), provided written consent to take part in this sub-study. For the sole participant under the age of 16 at follow up (i.e., age of consent), parental consent was also obtained.

Treatment setting

During the family-based inpatient treatment program, up to five families were admitted at a time. The overarching treatment focus for the majority of participants corresponded to the first phase in outpatient FBT [27]. This meant that throughout the admissions, staff emphasized collaboration with parents, while the therapeutic focus on the young patient was more of an indirect one. Without aiming to strictly adhere to manualized FBT, the guiding treatment principles during admissions were inspired by outpatient FBT [27, 36]. The main therapeutic content consisted of conjoint and separated family therapy together with parental counseling, supplementary individual therapy and milieu therapy with the overarching aim of supporting parents to support their child during the stay. During the inpatient treatment program, parents were supported to manage meals and weight restoration, while staff aimed to externalize the ED and adhere to a non-blaming and non-etiological stance. Each young patient and family was allocated a multidisciplinary team. The nucleus of this team consisted of a child- and adolescent psychiatrist working closely with a clinical psychologist, and two or three nurses. Families were offered family therapy sessions at least twice a week. Some patients were offered supportive individual therapy in addition to family therapy. Nursing staff had daily scheduled conversations with both parents and the young person, for preparing meals and evaluating the ongoing process. Patients and parents took part in the weekly treatment meetings. At discharge, all patients and families were referred back to their local clinic for further outpatient treatment.

Participants, recruitment and data collection

All participants ($n = 37$) had been admitted for family-based inpatient treatment between 2008 and 2014 and all had a primary admission diagnosis of AN. They presented with an extensive treatment history, including both outpatient and inpatient treatment prior to the family-based admission. Duration of ED prior to the family-based admission was on average 2.7 years (range;

0.5–6.0, *SD* = 1.8). Mean age at admission was 15.8 years (range; 12.4–19.5, *SD* = 1.8). The majority (33/37) were admitted voluntarily. Mean length of stay was 20.8 weeks (range; 3–58, *SD* = 13.5), including planned leaves from the ward as part of the treatment program. All families agreed to stay at the hospital with their child during the hospitalization. At the time of the follow up interview in 2015, the majority (65%) of the total sample (*n* = 37) had achieved normal body weight (i.e., estimated as achieving a BMI ≥18.5). Twenty two (59%) participants did not meet the criteria for any DSM-5 ED-diagnosis, 8 met criteria for AN, 2 for BN and 5 for OSFED. The mean age at the follow up interview was 20.2 years (range 15.8–25.3, *SD* = 2.6). The mean time period from discharge to the follow-up interview was 4.5 years (range; 1.3–7.0, *SD* = 1.7).

Ethics approval for this study was obtained from the Regional Committee for Medical Research ethics, South East Norway [REK2014/2223]. The 37 semi-structured interviews were administered by a team consisting of a senior researcher, two clinical psychologists, one psychiatrist and a psychiatric nurse. Twenty-six of the interviews were conducted on-site at the hospital, seven at the participant's home, three by telephone, and one in-person elsewhere. All interviews (including telephone interviews) were audiotaped and transcribed verbatim by a research assistant and the first author. The qualitative interviews lasted between 30 and 100 min.

Interview guide

The semi-structured interview guide was developed by a group of experienced clinicians to address a broad range of post family-based inpatient treatment user experiences. The guide was not constructed based on a specific theoretical model. The interview guide was structured into three sections, including questions covering the pre-admission phase, the admission and post-admission phase. Most relevant for the present paper's analysis was the post-admission items, and particularly the following questions: "Looking back on your life and the changes that have happened related to your eating disorder – how would you describe important turning points?" and "What do you think is most important in recovering from an eating disorder?"

Qualitative data analysis

To provide an overall structure for the analysis, we applied a thematic analysis (TA) guiding framework [43]. TA is commonly recognized as a pragmatic and flexible framework entailing six steps to guide the researchers: 1) familiarizing yourself with the data, 2) generating initial codes, 3) searching for themes, 4) reviewing themes, 5) defining and naming themes, and 6) producing the report [43]. To enable as much diversity as possible, we decided to include all eligible patients (*n* = *37*) in the analysis.

To manage the quite large number of transcripts, the QSR International's Nvivo11 Software [44] was used for both the initial phase of sentence by sentence coding (Step 2) and in aiding the iterative process of going back and forth between the gradually developing thematic map and checking back with the raw data in reviewing and ensuring that the evolving thematic map provided a good fit with the raw data (Steps 4 and 5).

Together with the first author reading and re-reading the complete data set several times, all authors familiarized themselves with reading selected parts of the data material (Step 1). The first author had the overall lead in initial coding, interpreting and moving the process of theme development forward, toward finalizing the analysis and writing up the first draft (i.e., Steps 2–6 in thematic analysis). Although we did not adhere to a strict schedule of co-analyzing the transcripts, scientific rigor and trustworthiness [45, 46] were ensured by the research team doing parts of the analysis together. This co-constructive effort was secured by TWH reviewing and supervising the gradual steps initiated by the first author, and HWO supervising the process of analyzing the transcripts as a whole. During the analysis both TWH and HWO performed the role as a "critical friend" [47]. Reflexivity was thus continually addressed through frequent dialogues and team meetings where "the two friends" together with the first author critically questioned the emerging theme development, and encouraged different interpretations from different positions [48, 49].

Overall, the analysis was predominantly inductive and hence not driven by a specific theoretical approach. The iterative process of developing, reviewing and finally defining and naming themes (Steps 3 to 5) was informed by a combination of both a semantic and interpretative stance. Semantic in this context meant that we initially aimed to navigate our curiosity predominantly to the surface level [43]. As the analysis proceeded, we recognized that a more interpretative lens was necessary to allow more nuance and richness to the analysis. Reviewing the process, we recognized that Steps 1 to 3 were mainly influenced by a semantic level of analysis, with Steps 4 and 5 integrating more interpretation. As is common in qualitative analysis, the finalized thematic structure underwent several major and subtle corrections before we finalized the thematic map which best represented and communicated the views of the participants. To provide readers with transparency about the distribution of accounts across themes and an opportunity to evaluate robustness of findings, we added numbers to the subthemes [50] (see Fig. 1 for details).

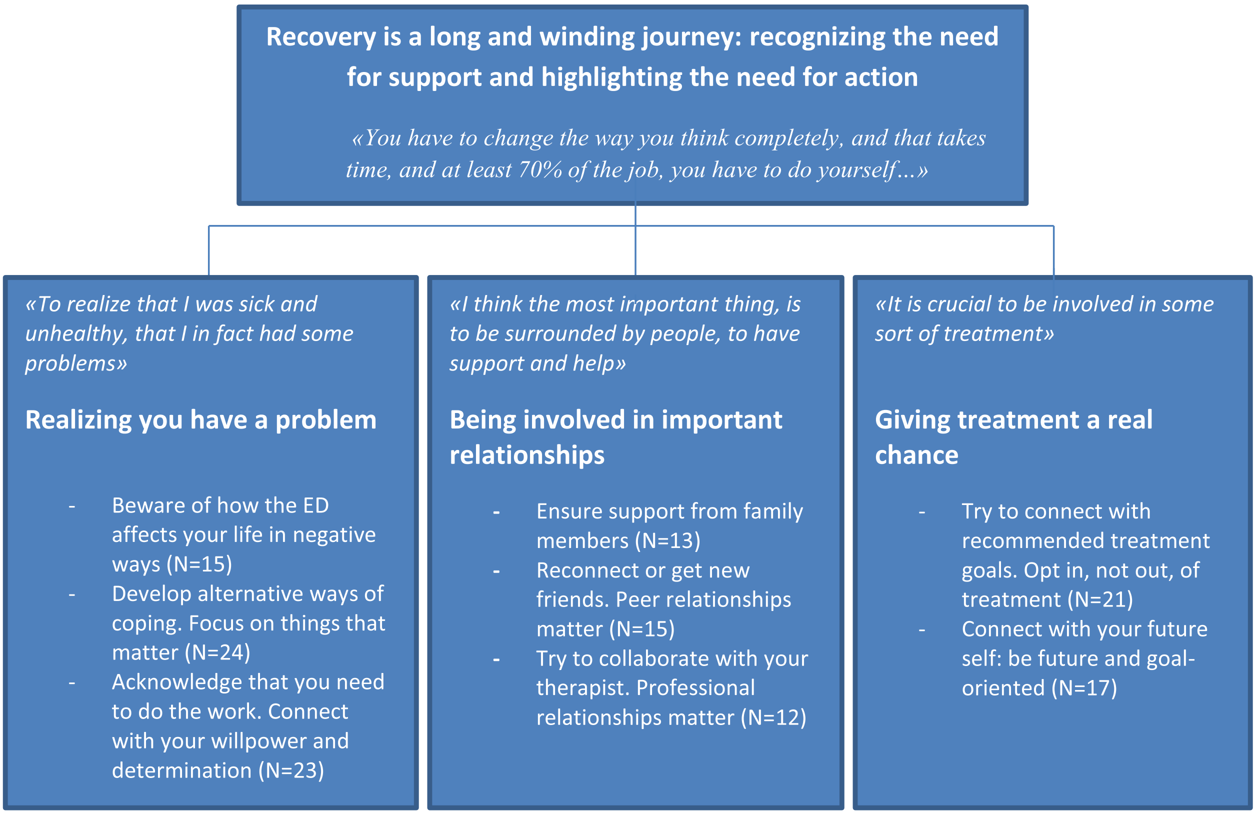

Fig. 1 represents the thematic structure on altogether three levels: superordinate theme, capturing 3 main themes with adjacent subthemes. Numbers in parenthesis equals the number of participants sharing views within each subtheme

Results

The qualitative analysis generated a thematic structure entailing three levels (see Fig. 1 for details). Illustrative quotes are provided on both the main theme and subtheme level, together with brief illustrations on the superordinate and main theme levels in Fig. 1. All names provided are pseudonyms.

Superordinate theme: recovery is a long and winding journey: recognizing the need for support and highlighting the need for action

The superordinate theme represents an abstraction of the three main themes and their adjacent subthemes, including a) participants predominantly viewed recovery as a gradually evolving process which typically included episodes of progress and setbacks and b) although the majority of the participants viewed support from others and their own agency as important ingredients for getting better, the latter was particularly emphasized. Furthermore, the superordinate theme captured the advantages of viewing the ED as a problem, or as problematic, in order to mobilize efforts toward change.

Main theme 1: realizing you have a problem

This main theme captured the participants' views on the necessity of recognizing that the ED represents a real-life problem, and that you yourself need to fight to achieve change, as problems do not just pass with time.

> To realize or admit that I was ill, like, that I really had some problems, that, *that* I feel was quite important. And I thought, yes, I started to realize that I had to do some things myself. I kind of had to decide that for myself, to *do* something. That's important [Sarah, 19]

Subtheme 1: Beware of how the ED affects your life in negative ways (N = 15)

Although some of the participants noted past and present ambivalence toward recovery, several accentuated the importance of being aware of how the ED affects relationships negatively and obstructs desired goals and future dreams. Reflecting back, all but one participant reflected on a slowly evolving realization of how the ED affects your life in negative ways.

> It's important to realize and see more clearly the negative influences the ED has, because it is, after all, a way of handling difficulties or mastering life, right, so if what you get from the ED is more or better than the burden you experience, then it's difficult, to let go. But if what you get from the ED is shit, and in fact worse than the other struggles you've got, then it becomes easier. But it is difficult. It's not easy to be attentive to the negative consequences the ED will have [Polly, 23]

Subtheme 2: Develop alternative ways of coping. Focus on things that matter (N = 24)

Only three participants explicitly conceptualized the ED as a "coping strategy" during their interviews. However, this subtheme captured our understanding of the participants' tendencies to conceive the ED or ED-behaviors as representing different ways of coping with other difficulties as low self-esteem, difficult life experiences or relationships, or as a means of regulating emotions. Several of the participants emphasized the necessity of letting go of the ED or ED behaviors in order to recover, and their reflections suggested that focusing on things that really matter can aid this process.

> It's been crucial to accomplish high school, and to get a driver's license, to start with higher education. There are new goals all the way, and it feels really great to accomplish those, and, it's this sense of mastering, which is very important. To feel you can live a pretty normal life, where the focus is on everything else *but* body and food. That's something I've been working with, to shift the focus [Andrea, 20]

Subtheme 3: Acknowledge that you need to do the work. Connect with your willpower and determination (N = 23)

The majority of the participants were clear that they viewed their own willpower and decision-making as necessary ingredients in the recovery process. Several challenged the idea of the existence of any ideal or perfect moment for change, and rather urged fellow peers to start to work actively for change, now.

> You're never ready for it. You'll never wake up one morning and suddenly think; now I am ready! Because, if this was how it was, it would have happened. So it's something you need to *do*, that's how it is. Just start! Just start. Make a habit out of it, and, easier said than done, but really. Never wait for the perfect moment. That's not going to happen. No, you will never be fully ready [Polly, 23]

Main theme 2: being involved in important relationships

This main theme captured views which emphasized the importance of others. Although recognizing support from parents, peers and others as important for the recovery process, the majority of the participants made a point that they themselves must reach out and do what they can to be involved in important relationships. Quite a few of the participants also emphasized the potential of a collaborative and supportive relationship with health care professionals. A few shared that being in love and engaged in a romantic relationship helped shift the focus towards more important aspects of life and thus, minimized the influence of the ED. Even relationships with pets were seen as potentially aiding toward recovery by some. As Joanne viewed it, relationships can be both supportive per se, and also represent a stepping stone towards accommodating other meaningful aspects of life.

