

Peer Review File

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Reviewer Comments

Reviewer A

This paper is a qualitative study on end-of-life care in prisons. This is an important area to explore. However, this paper needs major improvements before being considered a valid scientific piece:

-This paper needs to significantly improve its English grammar. Examples include (but are not limited to): the highlight box, sentence on line 83-85, 94-96,

Reply: Our apologies and thank you for your remark, we sent the manuscript again to an English native speaker for proofreading.

-Multiple statements are not accompanied by the proper references. Examples include (but are not limited to): line 87-89, 92-93, 127-129, 240-242

Reply: Thank you for this comment, we added references to your first example and wherever we find additional missing references. The part of the earlier lines 92-93 and 127-129 were removed and the example mentioned of the earlier lines 240-242 was a conclusion of the interviewees' remarks and therefore we tried to make this clearer by writing "This posed a problem in Austria, where hospitals were often unwilling to receive individuals from prisons, and beds were thus reported to be scarce." (259-260)

- The tone of the paper is confusing, as it reads like a literary piece in some sections (eg, the introduction lines 130-136), and a scientific paper in others (eg, the methods). I suggest writing in a consistent scientific tone.

Reply: We agree. Most literary parts have been removed in this revision to allow for a consistent scientific tone. Some parts (e.g. Crawford's letter) were kept as this manuscript was written for a Special Series that includes especially a Narrative Medicine perspective.

- For the results, I suggest writing direct quotes from your interviewees

Reply: Thank you very much for this remark. We added direct quotes for each theme in the text and removed table 1. Please see the highlighted version (aimed to be better readable) or track changes version.

- There is no rationale as to why the interviewees were from two different continents, and how that serves the study.

Reply: That is right. To make this more transparent we added "AK contacted three physicians (two females and one male) who were practicing medicine inside prisons. The interviewees were a palliative care professional already known to the authors and two doctors who were recommended by of a physician and a scholar working in the field. This resulted in the unusual distribution of one professional in New York State and two in Austria." (line 152-156)

Reviewer B

The subject matter of this paper is very interesting, and its findings raise some valuable issues. However, there are some major flaws, which would require correction before it could be considered for publication. I have provided comments on each section of the paper in order, and hope that these will be of help to the authors.

The abstract states that "the investigation is based on the qualitative methodology of thematic analysis" (line 48). Thematic analysis is a method, not a methodology, and as such is just one of the tools used to undertake this investigation. This needs to be more clearly stated.

Reply: Thank you for highlighting this mistake, we changed it in the abstract to "Braun and Clarke's thematic analysis was used to examine the data." (line 51-52) And explained the methods in more detail in the methods section.

The background section requires major revision. It currently provides no contextual information about the numbers of people in prison with palliative care needs or any other indication of the size of the problem in either of the countries included in the study; for example, on line 89 it is stated that more than half of Austria's prison population has no Austrian citizenship, but there is no sense of how large or small a number this is. More importantly, the background makes no reference to the existing literature about palliative care in prison, let alone an objective appraisal of the evidence from this growing body of work. Instead, it presents an account that is very anecdotal and quite emotional, drawing on details from a letter from one person in prison about his experiences. The background should provide a solid foundation for the rest of the paper, identifying key issues and relevant research, and make a case for a gap in knowledge that is at least partially filled by this study; unfortunately, this background section fails to do this.

Reply: You are right, thank you for your remark. We added:

"These two countries have different carceral systems. In Austria, the prison population rate is 97 per 100,000 inhabitants; in the US, it is 531 (4, 5). The global prison population is aging, and many older incarcerated individuals will die before they are released (7, 8). Incarcerated patients receive little attention in a dense medical curriculum, and they are not equally included in the ordinary health-care system (6, 7, 10). In 2011, there were 69 prison hospice programs in the US (11), whereas no data exists on Austrian end-of-life (EOL) care in prisons. However, older adults in prison experience disability and illness at much higher rates than the general population (12). Access to palliative care in prison is limited, but in the US, few special housing units or entire facilities for older and frail incarcerated persons have been created, and other institutions have set up hospice units (12, 13). One study found that 74% of older incarcerated persons reported distressing symptoms and 27% were afraid of dying in jail or prison rather than as a free person. The study suggested that an optimal medical

model for this population would include a geriatrics-palliative care approach that includes the management of all forms of symptom distress, comprehensive treatment, and connections with the community (14).” (line 90-104)

The stated objective of the study is merely that it aimed “to uncover thematic areas for further research”, and no specific research question, aims or objectives are presented. This again is a major flaw, as it leaves the reader with no clear sense of the purpose of the study and what it hoped to achieve. The methods of data collection and analysis are presented in a reasonable level of detail. However, there is no mention of ethical considerations, and no account of the specific ethical approval processes undertaken by the research team, beyond a brief footnote at the end of the paper.

