

PEER REVIEW HISTORY

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ARTICLE DETAILS

TITLE (PROVISIONAL)	Palliative and End of Life Care in Prisons: a mixed-methods rapid review of the literature from 2014 – 2018
AUTHORS	McParland, Chris; Johnston, Bridget

VERSION 1 – REVIEW

REVIEWER	Pasithorn Suwanabol University of Michigan, USA
REVIEW RETURNED	20-Sep-2019

GENERAL COMMENTS	<p>McParland and Johnston have submitted a contemporary systematic review of palliative and end-of-life care among prisoners. From a search of six databases, the authors identified 23 articles from 2014-2018 for full review. The authors justify this abbreviated search as a recent study of examined articles up to 2014. The authors characterize current practice of palliative and end-of-life care use in prisons, identify barriers and facilitators of use, how hospice can support prisons, and finally, in the Discussion, recommendations for how palliative and end-of-life care can be provided as this is part of a larger project in Scotland, which aims to provide recommendations for the provision of palliative and end-of-life care. The authors have conducted an exhaustive search of the existing literature and submitted a well-written and thoughtfully executed study. However, there are several issues to address, primarily with regard to the presentation of results and thematic analysis.</p> <ol style="list-style-type: none">1. Introduction could be shortened and the overall aim better described. For example, a brief description of the aging prisoner population is sufficient. Furthermore, would reframe the introduction to focus only on the equitability of care that extends to palliative care and move the knowledge gap that most studies are from the U.S. to the Discussion. The authors do not address the knowledge gap in their results so it may be better to state that some of these findings may not apply to a population outside of the U.S. and that future work should address this.2. Methods: Please provide more description to how quality scores were calculated beyond a citation. When viewing the tables and the scores, it is helpful to understand how these scores were derived. Further, how were the quality scores categories (e.g., high, very good etc) determined?3. Methods: Was a research librarian used for your search and would include a supplement of search terms.4. Results: Recognizing that themes may overlap, I would argue that many of the stated facilitators (e.g., fostering close relationships, person-centered care) are not actually facilitators or something that eases the provision of palliative care; these may be better suited under the following theme, How can hospices support prisons. There were several factors that were identified under this theme that may
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	<p>be more appropriate under the Facilitator theme such as access to specialist palliative care, minimal use of physical restraints, inmate hospice volunteers and structure to support this.</p> <p>5. Results: I'm not sure if the reflections embedded into your review are appropriate. Although they support some of your findings, this is an entirely different study than a systematic review.</p> <p>6. Finally, in the Discussion, please briefly summarize how your findings add to the Wion and Loeb work as this was your rationale for your abbreviated search.</p>
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REVIEWER	Susan J. Loeb The Pennsylvania State University USA
REVIEW RETURNED	23-Sep-2019

GENERAL COMMENTS	<p>*Thank you for the opportunity to review this well written and timely review on an oh so critically important topic in Corrections Health. The strengths are many: engaging an advisory group of prisoners to provide input in a variety of steps in the study from planning through dissemination; clear and informative decision tree; nicely justified the need for the review early and the contributions of the review in the discussion; and nice description of the analytic approach.</p> <p>My comments on areas that may benefit from enhancement follow:</p> <ol style="list-style-type: none"> 1. Please add more information on the Quallsyst tool for quality appraisal. (a table or figure would be best) as well as a sentence describing how widely it has been adopted for quality appraisals to justify its selection. 2. Similarly, please describe how Kotronoulas and colleagues are the experts to stand on the shoulders of for justifying the use aggregate SQS scores. 3. The Matrices (i.e., Tables of Evidence) would benefit greatly from the addition of a column of strengths & limitations of each study and would add greater transparency/insight into the quality scores that were arrived at. 4. In addition, the Key Findings Column would be a far easier read if a bulleted approach rather than a lengthy narrative approach were employed. 5. Could collapse Country Column with Citation Column to save some valuable real estate and similarly, combine the Quality Rating Column with the newly suggested column of Strengths & Limitations at the far right side of each Table/Matrix. 6. I question the relevance/inclusion of the Rothman et al., 2018 article in the review. 7. It was nice that the authors included a sample search strategy for CINAHL, but a) am not sure why it was selected and b) wonder why a more general statement of all terms explored overall was not included. <p>Thank you .</p>
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VERSION 1 – AUTHOR RESPONSE

