# **Peer Review File**

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# **Review Comments**

# <mark>Reviewer A</mark>

# Comment 1:

Dear Authors,

The strengths of this article are the following:

-You contribute to a current and exciting topic within the academic debate around palliative care and psychiatry in the specific target group of persons with SPMI. -The introduction is interesting and well written.

-You challenge academia and healthcare practice to reflect on a detailed case study, specifically on the use of palliative sedation in a person with SPMI.

-You pay close attention to medication management in the case study.

-The added table is adequate, as is the bibliographic list.

# Reply 1:

# Thank you very much for pointing out the strengths of our contribution.

# Comment 2:

Points for improvement:

-Another similar case was presented in 'Pia Baldinger-Melich et al, Treatment resistant catatonia — A case report, Clinical Neuropsychiatry (2016), 13, 2, 24-27, as was indicated in the list of references. The authors should make clear the unique contribution of this case with regard to the other.

# Reply 2:

We are grateful that reviewer A pointed this out.

We agree that the case report from Baldinger-Melich (2016) is an important one. However, the authors of this case report onl^y retrospectively discuss whether EOL care would have been appropriate, it was not provided. We believe this is the major difference to our case report and have added a half sentence to the discussion

("palliative sedation as a viable option is a feature of palliative psychiatry and <u>described here for the first time</u>»)

# Comment 3:

In this case, end-of-life treatment was provided without the caregiver himself being able to express this wish explicitly. The authors should be very aware that this case also raises many moral and legal questions, which are not always given adequate attention in the discussion section.

#### Reply 3:

We agree that this is a very important concern. Due to the limited word count, we could unfortunately not discuss all relevant ethical concerns and decided to not go into detail regarding this one as it is not specific to palliative psychiatry (substituted judgment in EOL decision-making is also a concern in persons dying from a somatic disease) · We have, however, noted this concern in the following sentence: "This case touches on many ethical questions, for example concerning coerced treatment, substituted judgement, and EOL decision-making. While we cannot expand on all of them, we would like to note..."

#### Comment 4:

Numerous abbreviations are used in the article and case study without displaying them in full, which makes reading difficult.

#### Reply 4:

# Thank you for this important comment which was noted by other reviewers as well. The abbreviations have been edited and displayed in full

Comment 5:

line 196: error in sentence structure (negative was used 2 times).

#### Reply 5:

#### The double negative has been reviewed.

#### Comment 6:

The case is written from a biomedical point of view, with very little attention to the experience and point of view of the patient and the caregivers. Given the length of the case study and the fact that the target audience may be broader than just physicians, this is a serious limitation of this article. The authors should make adaptations to the case study in order to be understood by a wider audience, including nurses, ethicists and therapists, in order to broaden the debate.

Reply 6:

This is an important suggestion and we agree that it is beneficial to open the case to a broader range of providers. Along these lines, we have significantly altered the case, using more common language and reducing medical jargon, and also

# highlighting the emotional impact the patient had on those in his care.

# Comment 7:

The case presents the medication policy, restraint procedures, ECT and the use of sedation. At one point the decision is made to discontinue all treatment, after which the patient, severely weakened, dies after some weeks. Palliative care would then imply that you actually "get to work" these last weeks. This, generally speaking, in a very holistic way. So how did this take shape?

# Reply 7:

#### Thank you for pointing out this important issue.

We have added more details about the end of his life. Unfortunately, the patient passed away in March 2020 at the beginning of the COVID-19 pandemic, during which time the hospital was disorganized and the psychiatry consultation-liaison service not operating as usual and was less involved in his care after the transition to comfort care was established

# Comment 8:

The authors indicate that the patient goes into crisis after a long period of stability, whereby care is not even offered residentially but outpatiently. The reason for the crisis is unknown. There is a period of 8 months between the crisis and death... Why this very sudden, rapid development?

# Reply &

We have restructured the case to clarify: there was never a prolonged period of well-being during the 9 month hospital course. The patient suffered multiple crises of unknown etiology and the treatment team's goal was always to stabilize on a regimen that could be utilized in a residential or outpatient setting and allow him to be discharged.