Reply: Thank you. To specify our objective we added:

“Previous studies have found obstacles to providing palliative care in prisons, including mistrust, safety concerns, and conflicting priorities of care and custody (7, 10). In this discussion, the voices of physicians who care for dying incarcerated patients are mostly absent.

1.3 Objective

This exploratory study aims to investigate the perspectives and experiences of physicians working with terminally ill patients in prisons in Austria and the US; it also seeks to determine key thematic areas for further research. By focusing on the physician’s experiences, this qualitative pilot study will generate insights into the palliative treatment needs of the carceral system.” (line 131-141)

We also added that we received an exemption from the ethics committee of the Medical University Vienna (both in section 2.1. and in the footnote):

“The ethical approval was exempted by the ethics committee of the Medical University of Vienna because the study was not classified as a clinical study and was planned and conducted in compliance with good scientific practice. The study was conducted in accordance with the Helsinki Declaration (as revised in 2013).” (line 170-174 and 517-523)

I question the suggestion on line 182 that this is a “diverse” sample of participants – a sample of three is too small to be considered diverse.

Reply: We agree. Thank you so much for highlighting – we removed the part from the manuscript.

The findings raise some interesting issues, but little attempt is made to draw out the differences between different countries and the impact of different prison systems.

Reply: We did not include a comparison between the different prison systems because we felt it was beyond the scope of this article. The interviews of three physicians would not allow to generalize for the countries’ respective systems. This pilot investigation aims to shed light on the experience of physicians caring for patients who are incarcerated. Further investigation might give deeper knowledge on how experiences of physicians within different countries and systems might differ.

Very little data is provided to evidence of the themes and none of the very few quotes provided is attributed to a specific participant. It is possible that because the sample size is so small the research team might have had concerns that individuals might be identifiable; however, if this is the case, it needs to be explained.

Reply: In the revised version we added additional direct quotes in the text and removed table 1. Please see the highlighted version (aimed to be better readable) or track changes version.

However, as you suggested, we do not want to attribute them to a specific participant in order to minimize the risk that someone might identify them. We added the explanation “The quotes below are unattributed to safeguard the participants’ anonymity.” (line 179-180)

The discussion of the key findings is extremely limited, and no attempt is made to compare and contrast the findings of this study with existing research. An argument is made on line 319 that this is an under-researched area; this is indeed the case, but because none of the published literature in this area has been considered, the claim that this study provides ‘novel insights’ is unsupported. Section 4.3 is entitled ‘Comparison with similar research’, but in fact largely draws on a few facts and figures about numbers of people in prison with particular needs, rather than the growing body of research that details the challenges for patients, staff and prison systems around dying in prison.

Reply: Thank you, we agree. We revised the discussion section and 4.3 in particular and linked the findings to existing literature. Please see the highlighted or track changed version attached.

Reviewer C

This article examines end-of-life issues in prisons through interviews with three physicians working in Austrian and New York prisons. The authors explore some of the challenges of providing care in these environments, including limitations on ability to provide certain aspects of care and for supporting people with terminal illnesses. Although this is an important and worthy topic, the manuscript would likely benefit from substantial revisions.

Possible Areas for Improvement:

- Sample: The study has a very small sample (interviews with three physicians) from an unusual distribution (New York and Austrian prisons). I’m not sure whether the authors can make many conclusions at all about end-of-life care in prisons with such a small sample size also in very different environments across the globe. I do wonder if the authors should consider expanding their sample by surveying many more health professionals in these environments before publishing their findings.

Reply: Thank you very much for your remark. We agree that this is both an unusual distribution regarding the origin of the interviewed physicians and that the sample

consists of only three physicians. As within the three-week-timeframe of this revision it is not possible to expand the sample we did our best to revise the manuscript. To make this more transparent we added “AK contacted three physicians (two females and one male) who were practicing medicine inside prisons. The interviewees were a palliative care professional already known to the authors and two doctors who were recommended by of a physician and a scholar working in the field. This resulted in the unusual distribution of one professional in New York State and two in Austria.” (line 152-156)

- Vague sweeping statements: The authors make a number of vague and sweeping statements in the article (E.g., “She highlighted that this also limited their free will”; “the government must enable an evaluation of the current situation”; “our society must think about alternatives”; “the underlying need is to stop mass incarceration”; “This is also the responsibility of democratic states”; “Structural change is needed”). I’d suggest re-reading the article for these types of statements and trying to be more focused and concise with the points that they are trying to get across to readers.
Reply: Thank you for this remark and exemplifying what you mean with quotes. This was really helpful for us, we re-read the article and tried to be more concise wherever possible, please see the highlighted version or the track changed version.

