

Peer Review File

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Reviewer A

This is a thoughtful review of a very important topic but warrants major revisions before consideration of acceptance. In general, while the themes of the review are comprehensive, many of the assertions are not supported with references and could be enhanced by additional citations. Additionally, there is very superficial mention of proposed solutions, and increased discussion of how to overcome these disparities, with references to established literature of evidence-based interventions is needed. When evidenced-based interventions are not available, authors should provide specific suggestions of areas of further investigation. Further, there are many typographical, punctuation, and syntax errors that need correction. A few specific areas for suggested improvement are listed below.

1. Additional citations are needed to support the claims in multiple sections of the manuscript. Please add citations for lines 70, 83-84, 97, 127-128, 145-146, 146-147, 251.

Please see citations [9], [11], [16], [32-34], [60], [61-62] [104-105]

2. Please review for punctuation, spelling, syntax, or spacing errors on lines 52 (added period), 81 (added period), 89 (removed comma), 119 (changed were to was), 141 (removed period), 185 (added period), 207 (changed to “However, disparities exist in providing palliative care services to minority patients including, access to palliative care utilization”, 211 (This disparity was observed in all hospital subtypes, even with hospitals **treating** many minority patients), 254 (removed and), 263 (changed to in), 280 (removed health care), 291 (text changed), 298 (changed to increased).

3. Lines 121-125 seem to represent the opinion of the authors and should be stated as such or modified to cite a widely accepted notion that health is a human right.

Added citations from the World Health Organization and the American Medical Association regarding healthcare is a human right : <https://www.who.int/news-room/fact-sheets/detail/human-rights-and-health>

[H-65.960 Health, In All Its Dimensions, Is a Basic Right | AMA \(ama-assn.org\)](https://www.ama-assn.org)

4. Access to care section: Additional studies are needed in this section to effectively address disparities in access to care. Are there prospective studies that have demonstrated how to improve access to palliative care consultation and hospice services? Are there other issues, beyond availability of palliative care and hospice services that drive access to high-quality end of life care? For example, could travel burden be a factor in limiting access to available palliative care? That is, it's not just whether services are available but also whether patients

can get in to receive those services. More content is needed to fully address this aspect of disparities in end-of-life care. **Added additional studies: Historically minority patients have been subject to lower socio-economic status and are significantly disadvantaged which in turn affects their ability to pay, find transportation for their appointments, and navigate the healthcare system [29]. regarding access to healthcare services. Interventions aimed at improving access to healthcare by delivering in-home services for ethnic minorities meeting eligibility requirements for hospice care have had mixed results [30, 31]. Both studies showed that multiple home visits by healthcare provider may have some effect on number of completed end-of-life paperwork, it is unclear whether they have any effect on actual practices at the end-of-life.**

5. Mistrust section—this seems to provide a very superficial review of mistrust and potential interventions.

a. could the authors cite some examples of interventions to lessen mistrust? Might look at studies of patient-provider racial concordance and the impact on mutual trust, as well as consider community partnerships which help build trust between health systems and racial minority populations. **Added RCTs for interventions: (see below)**

b. The last sentence of this section is light on proposing actual solutions. A clearer suggestion of interventions is needed. **(rephrased last sentence: See below**

In a randomized clinical trial examining the effect of racial concordance between providers and patients when disseminating information regarding prostate cancer In this randomized clinical trial, racial concordance was significantly associated with trust only among Black adults [54]. Another randomized clinical trial utilized community intervention in African American patients with HIV, which included one-on-one counseling sessions using basic Motivational Interviewing style to problem solve about adherence, as well as referrals to address unmet needs for social determinants of health (e.g., housing services, food assistance). Follow up surveys of patients reported improved adherence and reduced mistrust [55].

These clinical trials highlight the importance of increasing racial diversity in the healthcare workforce and utilizing interventions that are culturally tailored to minority patients which may help mitigate mistrust with regards to end of life care in minorities.

