Author’s response to reviews

Title: 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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Author’s response to reviews:

Dear handling editor, Dr. Adrian Meule

Thank you very much for the review of our manuscript. My coauthors and I really appreciate the careful review and we are very satisfied with the editorial decision to invite us to revise and resubmit. We feel the manuscript has improved due to the valuable feedback and suggestions. We have addressed each comment and integrated the suggested changes into the revised manuscript. We would like to remind you that the requested changes were made while trying to limit adding extra length to the paper.

Beneath you will find our responses to the comments. The referee’s comments are listed in boldfaced font followed by our responses in red, linked to locations in the manuscript. Changes have been highlighted in the revised manuscript using yellow shading and in the cover letter by using italics to emphasize the added or changed sentences.

All authors have read and approved the responses written in the cover letter, and all authors have read and approved the changes made in the revised manuscript.
Thank you again to the handling editor and both reviewers for your time and effort in reviewing this manuscript.

Kindest regards,

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Reviewer 1 (Renee Rienecke): The purpose of this study was to assess the experiences of adolescents during a family-based hospitalization, and to examine which staff behaviors and skills were deemed important by patients. Two main themes and 8 subthemes were identified.

1. The introduction may benefit from a more thorough discussion of findings regarding the therapeutic alliance in FBT, and how it differs for parents and adolescents.

   Thank you very much for your thoughtful comment and specific suggestion of adding a more thorough discussion of findings regarding therapeutic alliance in FBT in the introduction section. Inspired by your suggestions we have added a new paragraph on this subject (Introduction section, lines 95-103, page 5), and this now reads:

   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].

2. Method, pg. 7, line 143: How was "normal" body weight defined?

   Thank you for giving us the opportunity to clarify this. Normal body weight was defined as BMI ≥18.5 at follow-up. In the revised manuscript we have added this detail together with a reference to the naturalistic outcome study (Halvorsen et al., 2017). The sentence now reads (Method section, lines 153-154, page 7):
At follow up, the majority (65%) had achieved normal body weight, as defined by attaining a BMI ≥18.5 [11].

3. Method, pg. 7, lines 144-145: How were diagnoses determined?

Thank you for your question. Diagnoses at follow-up were determined by using the diagnostic items of the Eating Disorder Examination 16.0. To increase clarity we added this information in the revised manuscript. This now reads (Method section, lines 159-160, page 7):

ED diagnoses at follow-up were determined by using the diagnostic items of the Eating Disorder Examination 16.0 [11, 35].

4. Method, pg. 7, line 159: "Some patients were offered supportive individual therapy…"

How many patients received individual therapy? How was it decided who would get individual therapy?

Thank you for this relevant question. Unfortunately we do not have an exact record of how many of the participants received individual therapy, as this was not assessed in this study.

During the admissions, the decision on whether the young person was offered individual sessions were pragmatically arranged in collaboration with the family and the young person. This could for instance be arranged when the young person her/himself expressed thoughts on wanting to talk with a team member alone, and at other times if the treatment team thought that this could be a good idea to try out. Overall, individual sessions during the stay were intended as a supplementary support (i.e., add-on) to the overarching family-based treatment approach. The individual sessions was intended to support the family-based foundation and for instance help the adolescents to appreciate the increased care from their parents etc.

To enhance clarity on this subject we have extended the original sentence, which now reads (Method section, lines 176-178, page 8):

Some patients were offered supportive individual therapy in addition to family therapy, and this was arranged in collaboration with the adolescent and parents.

5. Method: Can the authors provide a bit more information on the hospital stays and how they corresponded to the different FBT phases? After 20.8 weeks in the hospital, were the adolescents still in phase 1 at discharge or had they started to move into phase 2? If they moved into phase 2, how was this accommodated within the structure of the inpatient stay?

Thank you for your highly relevant questions. Determining which corresponding FBT phase the adolescents and their families were in at the time of discharge is difficult to assess more accurately. Still, we believe that the vast majority of participants probably were in a phase that overall corresponded to phase 1. As for others, it would be more accurate to say that they were transitioning into phase 2, with potentially a few adolescents/families even progressing further. Still, this is difficult to determine more exact in this study. Aligning with your request on
providing more information, we have decided to add a sentence that specifies our overall stance (Method section, lines 165-166, page 8):

The overall treatment focus for the majority of participants corresponds to the first phase in outpatient FBT.

