# Social Work Competencies for Advancing Health Equity Research

Karen Bullock, PhD, LICSW, APHSW-C, FGSA



School of Social Work Global Public Health

#### DISCLOSURE STATEMENT

 There are no other financial relationships with any commercial interest.

### Learning Outcomes are to:

- Discuss how serious illness care often reproduces inequities and unless an equity-focused lens is used when designing, implementing, and evaluating treatment and/or interventions, such disparities abound.
- Identify numerous studies that have revealed the fact that U.S. healthcare systems consistently produce poorer quality serious illness outcomes for Black patients, compared with White patients.
- Effectively promote interventions that reduce disparities and increase equitable outcome. In spite of the fact that these are sparse and hindered by a limited understanding of the root causes of such disparities.

### Journal of pain and symptom management

**Author Manuscript** 

HHS Public Access

A Decade of Studying Drivers of Disparities in End-of-Life care for Black Americans: Using the NIMHD Framework for Health Disparities Research to Map the Path Ahead

Elizabeth Chuang, MD, MPH, Associate Professor, Sandra Yu, BA, [...], and Jessica Williams, PhD

- The sociocultural environment, physical/structural environment, behavioral and biological domains remain understudied areas of potential causal mechanisms for racial disparities in care.
- Studies focusing on individual factors should be better screened to ensure that they are of high quality and avoid stigmatizing Black communities.



#### Journal of Pain and Symptom Management

JPSM Park of Control o

Volume 64, Issue 5, November 2022, Pages e289-e299

Special Article

# A Review of Race and Ethnicity in Hospice and Palliative Medicine Research: Representation Matters

Ramona L. Rhodes MD, MPH, MSCS <sup>123</sup> Nadine J. Barrett PhD, MA, MS <sup>4</sup>,

Deborah B. Ejem PhD <sup>5</sup>, Danetta H. Sloan PhD, MSW, MA <sup>6</sup>, Karen Bullock PhD, LCSW <sup>7</sup>,

Kenisha Bethea MPH <sup>8</sup>, Raegan W. Durant MD, MPH <sup>9</sup>, Gloria T. Anderson PhD, LMSW <sup>7</sup>,

Marisette Hasan BSN, RN <sup>10</sup>, Gracyn Travitz BS <sup>11</sup>, Anastatia Thompson BS <sup>12</sup>,

Kimberly S. Johnson MD, MHS <sup>1314</sup>

- To evaluate the race and ethnic diversity of study participants and the reporting of race and ethnicity data in HPM research.
- 1253 studies screened, 218 were eligible and reviewed. There were 78 unique race and ethnic group labels. Over 85% of studies included ≥ one non-standard label based on Office of Management and Budget designations.
- One-quarter of studies lacked an explanation of how race and ethnicity data were collected, and 83% lacked a rationale. Over half did not include race and/or ethnicity in the analysis

### The Experience of Black Patients With Serious Illness in the United States: A Scoping Review

Rachael Heitner, MPH, Maggie Rogers, MPH, Brittany Chambers, MPH, MCHES, Rachel Pinotti Allison Silvers, MBA, Diane E. Meier, MD, FACP, FAAHPM, Brynn Bowman, MPA, and Kimberly S. Johnson, MD, MHS

#### Abstract

Context. Black patients experience health disparities in access and quality of care.

Objective. To identify and characterize the literature on the experiences of Black patients with serious illness across multiple domains – physical, spiritual, emotional, cultural, and healthcare utilization.

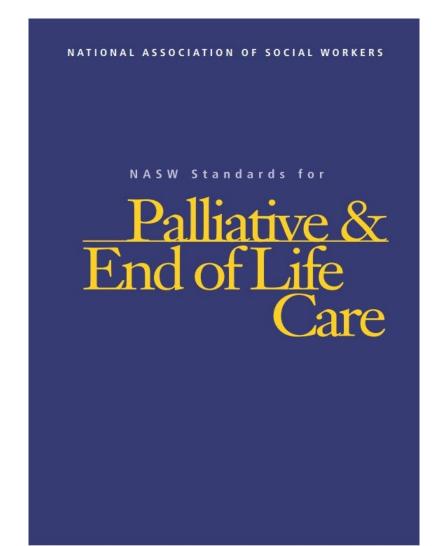
Methods. We conducted a scoping review of US literature from the last ten years using the PRISMA-ScR framework. PubMed was used to conduct a comprehensive search, followed by recursive citation searches in Scopus. Two reviewers screened the resulting citations to determine eligibility for inclusion and extracted data, including study methods and sample populations. The included articles were categorized by topic and then further organized using the Social-Ecological Model.