> Most important is to have people around, support and help and, yes, you need to understand that there are better things than just thinking of food, and of course you need to want it [change] yourself, but that usually progresses out of relationships so … [Joanne, 21]

Subtheme 1: Ensure support from family members (N = 13)

Many of the participants viewed support from parents and siblings as important for getting better. Quite a few were clear that parental support and parental involvement in treatment had been very important for getting better. Having family members who behaved in ways that enhanced the feeling of being understood seemed crucial, as the opposite could risk the likelihood of enhancing both feelings of loneliness and opposition. Reflecting on support from family members, several of the participants also stressed the importance of opening up and actively welcoming the support, as opposed to avoiding or opposing family-members' engagement and involvement.

> The fact is that people around you want the best for you, they want to help you and you really have to understand that they want to support you, and that they're not your enemies that want to hurt you. That's the EDs intention; it wants me to believe that everybody is cruel and want to hurt me [Kate, 21]

Subtheme 2: Reconnect or get new friends. Peer relationships matter (N = 15)

Although quite a few emphasized the importance of support from parents and family members during the recovery process, several of the participants underscored the importance of peer relationships. Specifically, the importance of keeping in touch with friends during treatment and illness was emphasized, as well as actively striving to reconnect if friendships had halted. Quite a few encouraged young persons to develop new friendships if feeling alone, reminding others that friends do not just show up; you need to take social initiatives yourself.

> I worked really hard to get back my friends. I remember I had to, in the beginning. I had to invite myself to all parties. I remember thinking this was embarrassing and really humiliating, but still I thought that I really had to do it, to give them the chance to know me over again, and take me into their lives, and that worked out really well. Now I have several friends, and I don't need to invite myself any longer, I've become a part of them [Brenda, 22]

Subtheme 3: Try to collaborate with your therapist. Professional relationships matter (N = 12)

Although mixed experiences were voiced when reflecting upon past therapeutic encounters, more than a few of the participants emphasized that being engaged in therapy and therapeutic collaborations can be vital for change to happen. Here too, several used the opportunity to reflect upon the importance of becoming actively engaged in the relationship with the health care professionals, alluding that little or nothing will happen if the young person remains silent or too passive or ultimately opposes the therapist.

> I now feel that I've met the person I can manage to get well together with. My key worker is so secure and I've managed to do a lot of important work and progress together with her [Anna, 18]

Main theme 3: giving treatment a real chance

This main theme captured the participants' views on treatment as a potentially active ingredient for the process of recovery. The theme captured participants' views about the importance of actively aligning with recommended treatment goals (i.e., normalizing eating behaviors and attaining normal weight) and the importance of working through treatment ambivalence and resisting the temptation to opt out of treatment. Additionally, a potential domain for therapy was accentuated through their reflections on goal attainment (i.e., Subtheme 2).

> Dare to let go, and give treatment a chance [John, 22].

Subtheme 1: Try to connect with recommended treatment goals. Opt in, not out, of treatment (N = 21)

> I haven't thought much about having kids. Still, I think it is important to stay in treatment, because I want to be able to take good care of my kids, which is a huge motivation for me, actually … [Catherine, 20]

Over half of the participants emphasized the importance of being invested in some sort of treatment. It was as if several of the participants wanted to inspire others struggling with EDs to give treatment a real chance. Although being involved in treatment was not necessarily viewed as synonymous with achieving change, more than a few participants highlighted the significance of opting in and not out of treatment. Looking back, quite a few realized that they had wanted to invest even more in treatment encounters, if they could rewind and do things over. The majority of the participants emphasized the significance, and even the necessity of, striving for normalizing eating behaviors for letting go of the ED, while others stressed the importance of giving normal weight a chance.

> You have to give normal weight a chance. Not just decide in advance that; "that's not for me", "*that* I don't dare", "that I don't want". It's all about being bold enough to do the changes [Jane, 21]

Subtheme 2: Connect with your future self: be future and goal-oriented (N = 17)

> Ask yourself, why, ehm, why do you do this? What do you want to get out of your life? What are your true dreams? What is your greatest wish? [Maria, 21]

Several of the participants noted that reaching new personal milestones had reinforced hope, motivation and self-respect. As a consequence, they indirectly supported the notion of the therapeutic benefit of clarifying attainable goals of personal significance. Several of the participants felt that having a future- and goal-oriented focus, both distant and proximal, would be beneficial to emphasize in treatment and fruitful for the young person with AN.

> Try to find something in your everyday life that is positive for you and that you really have an urge to accomplish, and if you have a goal you really long for, go for it, because when you accomplish it, that joy! [Esther, 19]

Discussion

This study aimed to investigate what adolescents with a lived experience of anorexia nervosa, who had taken part in a family-based inpatient treatment program at a specialized eating disorder unit, reported as important factors for recovery. As demonstrated by the superordinate theme, "Recovery is a long and winding journey: Recognizing the need for support and highlighting the need for action", the results revealed that participants distinctively emphasized the importance of support from others as well as personal responsibility. Although support from parents, siblings, health care professionals, friends and romantic partners was valued, the centrality given to their own motivation and self-determination was especially striking in this study. A self-orientation stance was a central finding throughout the thematic analysis, as the main themes *realizing you have a problem*, *being involved in important relationships*, *giving treatment a real chance* all captured views contingent upon the individual.

The importance ascribed to the person's own agent self is an aspect embedded in recovery stories documented previously in the literature [9, 13, 22]. Still, these views, emphasizing the young person's own wishes (i.e., motivation), willpower and determination, are particularly interesting in the present context, as our treatment setting offered family-based treatment of AN, which prioritizes the parental role in treatment and postpones the adolescent's role in treatment. Although the treatment offered did not strictly adhere to manualized outpatient FBT [27], the majority of the participants had experienced extensive efforts to involve family in treatment, including family-based inpatient treatment [36].

Family relationships are often significantly, and adversely, affected when a young person develops AN, and involvement of the young persons' family in treatment is recommended by international treatment guidelines [23]. Supporting parents to support their loved one is an overarching and integral treatment priority for family-based treatment models [24, 27, 51]. The predominant role of parents is based upon the assumption that young individuals afflicted with the ED lack the ability to make rational and healthy treatment decisions due to inherent characteristics of the eating disorder (e.g., the ego-syntonic symptom quality, effects of malnutrition, ambivalence to change, treatment resistance). As a consequence, it becomes vital during treatment to prioritize the support of the less afflicted and legally responsible family members (i.e., the parents), and to provide them with the necessary skills and confidence to make health promoting choices on behalf of the young person. By default, the main aim of treatment is to provide sufficient support to ensure that parents are capable of taking charge of the refeeding process to restore weight and normalize eating patterns [28]. Although family-based treatments have a promising evidence-base [29], a large proportion of patients and families participating in clinical trials fail to achieve remission [25, 30, 31]. A more modest outcome becomes especially visible when strict remission criteria are applied [3]. Consequently, several questions remain on how we can optimize treatment to enable a better fit for both the young person and his and her family.

One question brought forth by our findings is whether adolescent AN treatment sufficiently enables a focus on the young person, and whether treatment succeeds in aligning with the young person's own preferences and values, a hallmark of evidence-based practice [7]. In particular, it may prove relevant for individuals presenting with a clinical picture associated with non-response to FBT [25], or for individuals with extensive and not yet efficient treatment efforts, and finally, when the patient's age or developmental stage demand greater focus on individuation and autonomy [26, 52].

Qualitative research has found that adolescents value many core aspects of family-based treatment, such as increased responsibility attained by parents and externalization of the ED [20]. Still, others have found that some adolescents view family-based approaches as neglecting vital individual aspects valued as important [15, 18, 20]. Although the present study does not argue against working within a predominantly family-based framework, it may be relevant to investigate further whether there are issues valued as important from the young person's position that are insufficiently addressed in recommended ED treatments [20, 53]. Rather than challenging a family-based approach, these findings could be interpreted as shedding light on potential conflicts and dilemmas clinicians may encounter in providing family-based AN treatment, especially in the case of non-remission or relapse. The present study, in our view, suggests the importance of endorsing an increased adolescent-focused approach within a family-based framework, rather than advocating for a separate adolescent-focused therapy for the adolescent.

Reassuringly, the findings revealed that participants urged peers to opt in, and not out, of treatment, and that normal weight is considered as essential, and even prerequisite, for improvement. These findings align with previous qualitative research demonstrating the centrality of treatment for recovery [4, 18]. Findings showed that important relationships were perceived as beneficial for the recovery process. This is consistent with both theory and clinical observations illustrating that family dynamics are afflicted when a young person develops AN, and is in line with recommendations to involve the entire family in treatment [24, 54]. However, results also demonstrated that friends and romantic relationships, even pets, are viewed as important factors in recovery. This implies that clinicians and treatment providers should offer treatments that are attentive towards the young person's wider social context, which concurs with prior studies [53, 55–57].

Rather than pinpointing specific turning points, the majority of participants in this study reflected that recovery was an emerging and gradual process to overcome their eating disorder. Few shared explicit examples on discrete turning points, which could also be due to study design or the relatively young age of the sample. Personal narratives on turning points may continue to evolve and become construed as persons become older [9].

Overall, research investigating adolescents' "insider perspectives" on what is viewed as personally important for recovering from an ED is essential, as treatment outcome for this population is considered modest at best [6]. Consequently, many unanswered questions remain to be answered regarding how we can more efficiently provide and personalize treatment for adolescents needing specialized care for AN [58].

Strengths and limitations

Investigating young persons' views about factors important for recovery is an understudied area. This issue is worth investigating as it is important to understand whether young patients' preferred ideas and views aligns with recommended family-based treatments focusing on parental responsibility. An important limitation is related to the interview guide and data collection. The semi-structured interview covered a wide range of questions assessing participants' treatment experiences and was not developed with the sole aim of investigating the current study's research question (i.e., young persons' beliefs about important factors for recovery). More in-depth and nuanced reflections might have been obtained if the interview guide and interview process had been designed specifically for the sole purpose of this study. Four of the interviewers who collected data were previously employed at the treatment unit. As such, interviewees might have minimized disclosure of relevant information due to concerns of disappointing the interviewer. On the other hand, familiarity with the interviewer could also be viewed as strength, as participants might have felt at ease in disclosing sensitive information. Participants were not asked to provide feedback on transcripts or preliminary findings, which could have also provided greater depth and enhanced validity of the results.

Conclusions

This study offers valuable insights into factors considered important to the recovery process by young persons with lived experience of AN. Although voicing the importance of enlisting support from families, friends, and loved ones, participants distinctly emphasized their own responsibility, motivation and self-determination as critical factors for recovery. The view that external support is important aligns with the predominant relational stance embedded in a family-based treatment approach for AN. Whereas the self-orientation stance (i.e., the importance the participants place on their own agency), suggests that increased therapeutic focus is needed to facilitate the young person's own motivation and agency while working within a family-based framework, a framework that typically emphasizes fostering parental agency. Inspired by our findings, we recommend that clinicians address the young patient's own preferred ideas for recovery during treatment. This stance aligns with an evidence-based practice framework and is oriented toward the young person's own ideas and preferences, which may help foster treatment engagement and ultimately aid change.

Abbreviations

AN: Anorexia nervosa; FBT: Family-based treatment; TA: Thematic analysis

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Availability of data materials

The dataset collected and analyzed during the current study are not publicly available as this could compromise participant privacy. The corresponding author can be contacted on reasonable request with questions considering the dataset.

Authors' contributions

Together with JVN, IH made a substantial contribution to developing the interview guide. IH was supervising the data collection and all authors familiarized themselves with the data set by reading complete transcribed interviews. JVN transcribed the majority of the transcripts, proofread the whole data set and read and re-read the whole data set several times. The process of developing the theme structure and analyzing and interpreting the data material was a collaborative effort between JVN and TWH and HWO. JVN wrote the first draft of the manuscript. HWO supervised the whole process together with ØR and TWH, and all authors made contributions to the final paper. All listed authors are accountable for all aspects of the work, including issues related to accuracy and integrity. All authors read and approved the final version of the manuscript.

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Ethics approval and consent to participate

Ethics approval was granted by the Regional Committee for Medical Research ethics, South East Norway [REK2014/2223]. All participants gave their written consent to participate.

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no competing interests.

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RESEARCH ARTICLE

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Family members' reflections upon a family-based inpatient treatment program for adolescent anorexia nervosa: a thematic analysis

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Abstract

Background: Family-based outpatient treatment is usually recommended as the treatment of choice when a child develops anorexia nervosa. However, some young persons will inevitably require higher levels of care. Qualitative research on family perspectives may help inform strategies to adapt family-based practices into intensified treatment settings. Our overarching aim was to investigate family members' perspectives following a family-based inpatient treatment program for adolescent anorexia nervosa and to discuss clinical implications for treatment providers.

Methods: A subsample of eight families taking part in a naturalistic outcome study at a specialized eating disorder unit participated in the study (8 patients, 14 parents, and 10 siblings). The thematic analyses were inductive, predominantly descriptive, and guided by a multi-perspective framework.