Reviewer: 1

Reviewer Name: Pasithorn Suwanabol

Institution and Country: University of Michigan, USA

Please state any competing interests or state 'None declared': None

Please leave your comments for the authors below

McParland and Johnston have submitted a contemporary systematic review of palliative and end-of-

life care among prisoners. From a search of six databases, the authors identified 23 articles from 2014-2018 for full review. The authors justify this abbreviated search as a recent study of examined articles up to 2014. The authors characterize current practice of palliative and end-of-life care use in prisons, identify barriers and facilitators of use, how hospice can support prisons, and finally, in the Discussion, recommendations for how palliative and end-of-life care can be provided as this is part of a larger project in Scotland, which aims to provide recommendations for the provision of palliative and end-of-life care. The authors have conducted an exhaustive search of the existing literature and submitted a well-written and thoughtfully executed study. However, there are several issues to address, primarily with regard to the presentation of results and thematic analysis.

Response:

Thank you for taking the time to review our manuscript and providing this helpful feedback.

1. Introduction could be shortened and the overall aim better described. For example, a brief description of the aging prisoner population is sufficient. Furthermore, would reframe the introduction to focus only on the equitability of care that extends to palliative care and move the knowledge gap that most studies are from the U.S. to the Discussion. The authors do not address the knowledge gap in their results so it may be better to state that some of these findings may not apply to a population outside of the U.S. and that future work should address this.

Response:

Introduction has been shortened by the removal of sentence beginning “A recent study by Her Majesty’s Inspectorate for Prisons Scotland...”. The first two paragraphs were joined and the sentence beginning with “Both the quality and quantity of studies in this area...” has been cut. The remainder of the paragraph (from “Both the proportion and the absolute number...”) has been moved to the Research Implications section, (line 490) as it discusses the knowledge gap that most studies are from the U.S. It has been placed at the beginning of the second paragraph in that section, the first sentence of which (“Further primary research from other countries...”) has been changed to “There is also a need for more studies...” (line 496) in order to accommodate this move.

The section on equitability of care has been cut, and has been replaced with the paragraph that begins with “In some countries, policy and guidelines...”(line 87). In summary, this section has been significantly restructured as recommended.

2. Methods: Please provide more description to how quality scores were calculated beyond a citation. When viewing the tables and the scores, it is helpful to understand how these scores were derived. Further, how were the quality scores categories (e.g., high, very good etc) determined?

Response:

We have now added 2 tables which illustrate the qualitative and quantitative Qualsyst tools, as well adding an explanation of how the tool is used to the Quality Appraisal section (beginning “The qualitative and quantitative components of the Qualsyst tool can be found in tables 1 and 2. Papers are scored 2,1 or 0 for each question dependent on...”, line 177). The introduction of these tables means the original tables 1,2 and 3 are now numbered 3,4 and 5 respectively.

With regard to the categories applied to the evidence, there is a lack of consensus on the reporting of Qualsyst scores, and the tool does not provide guidance beyond the calculation of a percentage score. Some authors express scores as a percentage, while others employ hierarchical categories as has been done in this review. In previous reviews, decisions on the naming and placement of these categories appears to have been undertaken in order to facilitate understanding, and in the absence

of any formal guidance or consensus (for example: Bone et al, 2019, *European Journal of Public Health* 29(1); Ljungman et al, 2014, *PLoS ONE*, 9(7)). This has also been the case in our review. However, in response to the points raised at peer review, we recognise that categorisation has not enhanced understanding, and have instead advised simply that “Higher scores indicate a greater degree of methodological robustness” at the end of the Quality Appraisal section under Methods (line 189). We have noted that this has been the case in previous systematic reviews employing Quallsyst published in *BMJ Open* (Daly et al, 2018, *BMJ Open* 8(6); Halter et al, 2018, *BMJ Open*, 8(6)). We have also therefore removed the threshold of 80% as a marker of methodological robustness, and all references to it throughout the text. The previous last sentence (beginning “For this rapid review, evidence based on at least two...”) has been removed, as has the reference to a hierarchical categories of quality scores and the 80% threshold in table 5 (previously table 3).

3. Methods: Was a research librarian used for your search and would include a supplement of search terms.

Response:

The research librarian is referenced in the Methods section under Literature Search. They advised on and reviewed the search strategy, but the search was conducted by one of the authors. We have added a line to clarify this: “The final searches were conducted by one author (CM)” (line 142). An example search strategy can be found in appendix 2, but we have added a list of search terms employed to the Literature Search section as well (line 142-150).