Results. From an initial review of 433 articles, a final sample of 160 were included in the scoping review. The majority of articles used quantitative research methods and were published in the last four years. Articles were categorized into 20 topics, ranging from Access to Hospice and Utilization (42 articles) to Community Outreach and Services (three articles). Three-quarters (76.3%) of the included studies provided evidence that racial disparities exist in serious illness care, while less than one-quarter examined causes of disparities. The most common Model levels were the Health Care System (102 articles) and Individual (71 articles) levels.

Conclusion. More articles focused on establishing evidence of disparities between Black and White patients than on understanding their root causes. Further investigation is warranted to understand how factors at the patient, provider, health system, and society levels interact to remediate disparities. J Pain Symptom Manage 2023;66:e501-e511. © 2023 The Authors. Published

## Interdisciplinary Research and Engagement

- Social workers play an important role as clinicians in the delivery of equitable serious illness care and we can do so in research.
- Awareness, Skills and Knowledge to advance health equity, is rooted in our NASW Code of Ethics, which promotes "diversity, equity, inclusion" and "anti-racist" practices....
- Prepared to advance health equity in interdisciplinary serious illness care research and engagement.



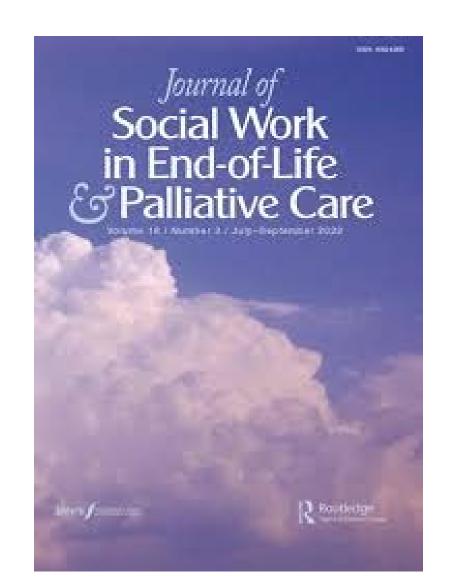
## Social Work Hospice & Palliative Care Network

 Our national network of psychosocial care professionals is actively dedicated to providing the best and latest information, professional resources, policy updates, new and emerging education and research best practices in hospice and palliative care.



#### Journal of Social Work in End-of-Life & Palliative Care

- *Publishes* original **research** and conceptual articles exploring issues crucial to individuals with serious, life-threatening, and life-limiting illness and their families across the lifespan.
- The focus includes, but is not limited to, the following areas: inter-professional practice and research; practice and policy innovations; practice evaluation; end-of-life communication and decision making; pain management and palliative care; grief and bereavement.



## Advanced Palliative and Hospice Social Worker Certification (APHSW-C)

- The first evidence-based certification for social workers in hospice and palliative care.
- The APHSW-Certification recognizes undergraduate and graduate level social workers with experience, specialized skills, and competency in hospice and palliative social work.



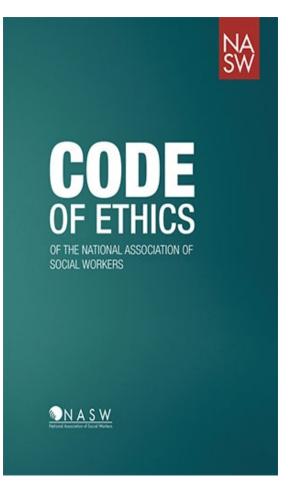


## Competencies: Awareness, Skills and Knowledge to provide safe, high-quality, advanced level care.

- Having earned a Bachelor's or Master's degree in Social Work.
- Completing a minimum of postdegree experience in hospice and/or palliative social work determined by the degree earned.
- Attesting to practice in accordance to the National Association of Social Workers (NASW) Code of Ethics.