Method: Can the authors describe any other programming the adolescents received during their inpatient stay? Were they participating in group therapy?

Thank you for your questions. The adolescents were not participating in group therapy. The main programming consisted of family therapy and supplementary individual therapy and the milieu therapy with the overarching aim of supporting parents to support their child during the stay. The unit has piloted a short/time-limited version of multi-family group therapy (that includes groups for the adolescent patients) at the ward, but this was done after the data collection was completed, and hence not relevant for this particular study. We have considered your questions and decided to enter a new sentence to clarify this, which reads (Method section, line 166-168, on page 8):

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.

6. Discussion: Improved collaboration was desired by the adolescents. However, FBT is structured the way it is in part because working collaboratively with a patient with an ego-syntonic illness, particularly at the beginning of treatment, tends to not be particularly productive. What do the authors think increased collaboration with adolescent patients who are ill enough to need hospitalization would look like?

Thank you for your thoughtful reflections and giving us the opportunity to share more of our thoughts on these complex issues.

Despite their relatively young age, the participants in our study entered the inpatient context as “on average” already quite experienced patients. They had experienced several failed treatment attempts and duration of ED prior to the family admission was on average 2.7 years. Although not necessarily having been exposed to manualized FBT prior to the family-based admission, the majority had experienced various efforts of family involvement (i.e., family-based interventions in a broader sense), both at their local specialized child- and adolescent outpatient service and for the majority; previous hospitalizations. When this is the situation we in general believe that re-thinking potential ways to enhance collaboration with the young patient, with the aim of stimulating treatment engagement, can be especially relevant to consider.

As we write in the discussion (lines 456-461, page 20) “…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 [48]. This warrants health care professionals to be especially mindful of how they interact with patients [30, 31, 34].
To supplement with some more information, we decided to add the following in the revised manuscript; toward the end of the discussion section. This reads (Discussion, lines 473-478, page 21):

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.

We are for example discussing whether we can involve the young patient (at least some) better in the treatment planning - in the pre admission phase. Can we for example develop better ways to increase the experience of “being in this together” by exploring more thoroughly personal goals and the young person’s own preferred ideas about change etc., in order to enhance the likelihood of a better vantage point for the admission?

As both motivation for change, readiness and / or confidence is complex interpersonal phenomena that can fluctuate even within a short time frame (i.e., for instance within a single therapy session), so can the degree of ego-syntonicity a patient is experiencing be influenced by the way the young person is met. As such, ego-syntonicity is not necessarily a good marker for guiding clinicians for how to intervene per se, as it is not a static phenomenon. To speculate further, we are inclined to think more about whether enhanced collaboration (i.e., as in felt or experienced) can contribute to increased ego-dystonicity and thus potentially fuel treatment engagement and personal motivation.

7. Some information on patients' progress during treatment would be helpful. How much weight did they gain? Were there improvements in eating disordered behaviors and psychopathology? If the current inpatient arrangement is effective in starting the process of recovery, how might increased collaboration with the adolescent affect that?

Thank you for your relevant questions and suggestions. We agree that having more information on the patients’ progress during treatment would have been helpful. Unfortunately, on eating disordered behaviors and psychopathology we can merely speculate, as we only have good enough data to display at follow-up, and these have been reported elsewhere (Halvorsen et al., 2017).

To your relevant question on adding information on progress during treatment we can only provide information on weight gain. Based on your suggestions we added this information in the revised manuscript. This now reads (Method section, lines 154-157, page 7):

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., &gt;12, which corresponds to approximately BMI 18.5 in adults).
To your last question, our shared clinical impression suggests that providing family-based inpatient treatment can be a feasible way of providing treatment when an adolescent is in need of inpatient treatment, and hence family-based inpatient treatment can be of aid in starting the process of recovery. Still, knowing whether increased collaboration with the adolescent could fuel or bolster these processes further, we can only speculate. Still, and again based on our clinical experience, it is tempting to hypothesize that increased collaboration (i.e., experienced/felt) could be of benefit for some of the young patients’, which again suggests the need to better assess and differentiate between those who would profit of increased collaboration, and when this would be a slippery path to pursue.