6. Lines 165-167: While some religions may have beliefs about the role of God in the time and place of death, this is not true of all religions. This sentence should be modified to more clearly reflect that or omitted altogether. **Changed to mainstream religions**

7. Lines 225-227: Seems out of scope for discussion of palliative care utilization. Authors could consider a separate section for disparities in end of life healthcare utilization including aggressive interventions such as hospitalization, intensive care, cardiopulmonary resuscitation, ventilator support, and “late” (within 14 days of death) chemotherapy. **These lines have been removed**

8. Lines 234-236: Bystander CPR rates do not seem germane to this discussion of end of life

care among patients with serious illness. I would instead focus the review, as authors have otherwise done, on issues related to the care of patients with serious illness over the course of their care trajectory. **This section has been removed**

9. Line 237: “eol” acronym has not been defined elsewhere and is not otherwise used in the manuscript. **(section on code status has been removed)**

10. Lines 251-256: The study referenced here references patients receiving home health and does not seem relevant to this topic of end-of-life care for patients with serious illness. I would suggest inclusion of additional studies related to disparities in symptom control among patients with serious illness or near the end of life.

Removed section on home health and added section to include other studies including disparities in symptom burden identification and treatment among patients with serious illness (references 110 and 114)

11. Line 259: I would suggest removing the editorial comment “equally concerning” in presenting this study’s findings. Opinions or interpretation of the findings should be clearly stated as such either later in the same section or in discussion/conclusions.

This is a valid comment. We have removed the language “equally concerning”

12. Authors use a blend of capitalized and uncapitalized terms for black and white, and additionally once use the term Caucasian. There are different perspectives on whether these terms should be capitalized and would defer to authors and editors regarding their preference—but would use the same approach for all mentions of these terms throughout this manuscript. **Changed all to capitalized**

13. Lines 287: To my knowledge, there is no clear link between advance care planning and improved end of life quality outcomes, and in fact many palliative care research and clinical organizations are de-emphasizing the role of advance care planning in improving end of life care. If authors feel that there is, in fact, a clear link, a citation should be provided. Otherwise, I would urge a decreased emphasis in this review on advance care planning and an increased emphasis on serious illness communication with an emphasis on elicitation of patient goals and values, provider communication regarding prognosis, and decision-making within the context of actual decisions facing the patient (rather than hypothetical future decisions as historically included in advance care planning). In general, the advance care planning section includes several unsubstantiated or uncited claims from the authors and requires additional references to research studies. **(Amber)**

I agree with this reviewer’s feedback. There is a move in the literature to deemphasize advanced care planning and move toward focusing on critical illness conversations. We have rewritten the section to explain the deemphasis and highlight the importance of engaging in goals of care conversations.

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7814859/>

<https://www.sciencedirect.com/science/article/abs/pii/S0885392420304243>

<https://jamanetwork.com/journals/jamainternalmedicine/fullarticle/225976>

14. Line 303: The authors' definition of "excellent fit" is not clear. Additional specificity needed to clarify what they hope to communicate here, and additional references are needed to substantiate their point. **Rephrased**

15. Hospice section: In addition to the points that have been clearly made in this section, additional consideration could be given to barriers to hospice care that relate to caregiver/support person burden. There may be disparate availability among racial minorities compared to whites to provide in-home hospice care for their loved ones. **Points added to new section on social determinants of health**

Social Determinants of Health

Race is considered a social construct, and the impact of social advantage on health is substantial. Social determinants of health, such as nutrition, transportation, social or caregiver support, and housing, can significantly impact the trajectory of patients' health. It is well established that these factors predict how long or well people live and also when and how they die, contributing to racial and ethnic disparities in end-of-life care [56]. Palliative care policy internationally prioritizes dying at home, and efforts are directed at increasing home deaths and reducing those that occur in acute care institutions [57]. However, priorities regarding end-of-life care may look different for those who are vulnerably housed and with limited resources for instance, Hubbell found that homeless people had several different concerns at the end of life, such as a fear of dying alone and concerns regarding burial and notification of family limiting access opportunities to palliative care [58]. Multiple studies have shown that being non-Hispanic black and having a lower income is associated with a significantly lower likelihood of enrolling in hospice [59]. Similarly, dying at home with hospice care requires significant caregiving, and the economic implications of increased responsibility for care are immense for those struggling to make ends meet. Many studies report that financial hardship for caregivers of patients with serious illnesses is most for minorities groups [60]. Improving access to quality end of life care care for those who are socioeconomically disadvantaged requires an interdisciplinary approach at all levels from individual providers to broader public health policies.