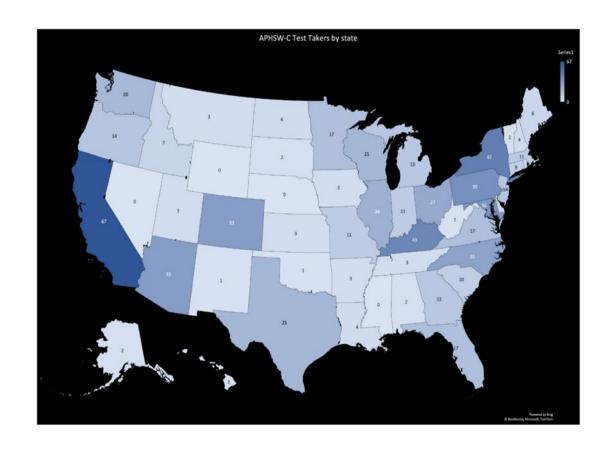


<sup>\*</sup>Recertification is required every 4 years, which includes an application and 40CE credits. You do not take the exam again for recertification.



## Competencies: Awareness, Skills and Knowledge to provide safe, high-quality, advanced level care.

- Holding state licensure in good standing to practice, if required for employment.
- Successfully passing a certification exam denoting advance practice competency.
- Committing to ongoing professional development.





#### Social Work Practice Standards

- 1. Ethics and Values
- 2. Knowledge
- 3. Assessment
- 4. Intervention/Treatment Planning
- 5. Attitude/Awareness
- 6. Empowerment and Advocacy

- 7. Documentation
- 8. Interdisciplinary Teamwork
- 9. Cultural Competence
- 10. Continuing Education
- 11. Supervision, Leadership, and Training



## Social Work Practice Standards

#### 1.05 Cultural Competence

- (a) Social workers should demonstrate understanding of culture and its function in human behavior and society, recognizing the strengths that exist in all cultures.
- (b) Social workers should demonstrate knowledge that guides practice with clients of various cultures and be able to demonstrate skills in the provision of culturally informed services that empower marginalized individuals and groups. Social workers must take action against oppression, racism, discrimination, and inequities, and acknowledge personal privilege.
- (c) Social workers should demonstrate awareness and cultural humility by engaging in critical self-reflection (understanding their own bias and engaging in self-correction); recognizing clients as experts of their own culture; committing to life-long learning; and holding institutions accountable for advancing cultural humility.
- (d) Social workers should obtain education about and demonstrate understanding of the nature of social diversity and oppression with respect to race, ethnicity, national origin, color, sex, sexual orientation, gender identity or expression, age, marital status, political belief, religion, immigration status, and mental or physical ability.

## Social Work, Health Equity, Patient, Family and Community Engagement

- Social work has roots in structural change efforts and patient advocacy.
- Social workers are trained and educated to foster relationship between individuals and broader systems of care; and communities at large.
- Moreover, social workers recognize "racism" as a social determinant of health and aim to eliminate structural and systemic barriers to equitable serious illness care.

**>** J Pain Symptom Manage. 2023 Jan;65(1):1-5. doi: 10.1016/j.jpainsymman.2022.09.009. Epub 2022 Oct 2.

#### Racism in Palliative Care Research: We Still have a Ways to Go

Stacy Fischer <sup>1</sup>, Mary Isaacson <sup>2</sup>, Rashmi K Sharma <sup>3</sup>, Kimberly S Johnson <sup>4</sup>
Affiliations + expand
PMID: 36198336 DOI: 10.1016/j.jpainsymman.2022.09.009

**>** JAMA Netw Open. 2023 Jul 3;6(7):e2321746. doi: 10.1001/jamanetworkopen.2023.21746.

#### Perspectives About Racism and Patient-Clinician Communication Among Black Adults With Serious Illness

Crystal E Brown <sup>1</sup> <sup>2</sup> <sup>3</sup>, Arisa R Marshall <sup>2</sup>, Cyndy R Snyder <sup>4</sup>, Kristine L Cueva <sup>5</sup>, Christina C Pytel <sup>6</sup>, Sandra Y Jackson <sup>7</sup>, Sherita H Golden <sup>8</sup>, Georgina D Campelia <sup>3</sup>, David J Horne <sup>2</sup>, Kemi M Doll <sup>9</sup>, J Randall Curtis <sup>1</sup> <sup>2</sup>, Bessie A Young <sup>10</sup> <sup>11</sup>