4. Results: Recognizing that themes may overlap, I would argue that many of the stated facilitators (e.g., fostering close relationships, person-centered care) are not actually facilitators or something that eases the provision of palliative care; these may be better suited under the following theme, How can hospices support prisons. There were several factors that were identified under this theme that may be more appropriate under the Facilitator theme such as access to specialist palliative care, minimal use of physical restraints, inmate hospice volunteers and structure to support this.

Response:

We have reviewed the themes highlighted above, and we recognise that there is potential for overlap, particularly between the facilitators of palliative care delivery and the ways in which hospices can support prisons to deliver palliative care. When assigning findings to the hospices theme, we aimed to select findings which were exclusively within the remit of hospices as opposed to the broader prison healthcare structure. Considering this, we agree that providing access to specialist palliative care services and minimal use of physical restraint would be more accurately described as facilitators of palliative care, and have moved these points as recommended. They have been placed in a new paragraph in the barriers/facilitators section (line 345-354). The findings are now preceded by the lines “Access to specialist palliative care services was identified by both prisoners and clinicians as important” (line 345) and “In countries where prisoners are escorted to hospices outside the prison by custodial officers, reasonable limitation of restraint measures may also improve care delivery” (line 349). In order to accommodate these changes we have changed the sub-themes under “the role of hospices” in our thematic map from “community hospices” and “prison hospices”, to “the benefits of prison hospices” and “inmate hospice volunteers”.

With regard to the above themes we have identified as facilitators, the decision to categorise them as such rather than under the hospices theme was driven by the fact that the evidence for the findings comes from a range of countries, many of which do not generally operate prison-based hospices. For example, the evidence for the ‘fostering close relationships’ finding comes from France, the UK, the US and Switzerland, with the US being the only country of the four where a prisoner is likely to be treated in a prison-based hospice. Using the UK as an example, the recommendation to support

prisoners to maintain relationships at the end of life would be more likely to be directed to NHS primary care staff than specialist palliative care or hospice staff. We recognise that in the US prison system some of the facilitators would be more appropriately placed in the hospices theme; however, we have sought to frame these findings as being factors which contribute to or facilitate the delivery of holistic palliative care in an international context.

5. Results: I'm not sure if the reflections embedded into your review are appropriate. Although they support some of your findings, this is an entirely different study than a systematic review.

Response:

These have now been removed as recommended.

6. Finally, in the Discussion, please briefly summarize how your findings add to the Wion and Loeb work as this was your rationale for your abbreviated search.

Response:

A section has been added to the end of the Discussion, titled "What does this review add?" (line 466-478). It briefly summarises the ways that some of the key findings of this review either reinforce or add to the findings of the previous review. This has caused some repetition in two adjacent sections, therefore we have deleted the first three sentences of the Research Implications section, which began "The findings of this study are largely in keeping with the..." to the sentence that ends "...growth in the research being conducted into palliative and end of life care in prisons". The Research Implications section goes on to outline the way this review adds to the previous review in terms of the volume and location of research included.

Reviewer: 2

Reviewer Name: Susan J. Loeb

Institution and Country: The Pennsylvania State University

USA

Please state any competing interests or state 'None declared': None declared

Please leave your comments for the authors below

*Thank you for the opportunity to review this well written and timely review on an oh so critically important topic in Corrections Health. The strengths are many: engaging an advisory group of prisoners to provide input in a variety of steps in the study from planning through dissemination; clear and informative decision tree; nicely justified the need for the review early and the contributions of the review in the discussion; and nice description of the analytic approach.

Response:

Thank you for taking the time to review our manuscript and providing this helpful feedback.

1. Please add more information on the Quallsyst tool for quality appraisal. (a table or figure would be best) as well as a sentence describing how widely it has been adopted for quality appraisals to justify its selection.

Response:

We have now added 2 tables (1 and 2) which illustrate the qualitative and quantitative components of the Quallsyst tool, as well as an explanation of how it is used in the Quality Appraisal section (beginning "The qualitative and quantitative components of the Quallsyst tool can be found in tables 1 and 2. Papers are scored 2,1 or 0 for each question dependent on...", line 146).