Reviewer 2 (David Kolar): The objective of the presented study was to investigate different views on family-based inpatient treatment for anorexia nervosa of former adolescent patients. The authors interviewed 37 former inpatients with a semi-structured interview and assessed the responses in a qualitative analysis using a thematic analytic framework, considering both semantic and inductive approaches. Two main topics constituted by eight sub-themes emerged and were discussed by the authors. The study is timely and important, as family-based treatment (FBT) is the current "gold-standard" for treating adolescents with anorexia nervosa, but comes at the price of reducing adolescents' individual control especially at the beginning of treatment in favor of parental control. Hence, qualitative studies exploring how adolescents perceive this form of treatment is crucial to understand and further increase therapeutic alliance with the adolescents during the treatment. In addition, qualitative studies investigating adolescents with lived experience regarding their perspective on treatment are especially rare in the field of eating disorders.

In my opinion, the manuscript is well written. The authors described their methods adequately, presented the results in an appropriate form and gave a thorough discussion of the views of their interviewees. I only found some minor points, which, from my perspective, should be clarified, added or revised prior to publication.

Introduction section:

The introduction is well written and I have no further comments.

Methods section:

1. On page 6 line 130 you mention that the participants gave informed consent to the study. However, as some participants were still adolescents at the time of the interviews, I was wondering whether the parents also gave consent to the study (if applicable according to local law). Please state this explicitly.

Thank you for your comments and questions, and giving us the chance to clarify.

One participant taking part in the study was under 16 at follow up, and for this participant parental consent was provided together with consent from the young person. This is aligning
with Norwegian legislation that states that a young person between 16 and 18 consent themselves, as long as research is not involving surgical procedures and / or medication.

In the revised manuscript we have stated this explicit, and this now reads (Method section, lines 139-140, page 6):

For the sole participant under the age of 16 (i.e., age of consent) at follow up, parental consent was also provided.

2. P. 7 l.147f. "(i.e. nurses working shifts to the clinical psychologist and/or psychiatrists)" - I did not understand this sentence. Could you please rewrite or clarify this?

Thank you for giving us the chance to clarify. The original sentence in the parenthesis (…) was originally added to emphasize that “staff” in this context includes different professions. Thinking it over, we have decided to remove this sentence, as we have come to believe that it is inevitable that “staff” during inpatient treatment is consisting of health care professionals from different professions, as all inpatient ED units have multi-disciplinary teams. The revised sentence now reads (Method section, lines 162-163, page 7):

Throughout family-based inpatient treatment, staff actively promotes collaboration with parents.

3. On p. 7 you state that up to five families were hosted at the same time (l. 154): were any of the interviewees treated at the same time? If so, their experience might be more similar to each other than to other interviewees. I would recommend to clarify this in the methods section and to discuss whether this had implications on your findings.

Thank you for your question and giving us the chance to clarify. Although we identify and agree with your thoughts, we have to admit that this call for clarification was a little bit tricky to resolve. We will try to explain as good as we can.

It is likely that some of the interviewees were treated at the same time (at least within the same year/time period), and that this could suggest more similar experiences. Still, we cannot rule out the chance that participants staying at the unit at the same time represents variations in experience, as they have their own designated team, they are admitted with their own family, they enter treatment with different experiences, they enter treatment from a different vantage point on a range of variables etc. (and we can speculate further and imagine that interviewees admitted at very different times can reflect similar experiences and views etc.).

Important for the current analysis and the present dilemma, as we view it, is that the authors responsible for analyzing the data material [JVN, TWH, HWO] did not gain access to or get an overview of who - or how many - of the participants stayed at the unit at the same time. This was valued as relevant as the main aim was not investigating potential group processes (still relevant for subtheme 2:5), but mapping out retrospective post-treatment views on collaboration and staff behaviors across a rather large sample (i.e., as all available [37] participants admitted between the years 2008-2014 were included). And - as the sub-themes are capturing views from at least 13 to up to 25 participants, we are not that worried that themes are built on only a few potentially
admitted at the unit at the same time (i.e., as would be a risk if we for instance had subthemes made up with only a few participants).