## Advancing Health Equity in Serious Illness Care

- Health inequity is focused on addressing observable disparities in health between groups that are avoidable, unfair and unjust [7].
- Unequal access to and utilization of palliative care/symptom relief is one
  of the greatest disparities in serious illness care [8].
- Equity is about improved access to existing care and/or modifying existing care to meet the needs of diverse patient populations, especially those that have been historically and legally denied access to care in U.S. healthcare systems.
- Addressing structural and systemic barriers to equitable palliative care is an ethical responsibility of health systems [9] and care providers.

## Social Workers Center Social Justice and Lead the Charge of Dismantling Structural and Systemic Racism

**>** J Pain Symptom Manage. 2022 May;63(5):e455-e459. doi: 10.1016/j.jpainsymman.2022.01.015. Epub 2022 Feb 11.

## Race Roundtable Series: Structural Racism in Palliative Care

Karen Bullock <sup>1</sup>, Tamryn F Gray <sup>2</sup>, Rodney Tucker <sup>3</sup>, Tammie E Quest <sup>4</sup>

"What is most exciting about REACH Equity is its goal to move from describing racial and ethnic disparities in health to developing actionable ways for health care providers and health systems to improve patient care and reduce these disparities."

- Dr. Kimberly S. Johnson, Director of REACH Equity

Unmet Needs in Health Disparities Research-It's Not Just About Patients

Nadine J Barrett <sup>1</sup>, Karen Bullock <sup>2</sup>, Kimberly S Johnson <sup>3</sup> <sup>4</sup>
Affiliations + expand

PMID: 35816348 DOI: 10.1001/jamainternmed.2022.2877

## Drivers of racial/ethnic differences in perceived end of-life care quality: More questions than answers

Karen Bullock <sup>1</sup>, Lena K Makaroun <sup>2</sup> <sup>3</sup>

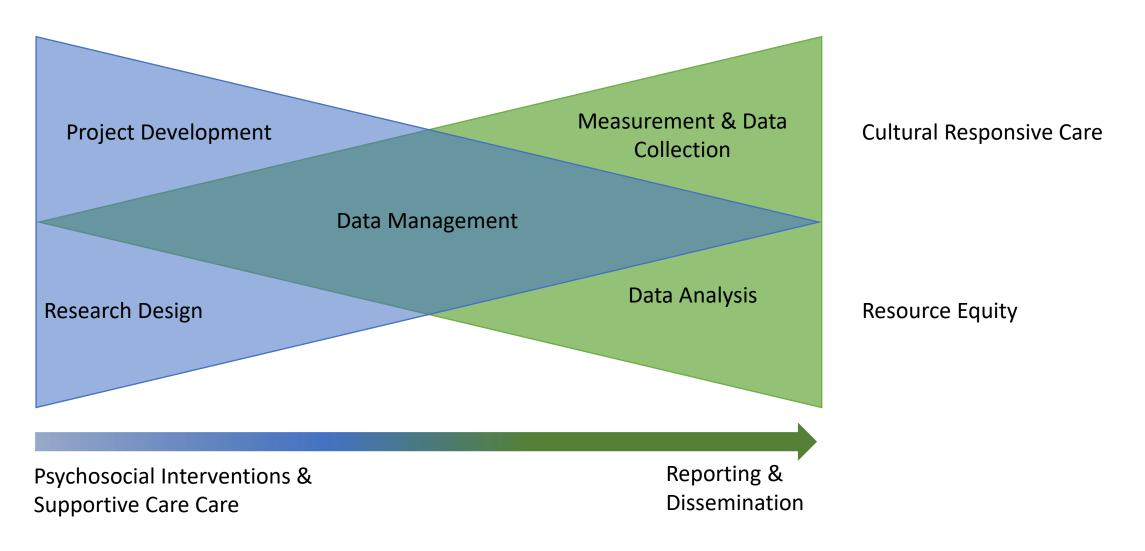
Affiliations + expand

PMID: 35226353 PMCID: PMC10152395 DOI: 10.1111/jgs.17663

## Engage Social Workers at All Stages of Research



## Social Workers in Interdisciplinary Research Stages



## Social Workers skills and competencies...

- Identifying equity-focused measurements and data collection, with an understanding of community context and environment.
- Maintaining focus on equity when selecting measures and collecting data in ways that maintain dignity of the population under study. Selected measures may need to revised and evaluated through a culturally responsive lens.
- Examining data with a cultural lens before implementation; directly and explicitly examining selected measures for implicit or explicit bias.