Results: Five main themes were identified: 1: *Expectations and evaluation of needs. Entering treatment from different vantage points*, 2: *Interactions with peers during the admission as highly beneficial or problematic*, 3: *Perspectives on staff expertise and the eating disorder unit's structure*, 4: *Influencing within family relationships in different ways*, and 5: *Being admitted is at best only half the job: reflections on leaving the eating disorder unit.*

Conclusions: Our study offers insight into how former inpatients and their family members experienced an inpatient treatment program designed to align treatment with the central elements of an outpatient family-based treatment approach for adolescent anorexia nervosa. Overall, the findings support emerging research underlining the necessity of strengthening the family-based treatment approach within intensified treatment settings. Moreover, the results emphasized the need for more knowledge on how to optimize inpatient treatment as well as the importance of providing smooth transitions between care settings.

Keywords: Eating disorders, Anorexia nervosa, Family-based treatment, Inpatient treatment, Qualitative research, Higher levels of care, User perspectives

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Plain English summary

Inpatient treatment of anorexia nervosa has traditionally been individually based. At large, this has usually meant that the young person with anorexia nervosa has been separated from their family during a hospital admission, while parents and family-members have had the chance to visit for treatment meetings, support and therapy sessions. Inspired by the promising research on outpatient family-based treatment, a treatment model that put a lot of emphasis on supporting the parents and "the family as a whole" during treatment, some treatment centers around the globe has started to hospitalize parents and siblings together with the young person with anorexia nervosa. The present study offers insight into how family members have experienced taking part in such a family-based inpatient treatment program. The family members demonstrated considerable diversity in viewpoints. Without prescribing definitive answers, we believe the results have several important implications for treatment providers working within a family-based inpatient treatment approach.

Background

Outpatient family-based treatment, either the well-known "Maudsley approach" [1] or manualized family-based treatment (FBT-AN) [2], is usually recommended when a young person develops anorexia nervosa (AN) [3]. Still, inpatient treatment is often required for child- and adolescent AN, both because of the complexity and symptom severity, but also due to the lack of accessible recommended outpatient treatments in many regions [4, 5]. Inpatient treatment is also frequently used when a young person with severe AN does not achieve adequate progress at an outpatient treatment facility [6, 7]. For some, a more intensive level of care is required even when the young person and their family receives highly specialized, evidence-based outpatient treatment, as no treatment is a panacea [8].

Inpatient treatment demands a lot of resources, including human and financial [4, 9]. Availability is typically limited, as most specialized treatment centers have strict admission criteria and offers only a few beds for a large catchment area [7, 10]. Inpatient care is recognized as a highly multifaceted and complex endeavor, and to date, no internationally agreed upon treatment guidelines for AN exist to guide clinicians on how to efficiently and effectively provide and manage inpatient care [4, 11]. Importantly, inpatient care has shown to have uncertain long-term effects, as many of the patients fail to maintain improvements achieved during admission [4, 12]. The latter is mirrored in the relative high relapse rates for this population-at-large, and underscores the importance of improving inpatient care as well as collaboration with the referral system to facilitate transitions [13].

Developing better ways to optimize the inpatient treatment setting for young persons with AN has been called for by recent ED studies [4, 11]. Due to promising evidence from the last two decades of development and research on outpatient family-based treatments, some treatment centers around the globe have begun to incorporate key tenets of outpatient family-based treatment into higher levels of care [6, 7, 10, 14, 15]. Most developments have been pioneered by highly specialized treatment centers aiming to align the core features embedded in evidence-based FBT within intensified treatment programs. This work aims to both optimize the provision of care during hospitalizations and importantly, to enhance the maintenance of effects following discharge [7, 10, 11, 14].

Research investigating the potential benefits of adapting family-based interventions at higher levels of care is emerging, yet remains scarce [7, 16–19]. A recent study from an Australian context investigated the effects of a brief admission prior to outpatient FBT and showed that admitting the family for an intensified two-week program offered the families an opportunity for relational strengthening and re-unification, thereby providing a stronger foundation for outpatient FBT [18]. Another study found that although outpatient FBT cannot be replicated at higher levels of care, treatment principles can be effectively adapted to a day treatment program [6, 16]. Our own research on outcome following admission to a family-based inpatient treatment program also found that enhancing the family-based focus during hospitalization is a promising approach for those who fail to respond to outpatient treatment [7].

With the current study, we aimed to extend our prior research on a family-based inpatient treatment approach for adolescent AN, which has to date focused upon outcome [7], treatment satisfaction [20], siblings' experiences [21], and user experiences [19]. In the present study, we provided a multiperspectival approach to extend our knowledge beyond the single-position approach previously applied in our qualitative studies [19, 21, 22]. Specifically, the research question focused upon how to characterize the multiple user perspectives of parents, siblings and patients' belonging to a single family following admission to a family-based inpatient treatment program at a specialized eating disorder unit (EDU) for adolescents with AN.

Methods

Research design

The study was a qualitative descriptive study and formed part of a larger naturalistic outcome study investigating different aspects related to a family-based inpatient program.

Ethics

Ethics approval was obtained from the Regional Committee for Medical Research ethics, South East Norway [REK2014/2223]. All participants provided written consent to take part in this research. All names in the results section are pseudonyms.

Participants and sampling procedure

Post-treatment perspectives from eight former inpatients and their family members were included (8 former patients, 14 parents, and 10 siblings). All participants took part in a family-based inpatient treatment program at a specialized EDU between 2008 and 2014. This subsample was purposively derived from the complete data set of thirty-seven inpatients participating in the main outcome study [7]. The eight families were selected because we had post-treatment interview data from patients, as well as their siblings and parents. This sampling choice mirrored our aim to investigate user perspectives from multiple positions within a single family and enable within and between family comparisons.

Mean age at admission was 15 years (range: 12–18) and mean age at follow up was 19 years (range: 16–21). Mean length of stay was 21.4 weeks (range: 8–58), including planned leaves as part of the treatment program. All patients had an admission diagnosis of AN. No statistically significant differences existed between the 8 participants and the 29 non-participating patients for the following variables: age at admission, duration of ED before admission, length of stay, weight and BMI percentile at admission and discharge, time elapsed between discharge and follow up and EDE-Q global score at follow up.

All patients had received previous outpatient treatment at specialized mental health services, as well as prior inpatient treatment at a medical and / or psychiatric unit. During the follow-up interviews, 5 of the former patients did not meet the criteria for any DSM-5 ED diagnosis. In seven of the eight families, the parents were married. Six of the parent interviews were conducted with both parents together; two of the interviews were conducted only with the mother. Siblings' mean age at admission was 11 years (range: 6–16) and mean age at follow up was 15.4 years (range: 11.9–23). None of the siblings reported any previous treatment experiences beyond visitation during hospitalization of their sibling. Only one of the siblings had attended a family session at the local outpatient clinic.

Overall, our sampling strategy was guided by the acknowledgement that each and every participant inevitably represented themselves and their subjective opinions and perspectives, and further, that the themes generated through the qualitative analysis would be judged more or less as representative or relevant within different clinical contexts by the reader, an approach to generalization often recognized as a case-to-case transferability [23].

Treatment setting

In 2008, the EDU changed the treatment program in order to provide a family-based inpatient treatment program. This restructuring was guided by a) the promising evidence-base from research on outpatient family-based therapy for AN, b) the wish to prevent separating the ill child from caregivers during hospitalizations and c) the specific legal situation in Norway, where children have a legal right to be accommodated by a parent during hospitalization. Since then, up to 5 families have been treated at the same time [7].

As outpatient FBT was originally a manualized version of the family-based treatment approach developed at the Maudsley hospital, the EDUs inpatient treatment program has undoubtedly been influenced by both sources. Although these two outpatient treatment models are today recognized by some differences, they share the common core features that, taken together, have been influential for treatment adaptations at the EDU. These features include charging parents with more responsibility during the admission (i.e., continually aiming to facilitate parental empowerment throughout treatment), externalizing the ED, together with aligning treatment with the non-blaming/non-etiological/non-authoritarian therapeutic stances embedded in both outpatient treatment models. Although the EDU has not adhered to a strict manualized FBT approach, the EDU has continually aimed to align treatment with the core features and therapeutic stances associated with outpatient FBT [2, 11, 24]. Generally, the treatment program corresponds to the first phase of outpatient FBT, as the main aim during admissions has been to enable AN symptom improvement. Contrary to standard outpatient FBT, however, the treatment team has had the final say on the meal plans during admissions. This decision-making process has commonly been done in close collaboration with the parents and only when viewed appropriate involved the patient, during the weekly treatment meetings (i.e., dependent on progress). During later phases of hospitalization, the focus has gradually shifted towards encouraging the adolescent to assume more responsibility for eating, with continued parental supervision. All families had weekly treatment meetings with a multidisciplinary team. Parents were provided with parental counseling. Staff had daily scheduled meetings with both parents and the young person. Families were usually offered family therapy sessions twice a week and some of the patients were offered individual sessions. Supplementary sessions were typically arranged in collaboration with the patient and parents. As a rule these individual sessions were intended to align with the overarching family therapeutic approach and could be viewed as predominantly supportive or motivational sessions, aiming to support the young person's treatment engagement together with helping them appreciate the greater responsibilities obtained by the parents. During some phases between 2008 and 2014, parents have been offered a parenting course inspired by the skills-based parent program developed at the Maudsley hospital [25], and for the majority of the time period (i.e., between 2008 and 2014) the EDU has provided weekly parent groups facilitated by staff, where the parents themselves were in charge of the content.

At discharge, all patients and families were transferred back to their local mental health services. Although siblings were welcome to take part in the admission, most families arranged for siblings to remain at home during the majority of the hospital admission. Siblings, however, could participate in family therapy sessions and family meals during visits to the EDU. Occasionally, a sibling group has been offered at the EDU led by a senior nurse or clinical psychologist.

Interview guides and interviews

Interview guides were developed separately for patients, parents and siblings by a group of experienced clinicians led by a senior researcher [IH]. Interview guides were piloted and revised before the final completion. Despite subtle differences, all interview guides were semi-structured and organized into three broad sections to cover perspectives related to the pre- admission phase, admission, and post discharge. Patients and siblings were interviewed individually. Parents were given the opportunity to choose whether they wanted to be interviewed separately or together.

Interviews were administered in 2015. A team of 5 senior clinicians and one advanced psychology student conducted the interviews, with one of the co-authors [IH] administering the majority of interviews (i.e., 14 of 26). The rest of the interviews were administered by the psychology student (i.e., 6 of the sibling interviews), and four specialist nurses (i.e., three specialist nurses conducted one interview each, and one specialist nurse and family therapist administered three interviews). Interviews were transcribed verbatim. Questions included how the participants had experienced the admission, whether they would have preferred any changes based on their experiences, an invitation to give their advice to the treatment providers and peers, together with questions on how they experienced the pre-treatment phase and transitioning back home. The interview guides are available upon request.

Qualitative analyses

Starting out our analysis was inspired by a multiperspectival interpretative phenomenological analysis (IPA) framework [26]. During the initial process of conducting the analysis according to the steps outlined in multiperspectival IPA, we [JVN & TWH] encountered several dilemmas. In particular, we were concerned whether our data were sufficiently rich enough to utilize an interpretative or hermeneutic approach such as multiperspectival IPA. After thoroughly discussing these important dilemmas we concluded that the raw data, together with the original research question, were most likely better managed while applying a predominantly pragmatic descriptive thematic analysis (TA) approach [27].

Both TA and IPA share much in common. They offer the researcher a set of steps, or a road map, for conducting the analysis, they can both be multiperspectival (i.e., involve participants from different positions as including parents, siblings and patients) and they both aim to generate themes based on the original data. Still the most striking difference, we believe, and this became crucial for our conclusions, is that while IPA has strong historic roots in specifically hermeneutics and phenomenology [26], TA represents a more pragmatic, a-theoretic framework that enables the analytic team to position the analysis in more flexible ways [27]. Critical for the current study was hence the assessment that our data was judged as more suitable for a descriptive TA approach, compared with the more interpretative stance recognizing the IPA framework.

Although unavoidably influenced by our initial analysis, we started over by re-familiarizing ourselves with the raw material while retaining the original multiperspectival approach. The first author [JVN] read and reread all transcripts together with preliminary coding, applying a more descriptive stance. At the same time, co-author TWH read the complete data set in order assist and collaborate in the evolving process, performing the role as a “critical friend” [28]. Again, we read and coded [chiefly performed by JVN] individual transcripts, one family at the time. We started out with the parents, followed by the index patient, and finally the siblings. Before finalizing the analysis, we scheduled weekly meetings to discuss the iterative process over a 2-month period. This work was done in accordance with the 6 steps outlined in TA [27]. After analyzing the individual interviews case- by- case, we used substantial time to explore whether we could find any thematic development that supported a shared family narrative, that is, we searched for themes potentially shared within the family as a whole, and also for similarities and discrepancies between families.

Results

A thematic structure of 5 main themes captured 14 subthemes, as outlined below (cf. Table 1 for a brief summary). During the analysis, we did not find evidence of a shared family narrative within the current sample. Rather than constructing "a shared family narrative" or mapping out themes on the "family level," it was interpreted that the participants' perspectives were predominantly influenced by both the position in the family (i.e., on an individual or between individuals level) and what we understood as the relationship to the ED. As outlined below, some of the subthemes were related to all family members, and these reflections are captured collectively under the same subtheme, whereas some subthemes represent views from one position alone (i.e., only the parents). All 8 families are represented with data excerpts.