Reviewer B

I found this an interesting, well-developed, review focusing on racial disparities in end-of-life care provision in USA. The article is most helpful in the way it consolidates evidence around some key factors linked with racial inequity. But the main question I'm left with is the choice

of factors around which the review is organised. It's not clear to me if these emerged from the literature that was found from a search using key terms – the methodology of the review isn't included – or if a set of cultural determinants was adopted (and if so, whose?).

Socio-economic factors are mentioned, but in my opinion not adequately explored given their primary shaping of health status into a social gradient of health (for example Marmot, The Health Gap). Admittedly the findings of the article note that health literacy, access to care, and trust in healthcare systems all correlate strongly with socio-economic status. But in a nation where healthcare access is strongly tied, for many, to employment I'd have expected to see some more explicit attention to this factor.

Recommendations are for reform of health system policies and behaviours, led by end-of-life care providers. Fundamental to implementing such reforms is attention to the structural issues identified by, for example, the WHO Commission on the Social Determinants of Health. I suppose health disparities is a more polite term than health inequalities, and there may a strategic reason for avoiding the latter terminology, but the overall effect of 'disparities' is to in effect blame the health system for not resolving social dilemmas. It might be helpful, albeit difficult, to distinguish between disparities that can be tackled by healthcare providers and disparities that must be addressed through social and political action.

I'd like to see included some further information about the methodology of the review. And ideally I'd also like to see some further comment about what seems to me the marginalisation of key social determinants, principally socio-economic status.

Added section on methodology and socioeconomic status (see above)

Methods

In conjunction with all authors, PubMed Central, Medline, and PubMed databases were searched using Racial Disparity and End of Life/Palliative Care combinations. A total of 46 studies were identified. No time or age parameters were set. We selected all types of study literature published in English with full text. Articles were excluded where the free full text could not be retrieved. Duplicate publications and gray literature were also excluded. Relevant articles were also found by scanning the references of found articles (backward search) and locating newer articles that included the original cited paper (forward search). All articles were reviewed, and the available evidence was synthesized and interpreted by the 2 authors to identify key domains in end-of-life care impacted by racial disparities and the factors contributing to them.

Reviewer C

This is an excellent piece of work and clinically really important. As a consultant clin. psych in this field, I found it incredibly helpful in terms of considerations for clinical delivery changes and thought provoking- thank you!

Just some very minor queries:

-Can you clarify definitions of White to exclude white minority populations or does your research suggest otherwise?

As race and ethnicity often overlap,^[29] many ethnic minorities are also racial minorities. However, this is not always the case, and some people are ethnic minorities while also being classified as white, such as some Jews, Roma, and Sámi.

- I do wonder if contributory factors include role related expectations around time pressures/ number of patients seen and competing clinical priorities ... i.e. when we have patients who are different to us there is some extra work involved in discussion and delivery of information etc and if staff avoid this simply because of extra work and time pressure. I run numerous staff supervision groups and see aspects of this in what is chosen as a priority for care. We see this in the UK where staff do not want to have the discussion with patients who are suicidal for example - shockingly dangerous practices because of time involved and waiting lists etc in managing this. Just thinking of practical influences of clinical delivery from clinicians perspectives. Of course, it is more complicated than just that...just a thought for the discussion/ influential factors. Maybe helpful to add or refer that to contextual explanations

Added section in communication section

Increasing demands on healthcare providers within time constraints may also contribute to poor communication between providers and minority patients further promoting healthcare disparities[81]. Caring for socially disadvantaged patients is challenging as they often have complex medical problems and experience poor physical and mental healthcare outcomes [82]. The time-pressured visits often illicit unconscious physician bias and promote physician centered communication worsening healthcare disparities for minority patients [83] .

- I am also left wondering about how much of this applies to any minority and what this says about how staff are taught to manage working with any patient different to themselves with compassion and respect. This is an area which in most healthcare training usually focuses on practical differences rather than attitudinal exploration and reflection..and it is precisely these attitudes which impact on behaviour so an important gap...is there relevant literature on this it may help with your conclusion though you do acknowledge there are many other areas to consider. Added section on training in cultural competence

“In addition, research suggests training physicians in cultural competence may improve physician-patient communication and collaboration, increase patient satisfaction, and facilitate adherence, thereby improving clinical outcomes and reducing health disparities

- LINE 263 is missing letter...the known disparities IN pain and symptom management Added in

- Just for the sake of consistency, do use a standard White or white across the paper. Changed

Reviewer D

Although the topic of the review is important, I would have liked to have seen more depth in the review.