Our justification for the use of the Quallsyst tool was its suitability for appraising papers reporting a variety of methods, which we had expected to find based on our initial scoping. Its adoption is largely in systematic reviews where this has also been the case. We have now added the following sentence to the Quality Appraisal section to clarify this: "The validated tool has been primarily adopted in systematic reviews where studies employing a wide range of methods are to be included." (line 174).

2. Similarly, please describe how Kotronoulas and colleagues are the experts to stand on the shoulders of for justifying the use aggregate SQS scores.

Response:

The original citation was not intended to justify the use of aggregate quality scores, and we have now rephrased it to clarify this (line 184-189). Our citation of Kotronoulas and colleagues was intended to credit the authors with the approach to reporting findings using Quallsyst which involved the presentation of the range and median of summary quality scores for individual findings, as we have done so in a similar manner and were encouraged to do so by reading their paper.

As we were performing a narrative synthesis, it was felt that providing median and range for summary quality scores within the text for individual findings would allow the reader to appraise the quality of the findings more effectively. However, if the reviewer or editorial team feel strongly that they should be removed then we will do so.

3. The Matrices (i.e., Tables of Evidence) would benefit greatly from the addition of a column of strengths & limitations of each study and would add greater transparency/insight into the quality scores that were arrived at.

Response:

This column has now been added*. We have also added 2 lines to the Quality of Included Studies section under Results, which begins "Partial or limited information on..." (line 247), which outline the key reasons why points were deducted using the qualitative tool. It was not possible to generalise in this way about the quantitative tool due to the variety and limited number of papers scored using it.

4. In addition, the Key Findings Column would be a far easier read if a bulleted approach rather than a lengthy narrative approach were employed.

Response:

The key findings have now been displayed in a tiered, bulleted approach*.

5. Could collapse Country Column with Citation Column to save some valuable real estate and similarly, combine the Quality Rating Column with the newly suggested column of Strengths & Limitations at the far-right side of each Table/Matrix.

Response:

These changes have been made as outlined*.

6. I question the relevance/inclusion of the Rothman et al., 2018 article in the review.

Response:

The Rothman et al. (2018) article was included in the review due to its focus on the epidemiological differences between incarcerated and non-incarcerated decedents. The inclusion of this study was discussed at full-text review, and it was considered that it met our inclusion criteria due to its being concerned with prisoners with end of life care needs. While it does not provide any information on

care delivery within the prison walls, it does provide context on current practice in the delivery of palliative and end of life care in prisons by describing the different health needs of prisoners and the ageing of the prison population in comparison with those in the general community.

7. It was nice that the authors included a sample search strategy for CINAHL, but a) am not sure why it was selected and b) wonder why a more general statement of all terms explored overall was not included.

Response:

We are unsure if point (a) refers to the selection of CINAHL as a database for this review, or simply the selection of the CINAHL example to illustrate our search strategy. Therefore we will try to address both points.

CINAHL was one of the databases used during the initial piloting of search strategies, which indicated that its inclusion would yield relevant results. The decision to pilot strategies on CINAHL was based on its inclusion in the previous systematic review. The selected databases were also discussed with the research librarian who provided advice on the strategies, and its inclusion was agreed to be worthwhile.

The CINAHL search strategy was selected as an example strategy, as we believe it provides a clear illustration to the reader of the way subject headings and keywords were combined, and that the use of MeSH terms would be beneficial to the readership of a medical journal.

In response to point (b), we have now added an exhaustive list of search terms which were employed in the Methods section under Literature Search (line 142-150).

[*these changes are highlighted in the revised manuscript, as opposed to being recorded using tracked changes. This was done to more clearly indicate where changes had been made within the tables.]

VERSION 2 – REVIEW

REVIEWER	Pasithorn Suwanabol University of Michigan, USA
REVIEW RETURNED	19-Nov-2019

GENERAL COMMENTS	Thank you for the opportunity to review a revision of this important manuscript. The authors have submitted a thoughtful and comprehensive revision of their important work. The provision of palliative care across incarcerated individuals is understudied and this narrative synthesis will inform future work designed to improve this care. I have no additional comments for this manuscript.
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REVIEWER	Susan J. Loeb Penn State University, USA
REVIEW RETURNED	28-Nov-2019

GENERAL COMMENTS	Thank you for your responsiveness to my critiques and those of the other reviewer. I believe that these modifications have enhanced the strength of an already strong manuscript.
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