# Comment 9:

What form of support did the parents (elderly?) receive in making the choice to allow their son to die, whom they had cared for for a very long time? Was there bereavement care? What role did their socio-economic and possibly philosophical/religious background play in this situation?

# Reply 9:

The primary team spoke with the patient's mother andfather on a frequent basis during the hospitalization. Bereavement care was offered to the parents and declined, as they expressed that their spiritual community would be supportive. We do feel that the religious beliefs of the parents likely influenced their decision to stop

# aggressive treatments, as they often expressed that God was waiting for their son to return.

# Comment 10:

The case raises numerous ethical questions: how far can you go in restricting freedom and what is the impact on all involved? What about the decision making capacity of the caregiver and how to involve them if little approachable? What ethics support (other than an ethics committee ruling) was provided to the team and close relatives? All these issues deserve more attention in the now rather brief discussion section.

# Reply 10:

We agree that these are important concerns. Due to the limited word count, we could unfortunately not discuss all relevant ethical concerns and decided to not go into detail regarding these as they are not specific to palliative psychiatry. We have, however, noted this: "This case touches on many ethical questions, for example concerning coerced treatment, substituted judgement, and EOL decision-making. While we cannot expand on all of them, we would like to note...'

# Comment 11:

More attention should be paid to the distinction between regular palliative care/terminal care in people with severe mental suffering; the use of palliative philosophy in the approach to care (e.g. Oyster Care- Decorte et al, Frontiers in psychiatry 2020); euthanasi a/ as si sted suicide; and the possibility of palliative sedation in SPMI. these are 4 distinct issues. The introduction makes this distinction somewhat, but does not adequately extend it to the case study presented.

# Reply 11:

# Thank you for this point. We have revised the introduction accordingly.

# Comment 12:

What was the role distribution of the different authors in the creation of the article?

# Reply 12:

We now provide the following list in the manuscript:

- (I) Conception and design: JE, CJ, MT
- (II) Administrative support: All authors
- (III) Provision of study materials or patients: JE, CJ
- (IV) Collection and assembly of data: JE, CJ
- (V) Data analysis and interpretation: JE, CJ, MT
- (VI) Manuscript writing and revision: All authors

# (VII) Final approval of manuscript: All authors

# <mark>Reviewer B</mark>

# Comment 1:

Congratulations to all the authors on their manuscript describing a thought-provoking case of malignant catatonia in relation to initiating a palliative approach in psychiatric care. There are many strengths to this manuscript, in particular its evocative description of the case at hand including how this patient's care was managed in an interdisciplinary team.

I have several suggestions for revision, which I have divided into Major and Minor Comments.

# Reply 1:

# Thank you very much for this appreciative review.

# **Major Comments:**

# Comment 2:

Line 84: It would be helpful to clarify what you mean by "futility" here. I think what you mean is that palliative has come to be associated with "giving up' on the possibility of cure or symptom control for the patient therefore leading to their death. However, given the contested notion of futility I do not find that this idea is clearly articulated with the current wording.

# Reply 2:

# That makes sense. We have edited it to 'giving up.'

# Comment 3:

Lines 108-116: I think these ideas are better placed earlier in the introduction. The structure of the introduction could be introducing palliative psychiatry & what it is, and then moving into the brief history and some of the challenges with adopting palliative psychiatry in mainstream mental health practices. I think clarifying what you think palliative psychiatry is at the beginning of the introduction will provide more clarity and context for readers reading the rest of the content.

# Reply 3:

Thank you for this insightful comment. We have restructured the introduction based on your suggestions.

# Comment 4:

Line 129: it would be helpful to state upfront if the patient was being treated as a competent patient or if there was a substitute decision maker involved. Please clarify (I assume incompetent, but given these details are highly relevant to decision making in palliative psychiatry requires explication here).

#### Reply 4:

During the initial phase of treatment, the patient was psychotic and was treated with antipsychotics to help alleviate his symptoms. He was agreeable to taking oral medications and his care was discussed with his parents, who were his surrogate decision makers. He did not require treatment o^ver objection as he was assenting to the treatment team recommendations.