Main theme 1: expectations and valuation of needs. Entering treatment from different vantage points

This main theme reflected the perspective that young persons with AN (hereafter abbreviated as YP-AN) and their family members entered treatment from very different vantage points. This variation was predominantly interpreted as contingent on roles and responsibilities at the time of the admission, together with what we determined as the relationship to the ED.

Subtheme 1: "We needed a time-out": parents appreciating the admission as a much needed restart for the family

> We couldn't handle the situation at home, we clearly needed help […] it's obvious. You feel very powerless as a parent when your child stops eating [Anna, *a mother reflecting back on a sensation resonating with most parents prior to the admission. Although engaged in treatment prior to the family-based admission; expressing strong feelings of being disempowered as parents, combined with a growing sense of that "somebody" has to intervene as things were beyond parental control*]

Although some of the parents recalled initial skepticism and ideally wanted to manage the situation at home without intensified treatment efforts, parents entered treatment with an overall high degree of readiness, as most "longed for the admission to finally start." Generally, parents recalled the pre-admission phase by interpersonal tension and high levels of within-family conflicts. They voiced multiple examples of how the family and individual family members had accommodated to the ED over time. Simultaneously, most parents

Table 1 Results

Main themes	Subthemes
1: Expectations and evaluation of needs. Entering treatment from different vantage points	Subtheme 1: "We needed a time-out": parents appreciating the admission as a much needed restart for the family – *parents* (*N* = 14) Subtheme 2: From opposition to realizing that "something had to happen" – *patients* (*N* = 8) Subtheme 3: The admission arriving as a surprise – *siblings* (*N* = 8)
2: Interactions with peers during the admission as highly beneficial or problematic	Subtheme 1: Sharing, learning and recognition of oneself in the other – *parents* (*N* = 14) and *siblings* (*N* = 5) Subtheme 2: Peer interactions as problematic: heightened pressure and symptom contagion – *patients* (*N* = 6) and *parents* (*N* = 2)
3: Perspectives on staff expertise and the EDU structure	Subtheme 1: Improved understanding of ED and insight into the young patients challenges – *parents* (*N* = 14) and *siblings* (*N* = 7) Subtheme 2: Strengthening parental authority and re-establishing normalized meal routines – *parents* (*N* = 9) Subtheme 3: Enabling necessary weight gain – *parents* (*N* = 8), *patients* (*N* = 3) and *siblings* (*N* = 4) Subtheme 4: The unintended potential of treatment keeping parents in a bystander position – *parents* (*N* = 5)
4: Influencing within-family relationships in different ways	Subtheme 1: Strengthening within family relationships – *siblings* (*N* = 5), *parents* (*N* = 10) and *patients* (*N* = 6) Subtheme 2: The potential of maintaining or increasing fragmentation – *siblings* (*N* = 5) and *parents* (*N* = 4)
5: Being admitted is at best only half the job: reflections on leaving the EDU	Subtheme 1: Leaving the EDU while the ED is still on board – *parents* (*N* = 10) and *patients* (*N* = 4) Subtheme 2: Being transferred back to where it did not work out in the first place – *parents* (*N* = 8) and *patients* (*N* = 5) Subtheme 3: For siblings, leaving the EDU meant leaving treatment for good: calling for better sibling involvement – *siblings* (*N* = 8) and *parents* (*N* = 10)

Note: To indicate the robustness of findings, the number of participants sharing views within each subtheme is listed in parenthesis recollected feeling renewed hope when reflecting on the time prior to the admission; anticipating that this new treatment effort could be helpful, “finally we were going to get help.” Looking back, all parents described “a sense of relief” when the referral to the EDU was accepted. Most parents also recalled they found it important that the EDU was deliberately providing space for the whole family, “as this was a family issue.”

Subtheme 2: from opposition to realizing that “something had to happen”

Contrary to their parents, all but one of the YP-AN remembered opposing treatment at the time of the admission.

> I was kind of… forced… I was really fed up with treatment and did not want to be there [Brenda, 20 years, 14 during the admission, *an extract resonating with most YP-AN at the time of the admission, as they overall recalled low readiness for a new treatment effort*]

Reflecting back from a more distant position, all eight former patients acknowledged that something had to happen at the time of the admission, as they remembered things were not working out at home or even at the treatment facility where they had received therapy.

> I guess I thought, “I’m not going to go there”. That it was totally unacceptable. I guess I didn’t imagine that I needed another admission, after [recently] being discharged at the medical ward… […] It was necessary, I see that *now*. That I got help somewhere, so, if it was at [name of unit] or a different place, I don’t know, but it was nevertheless essential that they stopped me from losing further weight… [Molly, 18 years, 15 during the admission*, although her vantage point was characterized by initial opposition, the excerpt showed how her perspectives on being admitted had changed over time*]

One YP-AN reflected contrary views, as she voiced high levels of pre-admission readiness, recalling that she felt extremely exhausted, and “ready for somebody to take over control,” as she recognized that everything pertaining to food and meals was far beyond control. She also remembered thinking that although she really wanted change, she was unable to make the necessary changes alone.

Subtheme 3: the admission arriving as a surprise

> I thought it was very peculiar. Very extraordinary, that my family had to be hospitalized. That my sister, that *she* had any problems? She was very conscientious and was feeling really, very well, I thought […] that she needed help, that there was a problem, that I found very strange [Sister, Catherine, 14 years, 10 during the admission, *reflecting back on the admission arriving as a surprise*]

None of the siblings had previously been involved in family-based treatment for AN. In general, siblings described that the admission came as a big surprise. For the two siblings that did not express this viewpoint, one was apparently well-informed and also very eager to take part in the admission. Resonating with the YP-AN views captured in subtheme 2, some of the siblings recalled feeling oppositional when they learned the admission was family-based and they were expected to participate. For some, the sensation of surprise thus developed into sheer resistance.

> I was very negatively inclined. I did not like the fact that we were supposed to be admitted, that I had to stay there. I never stayed there. Me and my little brother were always at home together with either mom or dad […] I remember they asked if I wanted to stay over, but I didn’t want to, I didn’t feel it was right… [Sister, Jenna, 15 years, 12 during the admission, *reflecting back on her immediate reactions when learning she was supposed to be admitted too*]

Main theme 2: interactions with peers during admission as highly beneficial or problematic

This main theme captured participants’ views on being admitted to a treatment setting in which they had the opportunity to interact with peers. Common for all participants was that the family-based admission represented the first time they were admitted together with other families. The subthemes revealed that peer interactions were viewed as predominantly beneficial (subtheme 1) or problematic (subtheme 2).

Subtheme 1: sharing, learning and recognition of oneself in the other

> I think everybody felt that it was really useful to recognize that others had, in fact, experienced the same, or at least something in the same way. That it wasn’t all about us. I believe that is important for parents too, to know that you’re not alone on this [Father, Paul, *reflecting back on the peer group for parents. Although facilitated by staff, the group focused on issues the parents raised on that particular day*]

Parents and siblings both viewed being admitted together with other families as largely supportive and meaningful. Parents emphasized that having weekly meetings scheduled with other parents was a very supportive experience. They typically recognized that their own within-family struggles, as well as the numerous challenges with the health care system, resonated with others, i.e., "increased feeling of connection," "we were not the only ones," "others held similar experiences as ours," "it was not only us that reacted to such behaviors." Additionally, some parents remarked that it was often easier to discuss issues with other parents compared to professionals.

For siblings who interacted with other siblings during the admission, the prospect of meeting others was viewed favorably, especially among siblings of the same age with shared interests. Whereas few parents spontaneously interacted with other parents or family members during the admission, siblings reported more frequent encounters.

> I think it was pretty nice. Then I understood that it wasn't only me that had it like that. Somebody else had the same, like me. It felt, I think it was a good thing to be together with somebody else that had similar challenges [Brother, Kenneth, 15.5 years, 12 during the admission; *on the perceived benefit of meeting other siblings during the stay*]

Subtheme 2: peer interactions as problematic: heightened pressure and symptom contagion

> For me, the surroundings were very negative… and I guess I was very susceptible too, and that I think everybody was [YP-AN, Jane, 21 years, 16 during the admission, *on being admitted with peers with severe challenges in a vulnerable phase, a sensation resonating with the majority of the YP-AN when reflecting back on interactions with peers*]

None of the patients shared stories of supportive interactions with fellow patients or other families. Quite the contrary, the YP-AN seemed to strongly feel that being admitted with peers was problematic. They recalled peer interactions frequently led to comparisons and negative competition. Some also acknowledged they, too, likely exerted negative pressure on others. Several of the YP-AN concluded that being admitted with peers with AN is potentially very problematic and should be handled carefully. Overall, parents perceived peer interactions between YP-AN as less problematic, although some did recollect that their child probably learned new and negative symptom behaviors, most likely due to observing and imitating peers during the admission.

Main theme 3: perspectives on staff expertise and the EDU structure

Both parents and siblings voiced that interacting with, and getting support from, experienced staff together within a structured treatment setting was beneficial for understanding the ED, strengthening parental authority, and re-establishing normalized meal routines. Several also emphasized that the EDU structure and staff expertise were crucial factors enabling weight gain and ED symptom improvement. Finally, this main theme also captured that, although staff expertise and the structure of the EDU were viewed as beneficial overall (especially voiced by parents), some aspects could, in certain instances, be interpreted as non-intentionally maintaining the ED.

Subtheme 1: improved understanding of the ED and insight into the young patients challenges

> That we learned more about the ED. That we could be present… and maybe that mom and dad learned to be more firm when telling my sister that she needed to eat [Brother, Kenneth, *on what he believed was especially valuable for the family; both a better understanding and that the parents were able to manage the meals more efficiently*]

Most of the parents, and some of the siblings, recalled benefiting from the staff's expertise, which improved their general knowledge of EDs, as well as their specific understanding of the unique challenges facing the YP-AN. Several of the parents, and siblings, implied that greater knowledge and awareness enhanced empathy, i.e. "when we were able to see how difficult it was, we could understand better how it really was for her." Despite having undergone extensive prior treatment, including previous hospitalizations, quite a few parents and siblings emphasized this was the first time they truly had the opportunity to learn about the ED. The educational program for parents was viewed as particularly beneficial in improving knowledge about the ED, and how the ED challenged the parental role.

> Attending the parenting courses was very helpful. Then you got something concrete to relate things to, and that helped, I think [Mother, Caroline, *recalling how learning more about ED and being introduced to how the ED typically challenges parenting was useful for her*]

Subtheme 2: strengthening parental authority and re-establishing normalized meal routines

> To learn to be calmer during meals. I think we were able to manage the meals more peacefully while on

> the unit, compared with previously, then there was no such thing as a calm meal! And we got rid of weighing the food [Mother, Ruth, *reflecting on the potential benefit of breaking patterns while being socialized into a meal structure compatible with a more normalized family life, and the prospect of unlearning of non-supportive behaviors*]

Parents highlighted several aspects of the EDU structure as particularly beneficial for breaking patterns and in reestablishing normalized meal routines.

> That I felt *so* secure, that the [meal] structure was so firm [...] that was the first thing I was very satisfied with, that somebody, like, took the responsibility from us, so we could have some real help, since we didn't manage it [at home] [Mother, Sarah, *on the potential benefit of parents being able to lean on a structure administered by the professionals*]

Following Sarah's excerpt, the father continued to describe how the established routines and structure at the EDU aided in re-installing parental authority, which had more or less vanished under the pressures of the ED.

> It was a very welcome feeling of not standing alone with everything [...] We were, in a way, defeated as parents, and how should I put it? Ehm, we had no authority, no influence; we were no longer defined by our daughter as caregivers in relation to food. I think our daughter didn't perceive that we had anything reasonable to say concerning food, because she was so convinced she was right. So, to come here and get support for the parenting, that felt very meaningful [Father, Peter, *on the EDUs potential of reinstalling and supporting parental authority*]

Sarah (wife) later joined in and summed it up:

> We regained a belief in our ability to function as parents [...] we recovered self-confidence and a belief in that we can be parents and authority figures for our daughter [Mother, Sarah]

Subtheme 3: enabling necessary weight gain

Although some of the YP-AN retrospectively acknowledged the necessity of weight gain to recover, parents and some siblings strongly emphasized the benefits of the admission in facilitating improvement on physical parameters. Weight gain and medical outcomes were predominantly ascribed to staff expertise, and enabled by the structure of the EDU, more than fueled by increased parental self-efficacy. Yet weight gain and related improvements were not uniformly perceived as linked with improved psychological well-being, as reflected in Caroline's quote below:

> To gain weight, you talked a lot about that, that it was supposed to help, and then you were supposed to get a clearer mind. We've witnessed quite the contrary with her [Mother, Caroline, *referring to how she remembered that although emphasizing the inevitable necessity of weight gain; how difficult it was when her daughter Jane actually gained weight, and that psychological symptoms did not immediately recede as she felt she had been told over and over again*]

Subtheme 4: the unintended potential of treatment keeping parents in a bystander position

> We didn't perceive ourselves as so important [during the admission]. It was more that our son was prioritized. That was most important [Father, Steven]

Although most parents voiced an initial need to step back and "let the experts take care of an unmanageable situation," the majority retrospectively perceived that treatment strengthened their role and position as caregivers (i.e., as reflected by the majority in subtheme 2 above). Still, we interpreted some parental views as acknowledging the potential of the treatment to maintain them in a bystander or sidelined position. For some, it was as if treatment failed to co-construct a collaborative relationship that strengthened their parental authority and relational agency.