Still, we believe that the processes and potential influences you mention are important and potentially present in our material/analysis, although beyond the scope of this study to investigate any further. We are very much inspired to bring these thoughts with us when we plan future research projects.

We hope that this comment is sufficient and that it is judged as appropriate that we do not elaborate on this any further in the paper.

4. On p. 8 l. 169f. you write "Four of the interviewers had been directly involved in the provision of the treatment." This is a bit unclear to me. Were they involved generally (like for example provided treatment at that unit at some time, did they develop the treatment) or were they involved specifically in the treatment of some of the interviewees? If so, this might have had an effect on the responses, as for example any criticism of the treatment could have been perceived as criticizing the person. Please clarify if the interviewers were directly involved in treating the interviewees.

Thank you for your comments and giving us the opportunity to provide more clarity on this issue. As you comment, four of the interviewers had at some time between the years 2008-2014 (i.e., corresponding to the time frame the participants had been admitted) been involved in the provision of treatment at the unit.

As you reflect, we also believe that this inevitably could have had an effect on the responses during interviews. Still this effect is difficult to determine and can be viewed as potentially two-sided; as both a) potentially increasing the likelihood of participants’ holding back information out of concerns of criticizing the person interviewing them, or this could also be thought as b) potentially enabling relevant post-treatment reflection not necessarily facilitated in the same way by a 100% unfamiliar interviewer; as we can imagine that some of the interviewees would appreciate to talk with a person who was somewhat familiar.

To provide transparency on this issue (that four interviewers were previously involved in treatment and hence imply that this could represent a bias in collection of the data) we stated in the original paper the following:

“Another limitation is that four of the interviewers were previously employed on the multidisciplinary teams providing treatment, which represents a source of bias in data collection. However, two out of three responsible for analyzing data had no previous work experience at the unit.”

To enhance transparency and aligning with your call for clarification, this paragraph has been adjusted and now reads (Limitation section, lines 491-494, page 21):

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.

5. Also on p. 8: You mention the main questions of the semi-structured interview. Were other "side"-questions specified or were all follow-up questions asked ad libitum? If other questions were prespecified, the authors might want to consider providing the interview questions used for the analysis of this study in a supplement file.

Thank you for your comments and questions.

We hope our choice to include and specify the main questions from the interview guide in the original paper provides sufficient transparency on which main questions were used to generate data for this specific analysis. As we originally wrote: 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?”

This solution; to provide the readers with the main questions directly in the running text and hence not as a supplementary, was chosen to deliberately enhance transparency. We hope that this clarification is sufficient.

6. On p. 9 l. 197 you state that final consensus on the topics was reached, but it was unclear to me if this means that final consensus between all authors or the first author and the two explicitly named collaborators in l.195 was reached.

Thank you for your observations and giving us the chance to clarify.

In the revised manuscript we have made this clearer, we believe, by adding information to the original sentence (both that the final consensus was reached by all collaborators and specifying that these collaborators in this analysis was JVN, TWH & HWO). It now reads (Methods section, lines 214-217, page 10):

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.

Results:

Clear and concise presentation of the results, no comments.

Discussion:
1. Please mention in the strengths and limitations section that several participants received treatment between admission to FBT and follow-up, as this could have influenced potentially their responses.

Thank you for your suggestions. Although difficult to determine (i.e., whether and if so, how, further treatment post discharge have influenced their post-treatment reflections pertaining collaboration and staff behaviors during admissions), we do agree that this is very likely. Inspired by your suggestions we have added information on this, which now reads (Strengths and limitations section, line 487-490, page 21):

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.