- Wider reading of the literature: There are lots of papers about palliative and end of life care in jails and prisons, as well as decarceration of older adults, which the authors might wish to review and consider incorporating into their manuscript. Examples include:

<https://pubmed.ncbi.nlm.nih.gov/25764177/>

<https://bmjopen.bmj.com/content/9/12/e033905>

<https://ajp.psychiatryonline.org/doi/10.1176/appi.ajp-rj.2018.130302>

<https://www.emerald.com/insight/content/doi/10.1108/IJPH-09-2021-0095/full/html>

<https://www.tandfonline.com/doi/abs/10.1080/15265161.2019.1618957?journalCode=uajb20>

<https://agsjournals.onlinelibrary.wiley.com/doi/abs/10.1111/jgs.17454>

<https://pubmed.ncbi.nlm.nih.gov/35584307/>

Reply: Thank you very much for this list of literature. We agree and revised both in the background section and discussion section (4.3 in particular) and linked the findings to existing literature. Please see the highlighted or track changed version attached.

Minor Points:

- Title: I’d suggest clarifying that the pilot interview study is with physicians caring for patients with terminal illness (rather than interviewing physicians who care for incarcerated patients generally)

Reply: We added your suggestion and the title now reads: “On Dying Alone in Prison and the Social Responsibility of Medicine: A Pilot Interview Study with Physicians Caring for Terminally Ill Incarcerated Patients in Austria and the United States”

- Abstract background: “the special working environment”: what do the authors mean by this?

Reply: Thank you for highlighting this unspecified expression. We changed it to “While studies of palliative care and end-of-life issues in prison have increased, especially in the United States and since the COVID-19 pandemic, they are still limited due to the constraints of carrying out research in carceral contexts. At present, there is very little knowledge of the experiences of physicians providing end-of-life care in prisons.” (line 43-47)

- Abstract conclusions: “provider-patient relationships seem hardly to be continuous:” doesn't having terminal illness introduce challenges for continuity of care?

Reply: What we try to express is that in a palliative care hospital/outpatient setting, the same team/physician sees the patient for the last months or weeks until they die. In the prison context, however, the physicians said that oftentimes due to transfers to other facilities with more medical equipment or to the hospital they could not continue the care of the patient with the terminal illness. We hope the expression “interrupted relationships” will make this more clear (line 54-55).

- Abstract conclusions; “The results present a starting point for further conversations and studies, as structural change is needed”: this sentence is rather vague and does not really say anything. I'd suggest rewriting so that it's clearer to readers what the implications of the study are

Reply: Thank you, you are right. We changed it to:

“The study reveals the difficulties physicians face when caring for dying incarcerated patients. Provider–patient relationships are hardly continuous. The findings represent a starting point for further research. Support from the medical and palliative care community is needed for adequate provision of end-of-life care within prisons, improved post-release conditions, and help for physicians working in existing structures.” (line 58-62)

- Highlight box: “Dying people in prisons do not have access to the same quality of care...”: is this necessarily true? Many incarcerated people were homeless, living in poverty, without health insurance, etc., and may have more access to care in jails and prisons than on the streets. The authors repeat this statement later in the highlight box (“They do not have equal access to medical care”), which is in some ways true and in some ways false. I'd suggest rewriting to allow for better nuance (e.g., “Incarcerated people often face challenges accessing evidence-based and compassionate care.”)

Reply: Thank you, that is a very important point and we agree. We added these nuances both within the results under “Possibility of release” and made changes the highlight box:

“Key findings

- Physicians caring for terminally ill people in prisons are unable to provide the same quality of care as in designated palliative care units or hospices. Incarcerated persons have very limited options for visits and saying their goodbyes.

What is known and what is new?

- Marginalized groups such as incarcerated persons receive little attention and often face challenges in accessing evidence-based and comprehensive care.
- This study highlights the palliative care needs in the carceral system and the difficulties in providing end-of-life care in this setting as identified by physicians caring for incarcerated patients.” (line 65)

Additionally, as this was also mentioned by our participants we added the following section:

“The participants also mentioned that persons in prison received better medical care inside rather than outside and that being released might have negative consequences for them. One interviewee explained, “Many of the really sickest people who get released die very soon after they're released—within weeks. We see it all the time. Because we take very good care of them. And they don't add that support on the outside.” Another story that was shared was the following: “One woman was released, but she had no place to go. So, she ended up staying in prison.” The interviews show that early release is not an easy answer to terminal illness in carceral contexts.” (line 391-398)

- Highlight box: “the government must enable an evaluation of the current situation”: what government? New York State? Austria? This is also a bit vague and should likely be rewritten.