> Paul [Father]: I think, for my part, that it was reassuring that somebody could help my daughter, like, "Now we know she gets what she needs", "Now she's going to get better", that I felt was very reassuring [...] still I felt that it was difficult. I didn't feel that *I* took part. I don't know if this was because I opted out or not, but I don't think so, it was like, you were supposed to join in and take part, still you were on the sideline [...] It was like, the one who controlled everything and had the direction, it was that therapist, or the one being present at that moment [that were in charge] and I was in a way set aside, as I felt it...
>
> Inger [Interviewer]: The therapist took over?
>
> Paul [Father]: Yes, it was like that in a way, and further, I noticed on my daughter too [...] like, she really needed to hear it from somebody [else] what she should do too, and it became much easier for

> her to listen to somebody else, of course, that knows this.

As we read this excerpt, together with other parental excerpts that touched upon Paul's perspectives, we recognized the potential of the YP-AN becoming dependent upon staff instructions and / or authority. This development could ultimately become a hindrance in aiding parental efficacy, and reinforce the idea that staff members are the "true" experts, thereby maintaining parents in a bystander position.

Main theme 4: influencing within-family relationships

This main theme captured contrasting views on how the admission was perceived as supportive and strengthening within-family relationships, while others viewed the admission as maintaining or increasing fragmentation.

Subtheme 1: strengthening within-family relationships

Parents and siblings shared a range of views relating to reduced relational distance, i.e., "we came closer," improved collaboration," "we managed to collaborate better." Several voiced enhanced within-family understanding of each other and the ED, i.e. "by being together we learned together and understood better," and reduced within-family conflicts, i.e., "things became calmer."

> Sarah [Mother]: We felt we came closer to each other, that our collaboration improved, or…
>
> Peter [Father]: Mhm… we experienced that as a family, too. All these conversations we had, and the groups and, yes, both the individual family sessions and couple sessions we had, and these group meetings with the other parents. Everything helped us to sort things out between us… so our relationship and to our daughter… I think it became a closer relationship [*Both parents reflecting on noticing improved collaboration and strengthened relationships*]

Although few of the YP-AN emphasized that having been admitted was aiding them directly (i.e., as personally perceived as supportive at the time), some reflected as Jane below, that although the admission paralleled an extremely difficult time period, looking back she had come to appreciate that the admission was of benefit for her parents, the family, and in strengthening relationships:

> When I think back, I do believe it is the worst thing I've ever experienced [reflecting back on the time of the admission] [still] I did observe, there, that my parents seemed a bit happier, calmer. At home, I felt it was like, police and thief, and our relationship was suffering when we were at home [prior to the admission], and I felt it was strengthened when we were there. They became more my supporters […] I would say it was of benefit for my family… [Jane, 21 years, 16 during the admission, *recalling that although the admission represented the worst of memories, it was beneficial for the family*]

Subtheme 2: the potential of maintaining or increasing fragmentation

Although we assume that "living with the ED" had contributed to an increased sense of separateness for the afflicted families, some of the participants voiced concerns that the organization of the admission might represent a further division for some families, i.e., "as we did not stay there together, we became even more divided".

> I feel in a way that we came closer to each other, but also that we in ways became divided. Mom was with my sister all the time [at the EDU], and then it was us three [at home]. We too came a bit closer, still it was a bit divided [Sister, Angie, 15 years, 12 during the admission, *reflecting on the feeling of both getting closer with some family-members, and at the same time; a sensation of being divided*]

This sense of disconnectedness was particularly echoed in some of the siblings' accounts. In particular, some of the youngest siblings found it challenging to spend less time with the parent who was frequently at the EDU; typically this was their mother. On the other hand, some siblings voiced the benefits of an improved relationship with their father as a consequence. This feeling of disconnectedness also resonated with some of the parents, who emphasized that if they could do "one thing over again," it would be to be admitted earlier to the specialized EDU, and to stay together as an entire family. These parents now believed that "they" as parents and "we" as the family would have benefited more from an earlier admission that included all family members.

Main theme 5: being admitted is at best only half the job: reflections on leaving the EDU

This main theme captured realizations that discharge did not represent the end of living with an ED, or even signify the end of treatment, as some of the family members may have anticipated or hoped for initially when admitted. Although many viewed several aspects of hospitalization as beneficial, both for themselves and their family, it was clear that discharge from the EDU represented at best only half the job.

Subtheme 1: leaving the EDU while the ED is still on board

> It was very final, at least for us, when we were discharged, it was like "goodbye" and that's it. We never made any calls and I guess there were no openings either? We never heard that we could, and we didn't do it anyhow. I guess we probably could have done it, and maybe have the chance to have a conversation with somebody, but we felt it was very final, that we were not supposed to make any calls [to the EDU] and I guess it often feels like this, that it is a bit abrupt after such a long admission [Mother, Linda, *reflecting back on discharge*]

The majority of the participants remembered the immediate phase following discharge as very difficult. The ED was still present and exerted a great influence on the YP-AN and daily life as a family. Despite practice managing the recommended meal structure at the EDU during planned leaves, several parents acknowledged a prolonged admission or additional follow-up at the EDU as potentially beneficial after discharge. Some parents suggested that a scheduled brief "booster" re-admission would be beneficial, without having to undergo a full relapse to gain re-admission at the EDU or inpatient treatment elsewhere. Although discharge was known in advance and planned to a certain extent, several of the parents still perceived discharge as occurring suddenly and implied that it was not properly planned.

Even some of the YP-AN who initially resisted hospitalization felt the admission ended abruptly with insufficient planning and predictability. Some even reflected that a longer admission would have been beneficial, as they realized they had remaining ground to cover.

> When I was admitted, at the time I didn't eat by myself [nasogastric tube] … Nor did I start with serving myself, and [thus] did never practice that, so, that I think was something we could have worked on… [Diana, 20 years, 17 during the admission, *on the potential benefit of having progressed further before being discharged*]

Subtheme 2: being transferred back to where it did not work out in the first place

> I didn't feel they had sufficient expertise; they didn't follow up appropriately [Father, Anthony, *on the decision of not going back to the local outpatient clinic after discharge*]

Most parents voiced concerns related to a treatment impasse at the local outpatient clinic prior to the admission, and found it difficult to accept a referral back to a treatment setting "where it did not work out in the first place." The majority had lost confidence in the local outpatient clinic and doubted the treatment team could provide assistance following admission to the family-based inpatient program. Skepticism was probably fueled by previous encounters and likely reinforced by receiving highly specialized treatment at the EDU. Similarly, several of the YP-AN also reflected on the paradox of being referred back to the same treatment setting where treatment had previously failed.

> I was sent back to the outpatient clinic where I had been prior to the admission and that did not work out at all. And the fact that I was sent back to that place, that was kind of… yes, it did not work out to say it bluntly. So, I'm having a hard time figuring out that one, why it was like that […] And I met a person at the outpatient clinic that didn't know much, and that was very frustrating and contributed to the ED growing and gained more space again [Molly, 18 years, 15 during the admission, *on finding it difficult to accept that she had to go back to where it did not work, while implying how crucial expertise can be to prevent things getting worse*]

One solution for some families involved seeking treatment at a private practice instead of returning to the local outpatient clinic. Although initiated by parents, the decision resonated with the YP-AN's skepticism in returning to treatment at the local outpatient clinic.

> We didn't go back to the outpatient clinic, because we couldn't see that there was any therapist there that understood anything of this, and I have to say that we were very lucky to get in touch with a private practitioner, so we started there [Mother, Caroline, *on the difficulties with trusting the local outpatient clinic for further follow up post discharge, and recalling how all in all satisfied she was with finding an experienced private practitioner for her daughter and their family*]

Subtheme 3: for siblings, leaving the EDU meant leaving treatment for good: calling for better sibling involvement

Siblings also recalled continued hardships for the families following discharge. None of the siblings received additional involvement in treatment post-discharge. Upon reflection, parents and siblings called for a greater focus on siblings during the admission, as "siblings are an equally important part of the family," including siblings beyond chance meetings and an occasional session with a therapist.

Discussion

The current study contributes novel knowledge regarding user experiences which can supplement emerging research on adapting core aspects of evidence-based outpatient FBT into higher levels of care [6, 7, 16, 17]. Findings revealed five main themes capturing 14 subthemes (cf. Table 1 for brief summary). No evidence was found of any shared post-treatment family narrative. Participants demonstrated considerable diversity in viewpoints, which was interpreted as being contingent upon their role in the family, responsibilities and relationship to the ED. Without prescribing definitive answers, we believe the results have several implications for treatment providers working within a family-based inpatient treatment approach.

Main theme 1: *Expectations and evaluation of needs. Entering treatment from different vantage points*. This main theme is a useful reminder of the importance of recognizing and valuing the individual needs of families, and refraining from making immediate generalizations of YP-AN and their family members. Families are inevitably constituted by individuals that think, feel and behave differently, even while navigating the apparent "same" social phenomena such as hospitalization. During the pre-admission phase, we believe it is critical to allow sufficient time to explore central issues together with the YP-AN, their family, and the referral system. The findings suggest that different levels of readiness for change, knowledge of the ED as well as preparedness for the admission, in addition to varied expectations and needs are important to explore in-depth prior to an admission. Therefore, we strongly recommend that pre-admission sessions move beyond simply sharing information about the treatment program. The treatment team should enable sufficient time to transparently explore the mutual expectations of family members and treatment providers, investigate previous treatment experiences in-depth, and begin negotiating roles and responsibilities aligning with the overarching family-based treatment approach. Theme 1 also suggests the potential of providing YP-AN and their family members more structured or planned interventions prior to the admission. Without prescribing specific types of interventions, we would recommend the consideration of motivational enhancement sessions for the YP-AN [29, 30] in addition to a brief education program for parents aligning with the skills and content espoused by a family-based approach [25, 31]. It is feasible that an investment in greater resources prior to the admission may optimize the starting point and help the admission become more efficient. Lastly, the first theme emphasizes the importance of enhancing the focus on sibling involvement prior to the admission. Parents should not be left alone in determining how siblings should be informed and / or involved, as sibling involvement should naturally constitute a part of pre-treatment planning for a family-based admission for adolescent AN.

Main theme 2: *Interactions with peers during the admission as highly beneficial or problematic*. The finding that parents valued the mutual support and sharing of experiences with other families is consistent with prior studies of parental peer support and treatment satisfaction in multi-family group therapy [1]. Similarly, the difficulties in navigating peer relationships experienced by YP-AN during admission have also been reported in previous studies [19, 32, 33]. Siblings' perspectives indicated the benefit of engaging with other siblings, highlighting the importance of enhanced sibling interactions during admissions. Overall, the second main theme suggests the importance of strengthening multi-family work during admissions [34]. Inspired by these findings, we recommend that treatment providers carefully review how peer interactions are enabled and managed during admissions, and to evaluate how the inpatient context can be further optimized to utilize the rich knowledge base embedded in the family members' lived experiences [1, 35]. Specifically, results remind treatment providers to carefully identify and counter negative peer dynamics between the YP-AN during admissions, and to create opportunities to facilitate peer support. The latter is a potential direction of further investigation in collaboration with YP-AN who have prior inpatient treatment experience.

Main theme 3: *Perspectives on staff expertise and the EDU structure*. The majority of parents viewed the EDU structure and staff expertise as aiding their perceived parental self-efficacy, which is one of the proposed mechanisms of change in family-based treatments [6]. It is encouraging that most parents reported observable behavior change or symptom improvement, not simply treatment satisfaction. Such improvements tended to generally be ascribed to the opportunity to interact with knowledgeable staff and being supported by the EDU structures. Although encouraging, we believe the EDU needs to continue focusing on enabling parental empowerment during admissions [6, 11]. Importantly, the current findings suggest that perceived enhanced parental self-efficacy was not universally experienced. Similar to outpatient FBT [8], inpatient admission is not a panacea, and there is no "one way" to empower all parents. As parents and families enter treatment with unique vulnerabilities, experiences and needs, the therapeutic task of empowering parents must be continually negotiated and tailored to the individual parent's needs and vantage point.

Main theme 4: *Influencing within-family relationships in different ways*. Findings indicated that treatment was generally perceived to strengthen within-family relationships. This is a reassuring finding, as preventing fissures in relationships and strengthening collaboration within families comprise the core tenants of family-based treatment. Findings are also in accordance with an Australian study of an intensive 2-week family admission program [18]. Although findings generally aligned with the rationale for offering a family-based inpatient program, findings also question the family-based foundation of the program design, as none of the participating families stayed for the entire length of the admission. Thus, it is reasonable to question how family-based the program "really" is, when important members of the family system were rarely represented at the EDU, and thus not actively engaged in treatment. Involving the "whole" family is usually advocated in the literature, as this constitutes a pillar when providing treatment. Still, the prominent stance of "including the family" is often far removed from the day-to-day realities. This seems to resonate with research showing that clinicians regularly fail to sufficiently involve family members even when providing standard FBT, a treatment model that explicitly aims to include the family [36, 37]. Admitting a family for a prolonged time period is obviously demanding on resources and represents a highly complex treatment situation for which clear evidence to guide treatment providers is scarce. Research is sorely needed to understand how to best optimize the inpatient setting and to investigate whether engaging the whole family to a greater extent during hospitalizations can improve outcome and facilitate successful transitions after discharge.