#### Comment 5:

Line 136: It would be helpful to have a brief description of Mr. B's mental status after being transferred back to psychiatry as it is unclear what catatonic features he had at this point, although the administration of lorazepam QID suggests that there was a suspicion for catatonia at that time.

#### Reply 5:

# Thank you. We have added the initial mental status feature for clarity.

#### Comment 6:

Lines 140-143: A few questions here:

Were any objective measures of catatonia taken (e.g., Bush Frances Catatonia Rating scale)? If so, it would be helpful to include those scores here. Even better would be if there was testing done pre- and post- lorazepam administration

#### Reply 6:

# Bush-Francis rating scales were taken throughout the hospital course. We have added them to back to the case to provide objective data to the reader.

# Comment 7:

Can you please clarify what the daily maximum of lorazepam Mr. B received? Given that we are discussing palliative psychiatry, it would be helpful context to know that he truly reached high-dose benzodiazepine doses (e.g. 24 — 30 mg of lorazepam in a day)

#### Reply 7:

Lorazepam 36mg daily was the daily maximum dose. This part of the hospital course is elucidated in the case.

# Comment 8:

Was he ever given IV lorazepam prior to starting ECT? Why or why not?

# Reply &

IV Lorazepam was not given because we were not able to maintain a consistent IV access point in our psychiatric unit given the level of hysical activity involved in the episodes. However, IM lorazepam was frequently administered during the episodes he had, and prior to ECT he often received as much as 20mg of lorazepam daily (between standing po and IM).

#### Comment 9:

Was there any specific catatonia or clinical guidelines being followed here in terms of determining best approach?

#### Reply 9:

Standard of care in terms of high dose benzodiazepines and ECT were attempted, as were second and third line treatments (amantadine, valproate etc). The challenge was the ongoing need for treatment of acti^ve psychotic processes and a history of unprovoked violence on a previous inpatient unit along with his unusually strong adverse reactions to most of the neuroleptic medications trialed in the course of his hospitalization.

# Comment 10:

Line 158: A more fulsome description of decision-making around these interventions would be helpful (and that goes for throughout the paper, e.g. in Line 179 when there is mention of lithium/aripiprazole being added, line 202 when there is discussion of restarting clozapine). How were these interventions chosen? Based off the literature? A clinical guideline? Anecdotal experience of the treating physician? **In general, I think being very clear about decision-making throughout this whole process helps create an argument/throughline to get to the point where palliative psychiatry is being discussed** (e.g., you try stuff within guidelines more experimental/less evidence-based treatments deciding that the time has come to introduce palliative psychiatry).

#### Reply 10:

# Descriptions have been added to elucidate some of the hypotheses and reasons for restarting clozapine and trial of lithium/aripiprazole.

#### Comment 11:

Line 168: What do you mean by "minor improvements in catatonic symptoms?" How did his MSE change?

# <u>Reply 11:</u> We have added detail and clarified the manner in which his MSE changed.

# Comment 12:

Line 183: What disciplines did the senior faculty members comprise (i.e., why were they involved)? Was bioethics consulted? Why or why not? Also, I again suggest starting a new paragraph here (just before "after lengthy discussions...").

# Reply 12:

Senior psychiatry, both inpatient and CL, as well as neurology chair, intensive care senior staff and bioethics were all involved. Our hope was to involve anyone who might be able to suggest a different form of treatment or an approach that had not yet been attempted

# Comment 13:

Line 212: It would be helpful to explicate on what you mean by "palliative approach" here. How was this explained to Mr. B's parents? What was the team's vision of what palliation would like like here (I'm glad you explain what the parents specified)? The reader only got a brief taste of how you were defining palliative psychiatry much earlier in the paper so I think a reminder is needed here, grounded in the context of the case.

# <u>Reply 13:</u>

We have reworked this section. We have added some detail here about what was explained to the parents, and also added information regarding the palliative approach and what it entails.