Reply: Thank you. We changed this part to:

“This work raises awareness within the medical community of the precarious situation of dying incarcerated persons. Physicians who work in prisons need to be supported, and collaborations aimed at discussion and education must be established. Prison regulations (e.g., visiting rules) and external institutions (e.g., nursing homes for formerly incarcerated persons), need to be reevaluated and adapted.” (line 65)

- Background: Dostoevsky apparently never wrote this quote: <https://lareviewofbooks.org/article/dostoyevsky-misprisoned-the-house-of-the-dead-and-american-prison-literature/>

Reply: This is uncomfortable, thank you very much for sharing this interesting and important article. We removed the quote.

- Background, Lines 73-79: I'm not aware that every medical student around the world has to make this pledge. Is that true? Students in US medical schools more often do some variation of the Hippocratic Oath.

Reply: Thank you for highlighting this, we now changed it to . “When students begin medical school, they often have to accept the World Medical Association’s Declaration of Geneva” (line 69-70)

- Rationale and knowledge gap, lines 115-117: “Terminal illness and limited life expectancy are often the starting point of encounters with patients in the hospital.” What? Perhaps if you work in hospice or palliative care but otherwise many, if not most, health care encounters in hospitals have nothing to do with terminal illness or limited life expectancy.

Reply: Of course! Thank you for pointing this out. We changed the sentence to “In hospitals, a terminal illness is often the starting point of the encounter between a patient and palliative care specialists.” (line 125-126)

- Rationale and knowledge gap, lines 127-129: in many prisons, patients can step outside or feel the wind, so “all of this is impossible for people in prison” seems a bit extreme.

Reply: We agree and deleted large parts of this section.

- Rational and knowledge gap, lines 131: “He has to rely on the food that everyone gets on their tray in San Quentin”: what about care packages? Commissary?

Reply: Thank you, we changed this whole section so that this line is no more part of the manuscript.

Thank you for the opportunity to review this paper!

Reply: Thank you very much for your detailed remarks and time!

Reviewer D

Thank you for the opportunity to review this interesting exploration of an often overlooked aspect of medicine - the care of the most marginalised.

Overall, the paper provides an interesting account of the experiences and challenges of physicians providing end of life care to incarcerated people which was well written and a pleasure to read.

I have a few suggestions to improve the manuscript.

Line 114 - rationale and knowledge gap

it would be helpful to more clearly explain the knowledge gap this study seeks to fill in a sentence or two at the end of this section.

Reply: Thank you, that is true. We now end this section with “Previous studies have found obstacles to providing palliative care in prisons, including mistrust, safety concerns, and conflicting priorities of care and custody (7, 10). In this discussion, the voices of physicians who care for dying incarcerated patients are mostly absent.” (line 131-134)

Line 153-5 - Participants

i suggest you move the first two sentences (about not being able to talk to inmates and

the study coming out of the correspondence with Crawford) to the rationale or objective sections as it is more background info than your actual methods.

Reply: Thank you, we agree and removed it from the manuscript.

line 174: i suggest moving the last sentence of the methods which gives the themes to the results section as these are results. you could move this sentence to just after the description of interviewee characteristics.

Reply: That is a good idea! Thank you. We moved it just after the description of the interviewee characteristics (line 181-183).

line 377 - conclusions

The study aim was to identify areas for further research, as well as to highlight this issue to the medical and palliative care community. It would therefore be useful to comment very briefly on next research steps to expand our understanding of what needs to change in this area.

Reply: Thank you very much, this is an important point. We added:

“These obstacles should be communicated to the medical and palliative care communities in order to emphasize the need for further research. Which steps should be taken to enable palliative care in carceral settings despite limited resources? How can health-care providers working in prisons be supported? How can suitable post-release institutions be identified?” (line 490-493)

Reviewer E

Dear authors, I very much appreciated the opportunity to review your work. I must commend you for exploring this important topic that is long overdue. I also appreciated how the current study was contextualized within the ethics of care and justice. Integration of the thank you-letter from Crawford mentioned in Introduction and Conclusion, I believe, highlighted your position as researchers committed to honoring lived experience. All the sections are carefully written with nuances. One minor addition that the authors might want to consider is additions of a few quotes from interviews that are representative of each of the five themes identified. This could perhaps enhance the Results section and trustworthiness of the study.

Reply: Thank you so much for your comment and feedback. In the revised version we added additional direct quotes in the text and removed table 1.