Main theme 5: *Being admitted is at best only half the job: reflections on leaving the EDU*. In accordance with previous literature [12, 38], transitioning between services represented a vulnerable phase for our families. In general, findings suggested that clinicians carefully plan discharge with the family, and maintain a collaborative relationship with the referral system during the admission. As suggested by our findings, we believe that planning for discharge, and the vulnerable phase after the admission, needs to be properly addressed early during the admission. This includes exploring the expectations of family members, as well as the treatment providers responsible for referral and aftercare, regarding the goals of admission. This effort ensures expectations and goals are transparent, and can help orient everyone involved about the "reality" of the admission being a temporary part of the journey toward recovery [4]. All YP-AN, by definition, will need further specialized care after participation in the family-based admission, and therefore, a plan for the follow-up phase should ideally be decided upon prior to the admission and negotiated based on treatment progression. Collaboration with the referral system should be given more attention prior to the admission, and during treatment, in order to minimize the likelihood of families perceiving discharge as abrupt and poorly planned.

Strengths and limitations

Investigating user perspectives from three different positions (patient, parents, and siblings) is viewed as a strength. Throughout the analysis, we maintained a focus on the family. In our view, the experience of families is perhaps paradoxically lacking in many qualitative studies of family-based interventions, which often focus on the single views of the patient, parents, or siblings. An obvious limitation is the retrospective nature of the study. Unquestionably, the time elapsed between discharge and follow-up interviews may influence participants' recollections. Still, time has also enabled participants to reflect from a potentially more mature, self-reflexive, and thus, less emotionally-laden position, compared to being interviewed shortly after discharge. Another limitation is the sampling strategy. As few intact families were available in the dataset ($N = 8$), results cannot be generalized broadly, and different families may have provided difference responses. Thus, the analysis does not claim to provide a narrative on how family members generally experience family-based inpatient treatment. In addition, the specialized EDU treatment setting which offered treatment comprises a specific context not necessarily generalizable to other regions and countries. Still, we believe the findings, in addition to clinical implications derived, offer valuable insight and are relevant for treatment providers aiming to optimize family-based treatment at higher levels of care. Another limitation is that several interviewers with varying levels of interview skills took part in conducting the interviews. This may have affected the richness of the data. We also question whether the retrospective interview data, as in the current study, provides the best data source to inform further treatment development, which is the overarching aim for our qualitative research projects. Future research should aim to generate more detailed descriptions to guide the development of family-based treatment for adolescent AN at higher levels of care. We suggest improving the system for administering interviews (e.g., to administer interviews both during treatment and soon after discharge), together with ethnographic fieldwork in order to study practice as it unfolds in real time. Lastly, a potential limitation worth mentioning is that the patient and sibling transcripts have been utilized in our previous research, although with a different research purpose. This can have influenced both analysis and findings in the current study.

Conclusions

Our study offers insight into how former inpatients and their family members experienced an inpatient treatment program designed to align treatment with the central elements of an outpatient family-based treatment approach for adolescent anorexia nervosa. Overall, the findings support emerging research underlining the necessity of strengthening the family-based treatment approach within intensified treatment settings. Moreover, the results emphasized the need for more knowledge on how to optimize inpatient treatment as well as the importance of providing smooth transitions between care settings.

Abbreviations

AN: Anorexia nervosa; FBT: Family-based treatment; EDU: Eating disorder unit; YP-AN: Young person with anorexia nervosa; TA: Thematic analysis; IPA: Interpretative phenomenological analysis

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Authors' contributions

Together with JVN, IH made a substantial contribution to developing the interview guides. IH was leading and supervising the data collection. JVN transcribed the interviews, read and re-read the whole data set several times. TWH read all transcripts. The process of developing the theme structure and analyzing and interpreting the data material was a collaborative effort between JVN and TWH, and done in dialogue with HWO, with JVN taking the lead throughout the process. JVN wrote the first draft of the manuscript. HWO supervised the whole process together with ØR and TWH, and all authors made substantial contributions to the final paper. All listed authors are accountable for all aspects of the work, including issues related to accuracy and integrity. All authors read and approved the final version of the manuscript.

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Availability of data and materials

The dataset collected and analyzed during the current study are not publicly available as this could compromise participant privacy. The corresponding author can be contacted on reasonable request with questions considering the dataset.

Ethics approval and consent to participate

Ethics approval was granted by the Regional Committee for Medical Research ethics, South East Norway [REK2014/2223]. All participants gave their written consent to participate.

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no competing interests.

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Klinikk psykisk helse og avhengighet
Psykisk helse, nasj. og reg. funksj., avd
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Til deg som har blitt behandlet for spiseforstyrrelse ved Barne- og ungdomsenheten ved Regional seksjon spiseforstyrrelser (RASP), Oslo Universitetssykehus, i tidsrommet 2008 – 2014

Forespørsel om å delta i forskningsprosjekt

Anoreksi er et av de vanligste, alvorlige helseproblemene som rammer unge mennesker. Vi i helsevesenet har et stort behov for å få mer kunnskap om hvordan det går videre med personer som må legges inn på sykehus i ungdomstiden pga anoreksi eller annen alvorlig spiseforstyrrelse. Dette er viktig for å kunne gi bedre hjelp til unge med spiseforstyrrelser og deres pårørende.

Retningslinjer for behandling av unge med spiseforstyrrelser anbefaler å inkludere foreldre i behandlingen. I 2008 begynte derfor Barne- og ungdomsenheten å bruke familieinnleggelser i stedet for å legge inn unge med spiseforstyrrelser uten foreldrene. Det foreligger lite forskning om hvordan det går med spiseforstyrrelsen og andre vansker hos unge som har vært innlagt sammen med familien sin, og helsevesenet mangler kunnskap om hvordan tidligere pasienter, foreldre og søsken opplever familieinnleggelser.

RASP har i perioden 2008- 2014 hatt innlagt ca 60 familier. Vi skal gjøre en etterundersøkelse for å kartlegge hvordan dere har hatt det siden dere ble utskrevet fra RASP og hvordan dere har det nå. Videre ønsker vi å kartlegge hvordan dere opplevde familieinnleggelsen og hva dere selv mener at har vært til hjelp for dere. Dette er bakgrunnen for at du nå blir spurt om å delta i dette prosjektet.

Foreldre som var innlagt sammen med deg, vil også bli invitert til å delta i undersøkelsen. Siden foreldrene deltok i behandlingen, er det viktig å få vite mer om hvordan de opplevde dette, om hva de synes har vært til hjelp og hvilke tanker de har om hvordan det har gått med deg siden. Dersom de samtykker i å delta, vil vi be om å få snakke med dem også og be dem om å fylle ut et spørreskjema.

Dersom du har søsken som var innlagt sammen med deg i Ungdomsenheten, ønsker vi også å snakke med dem og be dem fylle ut et kort spørreskjema vedrørende deres opplevelse av behandlingen i Ungdomsenheten og hvilken innflytelse spiseforstyrrelsens har hatt på deres liv.

Hva innebærer det å delta i prosjektet?

Dersom du er villig til å delta, vil dette innebære at du signerer og returnerer vedlagte samtykkeerklæringen i den frankerte konvolutten. Dersom du er under 16 år, må en av dine foreldre også samtykke for at du skal delta. Når vi har mottatt samtykke fra deg, vil du vil bli bedt om å fylle ut et spørreskjema som vil bli sendt hjem til deg i posten og deretter at en fra prosjektgruppen vil snakke med deg, enten her på RASP eller på et annet avtalt sted. Hvis det er i orden for deg, vil vi gjerne bruke lydbånd som i så fall vil bli slettet når prosjektet er ferdig. Videre vil informasjon fra den gangen du var innlagt i Ungdomsenheten bli hentet ut av journalen din ved RASP.

Dersom det er mest praktisk for familien din å komme til intervju samtidig, vil vi prøve å koordinere tidspunktene slik at dette er mulig. Reiseutgifter i forbindelse med intervjuet blir dekket av oss. Tidligere pasienter og søsken vil få et gavekort (kr 500) som en delvis godtgjøring for den tiden dere bruker.

Hvis du bor i utlandet, eller det av andre grunner er vanskelig å møte deg direkte nå, kan du likevel være med i undersøkelsen. I så fall vil vi avtale nærmere med deg hvordan dette kan gjøres. Hvis du ikke husker så mye fra behandlingen i Ungdomsenheten, vil det likevel være av stor verdi for undersøkelsen at du deltar.

Hva skjer med informasjonen om deg?
Alle data vil bli behandlet konfidensielt. Opplysninger fra et familiemedlem vil ikke bli formidlet til andre i familien. Det vil bli opprettet et register for å kunne behandle resultatene. Registeret vil ikke inneholde persondata (navn, initialer, fødselsdato eller personnummer), men bli kodet med et løpenummer. Navneliste med løpenumre vil bli oppbevart forsvarlig nedlåst og atskilt fra de andre opplysningene. Vi ønsker at navnelisten blir oppbevart etter prosjektslutt (beregnet til des. 2016), slik at vi kan kontakte dere igjen dersom det skulle være aktuelt med en ny oppfølging.

Når vi skal presentere resultatene fra undersøkelsen (i artikler og foredrag), vil dette gjøres slik at ingen enkeltpersoner vil kunne gjenkjennes. De som deltar i undersøkelsen vil få tilsendt en oppsummering av resultatene dersom de ønsker det.

Frivillig deltakelse
Vi håper du er villig til å delta i undersøkelsen. Dette er selvfølgelig frivillig og du kan også når som helst trekke deg underveis uten å oppgi grunn og da få slettet de opplysningene vi har registrert. Om du deltar eller ikke deltar i undersøkelse vil ikke være av betydning for senere kontakt med RASP eller helsevesenet forøvrig.

Hvis du ikke vil være med, er det fint om du returnerer svarslipp om dette slik at vi ikke kontakter deg igjen.

Ta gjerne kontakt med Inger Halvorsen eller Trine Naustdal – tlf 23 01 62 30 – dersom du har spørsmål. Hvis vi ikke er til stede, er det fint om du legger igjen en beskjed til oss så vil vi ringe deg tilbake.

Med vennlig hilsen

Prosjektansvarlige:

Inger Halvorsen	Trine Naustdal	Asbjørn Syversen
Overlege, prosjektleder	Enhetsleder, prosjektmedarbeider	Seksjonsleder

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Forespørsel om å delta i forskningsprosjekt

Vi viser til vedlagte kopi av informasjonsbrevet til de unge med forespørsel om å delta i etterundersøkelsen av pasienter som var innlagt hos oss i denne perioden.

Vi ønsker en bred kartlegging av hvordan den unge har hatt det siden hun/han ble utskrevet og hvordan hun/han har det nå. Ved siden av informasjonen fra den unge selv, vil foreldrenes opplevelse av hvordan det går med den unge gi viktig tilleggsinformasjon. Foreldres opplevelse av familieinnleggelsen og av hva de vurderer at har vært til nytte for barnet, for dem som foreldre og for søsken, har stor betydning for hvordan helsevesenet kan bedre behandlingstilbudet til unge med spiseforstyrrelser. Dersom søsken (som nå er over 8 år) var innlagt ved RASP sammen med familien, vil de også bli invitert til å delta i etterundersøkelsen. Deltagelse fra personer under 16 år krever samtykke fra foreldre.

Hva innebærer det å delta i prosjektet?

Dersom du samtykker i å delta, må du returnere vedlagte samtykkeerklæring i den frankerte svarkonvolutten. Du vil deretter bli bedt om å fylle ut et spørreskjema som vi sender til deg i posten og delta i en samtale/intervju, enten på RASP eller et annet sted hvis dette passer bedre for deg/dere. Dersom du/dere bor i utlandet, eller det av andre grunner ikke er mulig å gjennomføre et personlig intervju, vil vi avtale et tidspunkt for telefonintervju.
Hvis det passer for dere, vil foreldrene bli intervjuet sammen. Tidligere pasienter og søsken vil bli intervjuet hver for seg. Vi vil prøve å koordinere tidspunktene slik at intervjuene kan foretas samtidig, dersom dette passer best for familien. Reiseutgifter i forbindelse med intervjuet blir dekket av oss.

Hva skjer med informasjonen fra deg?

Alle data vil bli behandlet konfidensielt. Opplysninger fra et familiemedlem vil ikke bli formidlet til andre i familien. Det vil bli opprettet et register for å kunne behandle resultatene. Registeret vil ikke inneholde persondata (navn, initialer, fødselsdato el. personnummer), men bli kodet med et løpenummer. Navneliste med løpenumre vil bli oppbevart forsvarlig nedlåst og atskilt fra de andre opplysningene. Vi ønsker at navnelisten blir oppbevart etter prosjektslutt (beregnet til des. 2016), slik at vi kan kontakte dere igjen dersom det skulle være aktuelt med en ny oppfølging.

Når vi skal presentere resultatene fra undersøkelsen (i artikler og foredrag), vil dette gjøres slik at ingen enkeltpersoner vil kunne gjenkjennes. De som deltar i undersøkelsen vil få tilsendt en oppsummering av resultatene dersom de ønsker det.

Frivillig deltakelse
Vi håper du er villig til å delta i prosjektet. Deltagelse er frivillig og om du deltar eller ikke har ingen konsekvenser for senere kontakt med RASP eller helsevesenet for øvrig. Samtykket kan når som helst trekkes tilbake uten å oppgi grunn, og vi vil da umiddelbart slette de opplysningene du har gitt.