# Comment 14:

Line 225: What do you mean by "most likely futile treatment"? Were all attempts futile? Futile towards what? (I'm assuming you mean treatment of the catatonia, but again needs some specifying)

# Reply 14:

We agree that this had been unclear. Ho<sup>\*</sup>wever, following Reviewer F, s recommendation, we have de-emphasized futility in the manuscript, so the section in question has been deleted.

# Comment 15:

Line 227: I think it would be powerful and illuminating to add a sentence after the words "prioritize comfort measures" stating something like "In the treatment team's view, this amounted to taking a palliative approach within management of a mental

disorder" or something similarly explicit to again connect back to the idea that you have a provided a concrete example of palliative psychiatry in action, and that this was explicitly intended.

# <u>Reply 15:</u>

We implemented this as follows: "In sum, this constituted taking a palliative approach in the management of a mental disorder, more specifically, providing EOL care including palliative sedation for catatonic schizophrenia."

# Comment 16:

Line 241-243: So interesting! Thank you for including here. Given that you make this point, I wonder if you want to expand on it a tiny bit in the conclusion with a suggestion that perhaps mental health care providers should become more familiar/comfortable with these approaches in the interests of their patients?

# Reply 16:

We believe this illustrates that psychiatrists - while uniquely accustomed to discussing the possibility of dying by suicide - tend to less comfortable discussing death and dying in general as well as end-flf matters. Therefore, implementing palliative approaches will require a major cultural shift in psychiatry. We have added 2 sentences to that effect

# **Minor Comments:**

Comment 17:

Line 55: "relevant improvement" is an odd phrase. Do you perhaps mean meaningful? Or clinically significant?

<u>Reply 17:</u> *Edited to 'clinically significant.'* 

<u>Comment 18:</u> Line 55: should be "intermittently require" not "intermittently required"

Reply 18: *Edited*.

# <u>Comment 19:</u> Line 104: you can get rid of the word "may" and just keep the word "tend"

<u>Reply 19:</u>

# Edited.

# Reviewer C

<u>Comment 1:</u> Thank you for your work on this subject, which seems entirely relevant. A few comments: Please explain the abbreviations (DVT, ICU, DNR/DNI, etc.).

# <u>Reply 1:</u> *Abbreviations expanded upon.*

# Comment 2:

The case describes the situation very well, but some information is missing: after the investigations, what cause was chosen for the status epilepticus? When a brain biopsy was planned, what would have been the purpose of the exploration? Was there any specific research involved, and if so, what might have been the consequences? Why do you record the patient's wishes? Were they a factor in the decision? Finally, and most importantly, how did the palliative decision (the decision not to perform a biopsy) impact the patient's care? What were the consequences that explain this improvement in comfort?

#### Reply 2:

# Thank you for your insightful questions. The case has been edited extensively to address these gaps in information.

#### Comment 3:

You say that the doctors who decided to limit care were not the patient's usual doctors. What does this show?

# Reply 4:

We believe this illustrates that psychiatrists - while uniquely accustomed to discussing the possibility of dying by suicide - tend to be less comfortable discussing death and dying in general as well as end-qf4ife matters. We have added a sentence to that effect.

#### Comment 5:

Finally, it seems necessary to reflect on palliative psychiatry: did the case report correspond to Lopez's criteria of futility? What conclusions can be drawn? Are we talking here about psychiatric or neurological therapeutic decline? Does a distinction

between these 2 disciplines make sense in your practice or not?

#### Reply 5:

Following Reviewer F's recommendation, we have de-emphasized futility in the manuscript, so the section on futility criteria has been deleted

#### Reviewer D

#### Comment 1:

Thank you for an interesting case report adding to the literature on palliative psychiatry by addressing questions of futility in severe persistent mental disorder, as well as ethical questions regarding end-of-life decision-making in non-autonomous patients.

Here a few comments regarding the manuscript:

The title states that the patient was suffering from treatment-refractory schizophrenia. However, little is said about symptoms and quality of life before the acute onset deterioration. A rather low daily dose of olanzapine (10 mg) may suggest less severe symptoms, or that other treatment had failed. Here, a short description/comment could be added.