-Many of the references are older. The manuscript does not characterize variation over time in care provision, despite that care has changed rapidly in this area over the past 13 years.

Updated References to include more recent studies

-The writing was sometimes vague. An example: "One argues that health literacy, not race, is the independent predictor of end-of-life preferences,[12] while others propose that health literacy and race represent two separate but essential linked causal pathways that must be carefully assessed to improve how the healthcare system ascertains and protects minority individuals' advance care preferences [13]." It really wasn't clear what the authors were getting at. How does one carefully assess race, and what do they mean by separate pathways? There are many statements throughout that warrant more development. **Rephrased the mentioned statement**

-The take-home message of the manuscript needed to be clearer. Why would someone cite this manuscript as opposed to the primary sources? **Each section has been revised to offer a better synthesis of the information that is novel in the literature.**

Reviewer E

This manuscript provides an overview of the racial disparities in healthcare as it relates to palliative and end-of-life care. This manuscript provides a nice overview of the literature and contributes to summarizing an important area of the literature. However, this paper would be strengthened greatly by taking a more rigorous approach to the review of the literature such as a systematic review. It is unclear how and why authors chose to include certain articles in this review. Due to the approach taken, there are clear gaps in the overviews provided. See below for specific comments related to the manuscript.

1. It is unclear why, at the beginning of the introduction, the focus is on older adults but then shifts to end-of-life care more broadly. **Deleted**

2. The abstract refers only to "racial disparities" but the introduction discusses racial and ethnic disparities. It would be helpful to make consistent throughout. **Abstract changed**

3. Sentence on line 52 (p. 2) is missing a period at the end. **Added**

4. It is unclear how or why the themes discussed in this article (health literacy, access, etc.) emerged – more clarity around the process would be helpful. Valid point.

Addressed in Methods

4. In the "health literacy section," the authors make an important note about the limitation of patient education interventions to address this need but offer no suggested or proposed solutions. **Added data on other interventions**

5. Nuances of these categories would be helpful to discuss as it relates to variability across various racial and ethnic groups. For instance, most studies find that medical mistrust is high among African Americans, who are historically at risk. But among Latinos/Latinas/Hispanic patients, many patients report high levels of trust in their physician and/or paternalistic

orientations towards medicine. While some of the details are discussed around Black patients, the first sentence of this section makes it appear this applies broadly to multiple racial and ethnic minority groups. **Added citations for hispanic patients**

6. The section on “Cultural and Religious Values of Patients” (p. 4) provides a nice overview of research on Black patients but largely ignores other groups (e.g., Latinos/Hispanics) who are also influenced by cultural and religious beliefs as it relates to palliative and end-of-life care preferences. **Added information on hispanics and latinos:**

[71]. Similarly, religion and spirituality have a powerful influence on many Latinos. According to a recent Pew study of 4,016 Latinos, 92% consider themselves religious [72]. Many religious and spiritual considerations have similar implications across different cultures [73]. In a recent study of a diverse group of patients with advanced cancer, religiosity was associated with aggressive measures to prolong life, even after adjustment for race and ethnicity [74]. In focus groups, Latino surrogates indicated that suffering at the end of life was to be borne as part of a test of faith [75]

7. Sentence on line 229 (p. 5) seems to be missing some words (“...patients with advanced cancers among those who survived,” **Added period**

8. An overall comment is that some statements/review of the literature seem to lean towards less aggressive care being the preferred outcome rather than patients value- or goal-concordant care. It would be helpful to operationalize how quality end-of-life care is defined. **Added Definition:** High quality end-of-life care involves addressing a patient's psychosocial, spiritual and clinical needs and considering the needs of those close to them

9. Line 263 (p. 6) – Misspelling of “in” “The known disparities n pain...” **Corrected to in**

10. The conclusion (lin 331, p. 8) refers to this as a “systematic review” but this manuscript did not follow the approach or techniques of that type of literature review. **Changed to narrative**