2. As the authors correctly noted on p. 17 l. 389, only few participants viewed the treatment as "reciprocal and collaborative", and "involvement and collaboration" were highly valued. I think that this might be an inherent problem of family-based therapy compared to individual-based approaches like for example cognitive behavior therapy for eating disorders (CBT-E), as especially in the first treatment phase FBT relies on full parental control and the focus of the therapist is almost entirely on the parents. Within this framework, collaboration with the patient is somewhat limited by default. The authors discuss this finding mostly in the context of the common factors model (therapeutic alliance) and mention several ways to increase alliance within FBT (e.g. inviting feedback, p. 18, l. 420). A different solution might be to combine FBT with parts of individual-based treatments such as for example dialectical behavior therapy (DBT), which could increase collaboration and involvement by focusing on the immediate needs of the adolescent. There is emerging literature on for example combinations of DBT-informed skills trainings and FBT (see references [1] and [2]). I would encourage the authors to discuss whether augmenting FBT with other treatment approaches could change FBT towards a more collaborative approach from their perspective.

Thank you for your thoughtful reflections, comments, and encouraging us to discuss whether augmenting FBT with other treatment approaches could change FBT towards a more collaborative approach, as perceived from the young patient’s position. And thank you for providing us with references, which we have read with interest.

First of all; these are questions that we really appreciate - and spend time to reflect upon. Still, these are questions that we believe open up for many new dilemmas - that again lead to new questions with no straight forward answers.

Although we think that incorporating the following reflections in the manuscript is beyond the scope of the present study, we will try to share some of our related thoughts.

While potentially very promising, we believe research on augmenting FBT and integrating adjunctive modules (as elements from DBT/CBT-E/Multi-family/Cognitive remediation therapy/motivational enhancement and / or other add-ons) is still in its beginning stages [17].
Thus to date we believe it is difficult to know what is the best strategy for augmenting practice, for example within higher levels of care. More research is needed.

Still - as there is no one size fits all treatment (i.e., regardless of treatment context, treatment modality and level of care), we do believe in the importance of wisely augmenting treatments to provide a better fit for those who do not respond to the “prototypical” evidence-based models. Both (intentionally) for providing those who fail to achieve sufficient progress during evidence-based treatments - with something else, and for becoming better at tailoring and adapting treatment from the onset (i.e., so families/patients that presents with a clinical picture reflecting typical non-responders do not need to try something else, first – as time is crucial).

We appreciate that there are many dilemmas with augmenting practice in the context of treatment of adolescent AN, and maybe especially in our context; higher levels of care. Trying to adapt a predominantly family-based framework to an inpatient setting is a way of augmenting practice per se, and we are still in a process of learning. The latter brings us to another important dilemma, we believe. A dilemma related to the position one seeks to augment treatment from.

The availability of evidence-based treatments for ED, as outpatient FBT/CBT-E, is still very limited (especially at higher levels of care), and especially if we broaden our geographical perspectives and look on it globally. Hence, there is a potential that augmenting practice can be motivated prematurely, as we can imagine that treatment providers that seek to augment treatment could instead have benefitted from furthering and strengthening training and supervision within for example a more typical FBT-approach.

We can thus imagine that many treatment providers face equal dilemmas as we do. To simplify; shall we (now) try to integrate aspects from other evidence-based treatment modules or invest our time and resources to become even better at providing and adjusting treatment from a predominantly family-based approach - or lies the answer more in-between (i.e., as integration really point towards)?

In general, we believe the latter (i.e., integrating features or add-ons into a family-based framework) is a feasible path to follow, especially for higher levels of care, where the majority of cases are so called “complex” (i.e., typically long duration of ED, previous failed treatment, comorbidities, suicidality/self-harm behaviors, complicated family dynamics etc.). Within this context, we do believe that both features of “classical” DBT (especially the skills-based focus) and combinations with CBT-E, and maybe even other more affect-oriented approaches (i.e., attachment-based), can prove to be promising in the future.

Thinking on how integrating elements from other treatment modalities can potentially influence the young patients’ experience of collaboration is both interesting and very important – as we believe the degree of felt collaboration is very important for both treatment engagement and retention, and thus potentially influencing outcome.

Our preferred stance is that we believe it is possible to increase the experience of collaboration within any treatment model, as this is more related to how we manage to deliver and enable
treatment, more than the potential limitations embedded in the models per se (as manuals are flexible guidelines).

To sum up - thank you both for your valuable reflections and questions. All together these questions are truly inspiring us to further our work on optimizing the inpatient context for those in need of inpatient treatment – and we feel confident on that we would address, investigate and write more about these interesting and challenging topics in the future.