#### Reply 1:

The patient was indeed stable on low dose olanzapine for several years, indicating that he did not suffer from a severe illness up until the year leading up to his hospitalization. His psychiatric history has been expanded upon in the case for clarity.

#### Comment 2:

Color of skin. The abstract says that the patient was a black man. Why is this important?

#### Reply 2:

After careful consideration and discussion, we have decided to remove this detail, as it is not of significance to the case.

#### Comment 3:

Page 6, line 81: "Palliative psychiatry is an emerging subdiscipline of psychiatry which accepts that some of the most severe and persistent mental illnesses (SPMI) can be irremediable [...]". This wording suggests that there is a list of especially severe mental illnesses. Suggestion: "Palliative psychiatry is an emerging subdiscipline of psychiatry which accepts that there are cases of severe and persistent mental illness

# (SPMI) that can be irremediable".

# Reply 3: *Edited*.

# Comment 4:

Page 7, line 86. "Psychiatric patients". This is a common wording, but personally I prefer "patients in psychiatry" or, here, simply "patients".

#### Reply 4: *Edited*.

# Comment 5:

Page 7, line 107. Maybe this reference on death in psychiatry could be considered? McKellar D, Ng F, Chur-Hansen A. Is death our business? Philosophical conflicts over the end-of-life in old age psychiatry. Aging Ment Health. 2016;20(6):583-93. doi: 10.1080/13607863.2015.1031636. Epub 2015 Apr 14. PMID: 25870891

# Reply 5:

# Thank you for this thoughtful reference. It has been added as a reference.

# Comment 6:

Page 12, line 212. Here, the parents' decision-making is described, but there are no comments on the opinions of the healthcare staff involved. Were there discussions among the healthcare professionals? Did everyone agree to the palliative approach? In the discussion, we read that the palliative approach was suggested from the ICU and not from psychiatry. A brief comment on the reactions among professionals would be interesting.

# Reply 6:

# The case has been extensively edited to add perspectives of the medical team as well as the staff working with the patient.

# Comment 7:

Page 13, line 226. The parents made the decision, it says. This sounds strange to me, since I work in a country where such medical decisions (to abstain from lifesustaining treatment) are made by physicians and/or the patient (who has the right to decline treatment). Family may express their opinions, but the decision is not theirs. Maybe a short comment on this in order for international readers to understand better?

# Reply 7:

# Since the patient lacked capacity to engage in his own care, his parents served as his health care proxies and surrogate decision makers. This is addressed in the revised case description.

# Comment 8:

Discussion. I believe that the discussion could be more tightly linked to the introduction of the paper. For instance, in the introduction it is said that "Palliative psychiatry does not mean "giving up," on the patient, but rather that the goals of care have shifted to focus on patient dignity and autonomy while minimizing suffering, reducing physical and psychological pain, and attenuating the morbidity of more aggressive treatments. This often involves a shift toward short-term quality of life [...]". So, in what sense did the foregoing of treatment in the case of Mr. B differ from "giving up"? How was dignity and autonomy respected, given that the patient had no decision-making capacity regarding his care needs? I do not question the approach but would suggest a somewhat clearer discussion regarding these aspects.

#### Reply &

Thank you, we have implemented this suggestion: "As Mr. B seemed most at ease and capable of social engagement with stf and peers after receiving IV sedation on ICU level of care, this medication was continued with the goal of relieving his suffering from catatonic symptoms (palliative sedation). Sedation also reduced the need for restraints, thus preventing iatrogenic suffering and promoting Mr. B's autonomy and dignity. Treatments aiming at reducing this catatonia (such as ECT) were stopped as they were burdensome and of minimal clinical benefit. Treatments aiming at keeping him alive (such as nasogastric feeding or resuscitation) were forgone as he was unlikely to achieve a subjectively acceptable quality of life again.»

#### Comment 9:

Conclusion. Although Mr. B has been in focus for the case report, he is not mentioned in the conclusion.