Hvis du ikke vil være med, er det fint om vi får svarslipp om dette slik at vi ikke tar kontakt på nytt.

Ta gjerne kontakt med Inger Halvorsen eller Trine Naustdal – tlf 23 01 62 30 – dersom du har spørsmål. Hvis vi ikke er til stede, er det fint om du legger igjen en beskjed til oss så vil vi ringe deg tilbake.

Med vennlig hilsen

Inger Halvorsen	Trine Naustdal	Asbjørn Syversen
Overlege, prosjektleder	Enhetsleder, prosjektmedarbeider	Seksjonsleder

Oslo universitetssykehus HF
Ullevål sykehus
Postboks 4956 Nydalen
0424 Oslo

Sentralbord RASP: 230 16 230

Klinikk psykisk helse og avhengighet
Psykisk helse, nasj. og reg. funksj., avd
Regional seksjon spiseforstyrrelser

Til deg som er søsken til en som har blitt behandlet for spiseforstyrrelse ved Barne- og ungdomsenheten ved Regional seksjon spiseforstyrrelser (RASP), Oslo Universitetssykehus, i tidsrommet 2008 – 2014

Forespørsel om å delta i forskningsprosjekt

Vi tar kontakt med deg fordi vi ønsker å vite mer om hvordan søsken av unge med alvorlige spiseforstyrrelser har opplevd sin søsters eller brors sykdom, hvordan spiseproblemet og behandlingen har virket inn på deres egen hverdag, og hvilke tanker søsken i ettertid har om sine egne erfaringer med å delta i familiebehandlingen ved RASP. Dette er en del av en etterundersøkelse av barn/unge som har var innlagt sammen med familien sin ved Barne- og ungdomsenheten. Hensikten med undersøkelsen er å få mer kunnskap om spiseforstyrrelser og hvordan helsevesenet kan forbedre tilbudet til unge med spiseforstyrrelser og familien deres.

Hva innebærer det å delta i prosjektet?

Dersom du er villig til å delta, vil dette innebære at du signerer og returnerer vedlagte samtykkeerklæringen i den frankerte konvolutten. Dersom du er under 16 år, må en av dine foreldre også samtykke for at du skal delta. Vi vil så ta kontakt med deg for å avtale tid/sted for intervju. Dersom det er mest praktisk for familien din å komme til intervju samtidig, vil vi prøve å koordinere tidspunktene slik at dette er mulig. Reiseutgifter i forbindelse med intervjuet blir dekket av oss. Søsken vil få et gavekort (kr 500) som en godtgjøring for at dere bruker tid på å komme til intervju.

Hvis du bor i utlandet, eller det av andre grunner er vanskelig å møte deg, kan du likevel være med i undersøkelsen. I så fall vil vi avtale nærmere med deg hvordan dette kan gjøres. Hvis du ikke husker så mye fra din søsters eller brors spiseproblem og behandlingen ved RASP, vil det likevel være av stor verdi for undersøkelsen at du deltar.

Om du deltar eller ikke deltar i undersøkelsen, vil ikke være av betydning for hvilken hjelp du selv eller andre i familien din vil få dersom det skulle oppstå et behov for kontakt med RASP eller helsevesenet forøvrig i fremtiden.

Hva skjer med informasjonen fra deg?

Alle data vil bli behandlet konfidensielt. Opplysninger fra ett familiemedlem vil ikke bli formidlet til andre i familien. Det vil bli opprettet et register for å kunne behandle resultatene. Registeret vil ikke inneholde persondata (navn, initialer, fødselsdato eller personnummer), men bli kodet med et løpenummer. Navneliste med løpenumre vil bli oppbevart forsvarlig nedlåst og atskilt fra de andre opplysningene.

Når vi skal presentere resultatene fra undersøkelsen (i artikler og foredrag), vil dette gjøres slik at ingen enkeltpersoner vil kunne gjenkjennes. De som deltar i undersøkelsen vil få tilsendt en oppsummering av resultatene dersom de ønsker det.

Frivillig deltakelse

Vi håper du er villig til å delta. Deltagelse er selvfølgelig frivillig og avhengig av at du gir ditt skriftlige samtykke. Hvis du skulle ombestemme deg senere, har du rett til å kreve at vi tar dine svar ut av undersøkelsen.
Hvis du ikke vil være med, er det fint om du returnerer svarslipp om dette slik at vi ikke kontakter deg igjen.

Ta gjerne kontakt med Inger Halvorsen eller Trine Naustdal – tlf 23 01 62 30 – dersom du har spørsmål. Hvis vi ikke er til stede, er det fint om du legger igjen en beskjed til oss så vil vi ringe deg tilbake.

Med vennlig hilsen

Inger Halvorsen	Trine Naustdal	Asbjørn Syversen
Overlege, prosjektleder	Enhetsleder, prosjektmedarbeider	Seksjonsleder

Nr………..

Intervju tidligere pasient

Etterundersøkelse av unge med spiseforstyrrelser som var innlagt i Barne- og ungdomsenheten ved RASP fra 2008-2014

Dato:…………..
Begynte kl:…………
Avsluttet kl:………..

Sted:………………..

☐ **lydbåndopptak:** Start opptaket med dato, ditt navn og intervjuobjektets kodenr.
☐ **telefonintervju**

Intervjuer:……………………..

Anm. til intervjusituasjonen:

Kontroll av opptak ved:…………………
Dato:……………..

Del I
Innledning

Innhente samtykke ved opptak
Vi ønsker å ta intervjuet opp på bånd for å kunne skrive ned svarene deres så korrekt som mulig (transkribere). Lydbåndopptak ville oppbevares forsvarlig nedlåst og merkes med nummer (ikke navn).

☐ samtykker i opptak (husk å si dato, ditt navn og intervjuobjektets kodenr.)
☐ ønsker ikke opptak
☐ opptak ikke aktuelt

Evnt. kommentarer til å delta: *For eksempel hva hun/han syntes om å få henvendelsen, hvorfor hun/han svarte ja, om hun/han hadde noen betenkeligheter/var i tvil, evnt praktiske vanskeligheter forbundet med å delta.*

Har hun/han med spørreskjemaet? Evnt. spørsmål til dette?

Hvis de ikke har det med, gi hun/han frankert svarkonvolutt for å returnere utfylt skjema.

Informere om intervjuet
For eksempel: Mesteparten av intervjuet følger en bestemt struktur, der de samme spørsmålene skal stilles på samme måte til alle.
Først er det noen spørsmål om din livssituasjon.
Deretter ønsker jeg å få et bilde av hvordan du har hatt det mht spiseforstyrrelse i tiden fra du var innlagt ved RASP og frem til i dag. Intervjuet går så videre med å kartlegge hvordan du har det nå i dag mht spiseforstyrrelse og andre psykiske problemer.
*Etter dette skal jeg spørre deg om hvordan du opplevde innleggelsen ved RASP (**hoveddel**) og hva som har hatt betydning for deg mht å bli bedre av spiseforstyrrelsen.*

Del VI – Kvalitativ del
Om hvordan hun/han opplevde behandlingen ved RASP

Temaer **Hovedspørsmål (nummerert, temaer som skal dekkes)**
*Hjelpespørsmål: I kursiv**; eksempler** på oppfølgingsspørsmål som **kan** stilles for å få mer informasjon, for eksempel hvis de ikke svarer.*

Forvern

1. Hva tenkte du om at du ble henvist til RASP?

Var du enig i henvisningen?
Var det noe du var bekymret for?

Var det forskjeller mellom deg og foreldrene dine mht ønske om at du ble henvist til RASP?

2. Hvordan opplevde du forvernsmøtene?

Hvordan ble dere tatt i mot?

Hva var du opptatt av?
  - ble dette snakket om?

Hvordan var den informasjon du fikk?

Opplevde du å få være med på å planlegge innleggelsen?
  - hvordan?

Var det noe du savnet under forvernet?

Hva husker du som nyttig?

Noe som burde vært gjort annerledes?

Innleggelsen

3. Når du ser tilbake på innleggelsen, hvordan var denne for deg?

Generelt

Hva var mest nyttig for deg?

Hva var mest utfordrende/vanskelig?

Hvordan opplevde du opplegget for å hjelpe deg med å redusere undervekten?

Hvordan opplevde du den støtten og omsorgen du fikk fra personalet?

…… den støtten og omsorgen du fikk fra foreldrene dine?

Hvordan var det for deg når dere var hjemme i helgene?
... var dette nyttig?
….fikk dere den støtten dere trengte?

4. Hvordan var det for deg at foreldre var innlagt sammen med deg?

Familie-innleggelse

Hadde det noen spesielt positive og/eller negative konsekvenser?

Hvordan virket innleggelsen på samarbeidet mellom deg og foreldrene dine?

Har innleggelsen hatt betydning for hvordan forholdet mellom deg og foreldrene dine har vært etter innleggelsen?

… for forholdet mellom andre familiemedlemmer, f.eks. mellom foreldrene dine?

5. Hadde du søsken som deltok i behandlingen?
Isåfall, hvordan var det for deg*?*

Søsken

Hvordan tror du det var for henne/han?

Har det at hun/han deltok under innleggelsen hatt betydning for det forholdet dere har til hverandre?

6. Var det noe du skulle ønske at hadde vært annerledes under familieinnleggelsen?

Negative Erfaringer

Beskriv:

Opplevde du noen spesielt negative erfaringer? Beskriv

Ettervern

7. Hvordan har oppfølgingen fra RASP vært etter utskrivelse?

Hvordan ble overføringen til BUP og andre lokale tiltak (for eksempel fastlege) ivaretatt?

Fikk du og familien din tilbud om fortsatt kontakt med RASP etter utskrivning?
-- i så fall, var dette nyttig?

--hvis ikke, burde dere fått det?

Er det noe som burde ha vært annerledes?

8. Hvilken betydning har familieinnleggelsen hatt for deg i ettertid?

Hva hadde vært annerledes hvis du hadde blitt lagt inn på RASP uten foreldre?

Råd til RASP

9. Hva bør RASP legge vekt, eller endre på, på i vårt arbeid med ungdom med spiseforstyrrelser?

I forhold til den unge med spiseforstyrrelse?

I forhold til foreldrene?

*I forhold til søsken***?**

10. Hvordan hadde du det på den tiden du var innlagt ved RASP?

Hvis du skulle plassere deg på en skala fra 0 til 10, hvor 0 er svært dårlig og 10 svært bra:

Hvordan hadde du på den tiden du var innlagt ved RASP?

Hvordan vil du plassere deg i dag på en slik skala fra 0 til 10:

Vendepunkter og nyttige faktorer

1. Når du tenker tilbake på livet ditt og de endringene som har skjedd mht spiseforstyrrelsen, hvordan vil du kort beskrive viktige vendepunktene?

Vendepunkter

Hva har hatt betydning for at du har blitt bedre?

Hvilke hendelser eller endringer i livssituasjonen har virket positivt?

Er det ting du selv, eller andre, har gjort annerledes som har bidratt til bedring?

2. Hva tror du er aller viktigst når det gjelder å frisk av spiseforstyrrelser?

3. Når du ser tilbake, tror du det har kommet noe godt ut av de erfaringene du fikk pga spiseforstyrrelsen?

4. Har du noen råd til andre med spiseforstyrrelser

Til slutt: Spørsmål eller kommentarer til undersøkelsen:

Husk gavekort og reiseregning!

Nr………..

Intervju med foreldre

Etterundersøkelse av unge med spiseforstyrrelser som var innlagt i Barne- og ungdomsenheten ved RASP fra 2008-2014

Hvem ble intervjuet?

mor stemor

far stefar

Dato:
Begynte kl:
Avsluttet kl:

Intervjuer:

Sted:
☐ **lydbåndopptak:** Start opptaket med dato, ditt navn og intervjuobjektets kodenummer

☐ **telefonintervju**

Kontroll av opptak ved:
Dato:

Anm. til intervjusituasjonen:

Del I
Innledning

Innhente samtykke ved opptak
Vi ønsker å ta intervjuet opp på bånd for å kunne skrive ned svarene deres så korrekt som mulig (transkribere). Lydbåndopptak ville oppbevares forsvarlig nedlåst og merkes med nummer (ikke navn).

☐ samtykker i opptak (husk å si dato, ditt navn og intervjuobjektets kodenr.)
☐ ønsker ikke opptak
☐ opptak ikke aktuelt

Evnt. kommentarer til å delta:
For eksempel hva de syntes om å få henvendelsen, om eventuelle betenkeligheter/tvil eller praktiske vanskeligheter forbundet med å delta.

Har de med spørreskjemaet?
Evnt. spørsmål til dette?

Hvis de ikke har det med, gi dem frankert svarkonvolutt for å returnere utfylt skjema.

Informere om intervjuet:
*Først noen bakgrunnsopplysninger og deres vurdering av hvordan det går med den unge, deretter deres opplevelse av behandlingen (**hoveddel**) og tilslutt om tiden etter at dere ble utskrevet fra RASP.*

Del II
Bakgrunnsopplysninger

1. Hvor bor den unge med spiseforstyrrelser i dag?

1.☐ bor alene
2.☐ sammen med meg/oss
3.☐ sammen med ektefelle/samboer
4.☐ sammen med barn
5.☐ annet; Beskriv:………………
………………………………

2. Hva er hennes/hans sivilstand:

1.☐ enslig/singel
2.☐ gift/samboende
3.☐ Annet: beskriv:…….