<u>Reply 9:</u> *We have rectified this.* 

# <mark>Reviewer E</mark>

#### Comment 1:

I congratulate the authors to their very clearly written manuscript on a case in which a psychiatric morbidity and its complications eventually lead to the need for palliative end-of-life care. In my opinion, this case is a welcome addition to the literature.

# <u>Reply 1:</u> *Thank you very much for your positive review and the helpful suggestions.*

<u>Comment 2:</u> I have the following comments: Abstract Line 65: require (not required)

Reply 2: *Edited*.

<u>Comment 3:</u> Case presentation Please provide a visual timeline with the most important milestones of the case.

# Reply 3:

# Thank you for this suggestion. A figure with a visual timeline has been added to the manuscript.

# Comment 4:

Please tone down/leave out/use symptomatological terms for some of the descriptions of the patients behaviors and symptoms (e. g. "grab and pull at his genitals"). They are not necessary to convey the full extent of the patient's illness and suffering and the challenge he presented for the care team(s). Rephrasing some of them would go a long way in protecting the patient - albeit posthumously.

# Reply 4:

# Thank you for this thoughtful comment. Some of the descriptive but unnecessary terms have been taken out.

Comment 5:

Please provide more info on the psychiatric history of the patient including on previous episodes of catatonia or NMS.

# Reply 5:

Both his prior history of catatonia and NMS were added to the case discussion (line 123).

<u>Comment 6:</u> Case discussion Please expand the discussion on the fact that NMS due to clozapine was diagnosed. That alone could be considered sufficiently interesting to write up the case. Please also be specific in the presentation of the medication that the patient received during the initial febrile episode. Was he still on olanzapine as well? If not, how many days of wash-out lay between the last dose of olanzapine and initiation of clozapine?

# Reply 6:

This is a very interesting point about NMS due to clozapine being diagnosed. It was difficult to include a discussion about this fact in the manuscript due to word count constraints. The case has been updated to reflect more clearly the timeline of antipsychotic administration.

#### Comment 7:

Please also mention the overlap (in clinical presentation, in treatment, likely in genetics) of NMS and malignant/pernicious catatonia. See e. g. Hirjak, D., Sartorius, A., Kubera, K.M. et al. Antipsychotic-induced catatonia and neuroleptic malignant syndrome: the dark side of the moon. Mol Psychiatry 26, 6112-6114 (2021). https://doi.org/10.1038/s41380-021 -01158-2

#### Reply 7:

# We thank the reviewer of pointing out this overlap. We have revised the manuscript accordingly and added one sentence in a footnote with citing the mentioned article to clarf this.

# Comment 8:

Please expand on the fact that the intensivists (and not the psychiatrists) suggested the shift to palliation. That issue appears to be at core of what is needed to promote the idea of palliative psychiatry.

#### Reply &

We believe this illustrates that psychiatrists - while uniquely accustomed to discussing the possibility of dying by suicide - tend to less comfortable discussing death and dying in general as well as end-flife matters. We have added a sentence to that effect.

# <mark>Reviewer F</mark>

#### Comment 1:

The authors have described the background of palliative care in psychiatric illness, including the lack of clear role/guidelines, and then describe a case of shared decision-making to establish a treatment plan focused on symptoms management rather than

life sustaining therapies for patient who was unable to achieve acceptable quality of life due to treatment resistant malignant catatonia. The case has important implications for describing how palliative care, which is holistic patient centered care for those with serious illness, can and should be used for difficult-to-manage cases of psychiatric illness in which quality of life is severely and irreversibly impaired. The case further illustrates current challenges with engaging in a patient centered approach for those with psychiatric illness, which include lack of guidelines/precedent when treatment selection or refusal may result in shorter life, and team discomfort with end- of-life discussion.

While the patient case presented outlines shared decision making for limiting life sustaining treatments in psychiatric illness and should be shared with the academic community, the authors approach as written greatly overemphasizes the concept of futility, which may promote further misconceptions about palliative care in the psychiatric community. Palliative care has many applications for patients with psychiatric illness beyond treatment futility, including establishing acceptable and unacceptable quality of life based on patient values, making decisions about treatment limits (for example, electing to avoid more invasive procedures like ECT, or tube feeds in the case of anorexia, but accepting other forms of therapy.) I recommend the following:

De-emphasize futility. The authors accidentally overemphasize the role of futility as it relates to palliative care. On page 6 line 84, the authors indicate that "palliative" does not reflect "futility", but then spend the bulk of the manuscript describing how the patient transitioned to end of life care because the treatments appeared "futile" (page 13 line 225). Comfort focused care is certainly appropriate when other medical treatments are "fhtile" (e.g. absolutely no benefit to the patient), but is also indicated in other circumstances.

#### Reply 1:

# Thank you for this important suggestion. We have no<sup>w</sup> revised the introduction and discussion accordingly.

#### Comment 2:

Clarify the patient's evolving prognosis at key timepoints in the case (likelihood of remission, burdens of treatments, expectations for physical and mental function/long term outlook). The authors should clearly describe the point in the patient's case when clinicians felt that the patient was unlikely to achieve meaningfully sustained remission of his psychiatric illness. This would represent the point when, by the authors' own definition, the patient's psychiatric care becomes synonymous with palliative care (page 7 line 88-9). The treatment course down to exact temperatures, medication dosages, etc. does not need to be as detailed. Consider instead emphasizing opportunities (or missed opportunities) along the treatment course for discussing

whether or not the patient was likely to achieve what he would perceive as acceptable quality of life.

#### Reply 2:

# Thank you for this comment. The case has been edited to include such details and perspectives as suggested.

#### Comment 3:

The authors accidentally imply for the patient's case that a "palliative approach" is synonymous with comfort-only-care. When describing the goals of care conversation that occurred after many months of not achieving remission, they write that the family "opted for a palliative approach" (page 12 line 212) by electing to limit life sustaining care and allowing natural death. This is erroneous because the patient had been receiving palliation for months with attempts at aggressive symptoms control in the face of not achieving remission.

#### Reply 4:

# Thank you for this comment. The decision to pursue a more palliative approach by the parents has been elaborated on for clarity.

#### Comment 4:

More properly define palliative care in psychiatric illness in the introduction and then re-emphasize in the conclusion. This should be described before ever discussing futility. On page 8 lines 108-110 there is nice description, but unfortunately the authors begin with a defensive justification of palliative care by starting the definition with what palliative care isn't ("giving up"). This inadvertently promotes the idea that palliative care needs to be defended. The authors further describe. The lines following this (111-116) are also quite problematic. Treatment teams should always abstain from beginning treatment (aggressive or not) without discussion with the patient/surrogate about risks and benefits, and expected course with treatment. This is not unique to palliative care, but is instead standard medical practice. A palliative care approach in psychiatry (or any specialty) reflects creating a holistic care plan that aligns with a patient's values and priorities, with an emphasis on realistic shared decision-making when patient's quality of life is negatively affected by uncontrollable disease or intolerable treatment side effects.

# Reply 4:

# Thank you for this point. We have rewritten the introduction accordingly.

#### Comment 5:

Regarding substance use disorder mentioned in 111-116, even for patient's whose care

plans may result in shorter life expectancy (for example if a patient establishes limits of DNR/DNI), risks of controlled substances (including the development of a substance use disorder) should always be compared to the benefits and are not always appropriate, even for patients with a care plan that focuses on quality of life. The development of a substance use disorder in patients who are not imminently dying can have serious implications for their quality of life toward the end of life, including disrupted interpersonal relationships, poor engagement with the medical care, and (sadly), stigma within the medical system.

# Reply 5:

#### We agree with you and have deleted this example.

#### Comment 6:

Overall, while this is an excellent case of shared decision-making regarding treatments in the face of refractory psychiatric illness, the authors make multiple misleading statements and assumptions that distract from the important points about the case. The manuscript will need to be heavily revised to avoid promoting misconceptions about palliative care.

# Reply 6:

We are grateful for this positive feedback and have revised the manuscript in order to meet all these suggestions.