3. Hennes/hans utdanning/klassetrinn/studier:………………………………

4. Hennes/hans yrke (evt skoleelev, student, hjemme m. barn): ……………………………….

5. Foreldrenes vurdering av hennes/hans arbeidsevne siste 4 uker: ……………………………

6. Foreldrenes vurdering av hennes/hans funksjon i forhold til familie og venner siste 4 uker:
……………………………………………………………………………………………

……………………………………………………………………………………………

Del III
Om hvordan de som foreldre opplevde behandlingen ved RASP

Temaer **Hovedspørsmål (nummerert, temaer som skal dekkes)**
*Hjelpespørsmål: I kursiv***; eksempler** *på oppfølgingsspørsmål som* **kan** *stilles for å få mer informasjon, for eksempel hvis de ikke svarer.*

Forvern

1. Hva tenkte dere om at deres datter/sønn ble henvist til RASP?

Var dere enig i henvisningen, i tvil, bekymret for den unges reaksjon?

Var det forskjeller mellom dere foreldre mht ønske om at hun/han ble henvist?

2. Hvordan opplevde dere forvernsmøtene?

Hvordan ble dere tatt i mot?

Hva var dere opptatt av?
- ble dette snakket om?

Hvordan var den informasjon dere fikk?

Opplevde dere å få være med på å planlegge innleggelsen?
- hvordan?

Var det noe dere savnet under forvernet?

Hva husker dere som nyttig/verdifullt?

Noe som burde vært gjort annerledes?

Innleggelsen

3. Når dere ser tilbake på innleggelsen, hvordan var denne for dere?

Foreldrene

Hva var mest nyttig for dere foreldre?

Hvilke forskjeller var det (evnt.) mellom mors og fars opplevelse av innleggelsen og/eller hva som var viktig?

Hvordan virket innleggelsen på samarbeidet mellom dere foreldre?

Og på forholdet mellom familiemedlemmene?
-- for eksempel mellom dere foreldre
-- forholdet deres til barnet med spiseforstyrrelse
-- til deres andre barn
-- forholdet søsknene i mellom?

Hva var mest utfordrende/vanskelig for dere foreldre?

Opplevde dere den gangen at det var nyttig at dere foreldre var innlagt sammen med den unge?

På hvilken måte?

Hadde det noen negative konsekvenser?

--f.eks. for den unge, foreldrenes arbeid, omsorgen for søsken, konfliktnivå, totalbelastningen på foreldre/familien?

Hvordan var det for dere når dere var hjemme i helgene?
... var dette nyttig?
....fikk dere den støtten dere trengte?

4. Hvordan tror dere at det var for deres sønn/datter å være innlagt?

Den unge

Hva tror dere var mest nyttig for henne/han?

Hva var vanskeligst/mest negativt for henne/han

Hvordan tror dere var det for henne at dere var innlagt sammen med henne?

5. Deltok søsken under innleggelsen?

Søsken

- I så fall, hvordan tror dere dette var for dem?

Hva var nyttig for søsken?

Hva var vanskelig/negativt for søsken?

- Hvis de ikke deltok, hvordan tror dere dette var for dem?

Hvordan ble søsknenes behov for informasjon og omsorg ivaretatt?

6. Var det noe dere skulle ønske at hadde vært annerledes under familieinnleggelsen?

Negative Erfaringer

Beskriv:

Opplevde dere noen spesielt negative erfaringer? Beskriv

Ettervern

7. Hvordan har oppfølgingen fra RASP vært etter utskrivelse?

Hvordan ble overføringen til BUP og andre lokale tiltak (for eksempel fastlege) ivaretatt?

Fikk dere tilbud om fortsatt kontakt med RASP etter utskrivning?
-- i så fall, var dette nyttig?

--hvis ikke, burde dere fått det?

Er det noe som burde ha vært annerledes?

Råd til RASP

8. Hva bør RASP legge vekt, eller endre på, på i vårt arbeid med familier der en ungdom har alvorlig spiseforstyrrelse?

Del IV
Om tiden etter familieinnleggelsen

1. Hvordan har livet deres vært i tiden etter innleggelsen?

Hvordan har den unge og resten av familien hatt det?

2. Hvilken betydning har familieinnleggelsen hatt for deres familie?

Hva hadde vært annerledes hvis den unge hadde blitt lagt inn på RASP uten Foreldre? For eksempel mht deres forhold til den unge, samarbeidet mellom dere foreldre og/eller måten dere ville ha jobbet med spiseforstyrrelsen?

-

Til slutt

3. Når dere ser tilbake, tror dere det har kommet noe godt ut av de erfaringene dere fikk pga spiseforstyrrelsen?

4. Er det noe helsevesenet burde gjort annerledes?

. For eksempel i forhold til den unge, foreldrene, søsken, samarbeid mellom instanser/behandlere?

Råd **5. Hvilke råd vil dere gi andre foreldre som opplever at et barn får SF?**

Andre ting **6. Er det andre ting du/dere hadde ønsket å bli spurt om, eller andre Erfaringer eller tanker du/dere vil dele med oss?**

Andre kommentarer:

OBS. Husk reiseregning med frankert svarkonvolutt

Lydbåndopptakernr.: … **Folder (A-E):….** **Filnr.: LS_…………….**

Nr………..

Intervju søsken

Etterundersøkelse av unge med spiseforstyrrelser som var innlagt i Barne- og ungdomsenheten ved RASP fra 2008-2014

Dato:
Begynte kl:
Avsluttet kl:

Intervjuer:

Sted:

☐ **Lydbåndopptak** Start opptaket med dato, ditt navn og intervjuobjektets kodenr.

☐ **Telefonintervju**

Kontroll av opptak ved:
Dato:

Anm. til intervjusituasjonen:

Del I
Innledning

Innhente samtykke ved opptak

Vi ønsker å ta intervjuet opp på bånd for å kunne skrive ned svarene deres så korrekt som mulig (transkribere). Lydbåndopptak ville oppbevares forsvarlig nedlåst og merkes med nummer (ikke navn).

☐ samtykker i opptak (husk å si dato, ditt navn og intervjuobjektets kodenr.)
☐ ønsker ikke opptak
☐ opptak ikke aktuelt

Evnt. kommentarer til å delta:

For eksempel hva hun/han syntes om å få henvendelsen, hvorfor hun/han svarte ja, om eventuelle betenkeligheter/ tvil eller praktiske vanskeligheter forbundet med å delta.

Informere om intervjuet:

Først noen bakgrunnsopplysninger, så hvordan du opplevde innleggelsen ved RASP og tilslutt om hvordan spiseforstyrrelsen har virket inn på ditt liv og hva som har vært nyttig for deg. Hvis over 12 år: blir bedt om å fylle ut et spørreskjema til slutt.

Vær så snill å si ifra dersom noen spørsmål er vanskelige å forstå eller ikke passer til din situasjon.

Deltagers alder:…………………….
Kjønn:………………………………
Alder under innleggelsen: …………………
Andre søsken, alder/kjønn:…………………………
Deltar evnt. andre søsken i undersøkelsen: 1.☐ nei 2. ☐ ja; hvem:……………………..

Del II
Bakgrunnsopplysninger

1.Boforhold:

1.☐ bor alene
2.☐ sammen med foreldre
3.☐ sammen med ektefelle/samboer
4.☐ sammen med barn
5.☐ annet; Beskriv:………………
………………………………

Bor du sammen med din bror/søster som var innlagt pga spiseforstyrrelser?……..

2. Sivilstand (hvis voksen, hopp over hvis mindreårig):

1.☐ enslig/singel
2.☐ gift/samboende
3.☐ Annet: beskriv:…….

3. Fullført utdanning/klassetrinn/evnt studerer nå:………………………………

4. Yrke (evt. skoleelev, student, hjemme m. barn): ……………………………………

Del III

Om hvordan du opplevde din søster/brors behandling ved RASP

Temaer **Hovedspørsmål (nummerert, temaer som skal dekkes)**
*Hjelpespørsmål: I kursiv****; eksempler*** *på oppfølgingsspørsmål som* ***kan*** *stilles for å få mer informasjon, for eksempel hvis de ikke svarer.*

Før familieinnleggelse

1. Hvordan ble du klar over at din søster/bror hadde spiseforstyrrelse?

Hvem ga deg informasjon?

Var det ting du lurte på, som du hadde trengt mer informasjon om?

Forvern **2. Var du med til RASP før din søster/bror ble innlagt?** (hvis nei, gå til 3.)
I så fall, hvordan var dette for deg?

Var med på møte/samtale ved RASP?
Ble du vist rundt på avdelingen?
Hvordan ble du tatt i mot?
Hva var nyttig/ikke nyttig for deg i den første kontakten med RASP?
Hvem ga deg informasjon om familieinnleggelsen (foreldrene/din søster/bror/ personalet vedRASP/BUP)?

3. Hvilke tanker hadde du på forhånd om at familien din skulle legges inn ved RASP?

Hva tenkte du om at du selv skulle være med under innleggelsen?
Hadde du tro på at denne behandlingen ville være nyttig for din søster/bror, for foreldrene dine og/eller for deg selv?
På hvilken måte?

Under familieinnleggelsen

4. Når du ser tilbake på den tiden din søster/bror var innlagt, hvordan var denne tiden for deg?

Innleggelsen

Hvordan var det for deg at du var med under innleggelsen?
Hva var mest nyttig for deg?
Hva tror du var nyttig for de andre i familien?
Hvilke ting var vanskelig for deg?
Opplevde du at personalet var oppmersomme på hvordan søsken hadde det?
Fikk foreldrene dine hjelp til å ivareta deg i denvanskelige situasjonen da din søster/bror var syk?

5. Hvordan var det for deg i perioder hvor du var hjemme, mens en eller begge av foreldrene dine var sammen med din søster/bror på RASP?

6. Er det noe du skulle ønske at hadde vært annerledes under familieinnleggelsen?

Dine behov *Burde dine behov blitt bedre ivaretatt?*
For eksempel mht informasjon, samtaler, skoletilbud, fritidsaktiviteter, kontakt med andre familier/andre søsken

Familien *Burde noe vært annerledes mht din søsters/brors behandling?*
... mht samarbeidet med dine foreldre?
....mht hvordan dine andre søsken ble ivaretatt?

Negative Erfaringer *Opplevde du noen spesielt negative erfaringer? Beskriv*

7. Hvilken virkning tror du familieinnleggelsen hadde på din kontakt med de andre i familien den gangen dere var på RASP?

Virkning på kontakt

8. Hvilken virkning hadde innleggelsen og på kontakten din med venner?

Venner

F.eks på kontakt med venner på skolen
Eller på fritidsaktiviteter

Etter utskrivning fra RASP

Ettervern **9. Har du hatt kontakt med RASP etter at din søster/bror ble utskrevet? I så fall, hvordan har dette vært for deg?** (hvis nei, gå til 10)

10. Har du andre erfaringer med å delta i din søsters/brors behandling? Hvordan har dette vært for deg?

11. Hvordan har livet til familien din vært etter innleggelsen, slik du har opplevd det?

Hvordan har du hatt det?
Hvordan har din søster/bror og dine foreldre hatt det?

12. Hvilken betydning tror du familieinnleggelsen har hatt for familien din?

Har det hatt betydning for hvor mye kontakt du har med de andre i familien?
Eller hvor mye dere snakker sammen?

Del IV
Om hvordan spiseforstyrrelsen har virket inn på livet ditt

1. Hvilken *innvirkning* har din søsters/brors spiseproblem hatt på ditt eget liv?

For eksempel i forhold til relasjoner til andre familiemedlemmer, venner, bekymringer, skole, fritid

Har det påvirket ditt eget forhold til mat, spising og vekt?

2. Hvordan du hadde det når din søster eller bror var innlagt på RASP pga spiseforstyrrelse

Skala
0-10

A. Når du tenker på hvordan du selv hadde det på den tiden din søster/bror var innlagt på RASP, kan du prøve å angi på en skala fra 1 til 10 hvordan du hadde det den gangen? (skala på løst ark)

0 svært dårlig, 10 svært bra:

B. Hvordan vil du plassere deg i dag på en slik skala fra 0 til 10:

3. Når du tenker på din egen erfaring med å ha en søster eller bror med spiseproblemer, hva synes du at har vært nyttig for deg?

4. Når du ser tilbake, tror du det har kommet noe godt ut av at de erfaringene du fikk pga din søsters/brors spiseforstyrrelse?

RÅD

Til RASP

5. Hva bør RASP legge vekt på, eller endre på, i vårt arbeid med familier der en ungdom har spiseforstyrrelse?

For eksempel i forhold til den som er syk, foreldre eller søsken

Til helsevesenet

6. Er det noe helsevesenet ellers burde gjort annerledes?

Råd til søsken

7. Hvilke råd vil du gi til andre søsken som opplever at en søster eller bror får spiseforstyrrelse?

Andre ting

8. Er det andre ting du hadde ønsket å bli spurt om, eller andre erfaringer eller tanker du vil dele med oss?

9. Til slutt: Har du noen spørsmål eller kommentarer til undersøkelsen?

Hvis over 12 år: Fyll ut spørreskjema

Husk: Gavekort
Refusjonsskjema for reiseutgifter (hvis søsken har reist alene)

Lydbåndopptaker nr.: … Folder (A-E):…. Filnr.: LS_…………