### Social Workers skills and competencies...

- Integrating community feedback throughout the design and data collection process.
- Creating data biographies that carefully tracks metadata to uncover bias and disparities. Limit the scope of the data to what is essential and minimize the collection of personally identifiable data.
- Take the lead on integrating qualitative/ narrative data to contextualize quantitative data.

## Advancing Equity Beyond the Research Design

- Engage the community of interest to reflect input, experiences, and perspectives; stakeholder/community representative (i.e., clergy, faith leaders).
- Ensure participants feel valued and respected.
- Clearly define terms and explicitly state the underlying assumptions.
   Acknowledging the potential burden of participation in certain types of equity-focused research.
- Recruit and retain groups historically underserved, marginalized and deemed to be "hard to reach."

## Research to Advance Health Equity

 Disparities in serious illness care persist for many historically marginalized communities.

 Research addressing disparities experienced by the following demographic groups and populations is essential.

- » Black or African Americans
- » Hispanic/Latina/o/x
- » Asian, Native Hawaiian and Other Pacific Islanders
- » American Indians/Native Americans/ Indigenous
- » LGBTQIA+

### Take Away Points:



Journal of Pain and Symptom Management

Volume 63, Issue 6, June 2022, Page 1140



Association and Causation Without Adequate Representation: An Evaluation of the Reporting of Race and Ethnicity of Study Participants in Hospice and Palliative Medicine Research (GP751)

Ramona Rhodes MD, Deborah Ejem PhD, Nadine Barrett PhD MS MA, A'mie Preston PsyD,
Cardinale Smith MD PhD, Karen Bullock PhD LCSW, Kenisha Bethea MPH,
Marisette Hasan BSN RN, Kimberly Johnson MD MHS

- Increase knowledge of the variability in racial, ethnic and cultural differences in patient recruitment and participation in hospice and palliative medicine research.
- Social workers are an underutilized resource and may have the capacity to increase diversity, equity, and inclusion in interdisciplinary palliative care research.

 Additional research is need to document the characteristics of Social Workers on research teams, their specific roles and the degree to which they function as educators, interventionists, research assistants and/or project leads (PI/Co-PI) in serious illness research.

• The contributions of Social Workers as members of research teams addressing health inequities are critical to promoting social justice, equity and the engagement of culturally diverse individuals and families.

## Thank you!



#### References

National Hospice & Palliative Care (December 2022). *NHPCO Facts and Figures 2022 Edition*. <a href="https://www.nhpco.org/wp-content/uploads/NHPCO-Facts-Figures-2022.pdf">https://www.nhpco.org/wp-content/uploads/NHPCO-Facts-Figures-2022.pdf</a>

Sanders, J., Curtis, J.R., & Tulsky, J.A. (2018). Achieving goal-concordant care: A conceptual model and approach to measuring serious illness communication and its impact. *Journal of Palliative Medicine*, 21:S2, S-17-S-27.

Daodu, O., Joharifard, S., Saint-Vil, D., Puligandla, P. S., Brindle, M. E., & <u>Canadian Association of Pediatric Surgeons</u> (2023). How can Pediatric Surgeons Address Racism and Become Actively Anti-Racist?. *Journal of Pediatric Surgery*.

American Cancer Society (2022). Cancer facts & figures for African Americans. <a href="https://www.cancer.org/research/cancer-facts-statistics/cancer-facts-figures-for-african-americans.html">https://www.cancer.org/research/cancer-facts-statistics/cancer-facts-figures-for-african-americans.html</a>

Bullock, K. (2012). The influence of culture on end-of-life decision making. In Morrissey, M.B., & Jennings, B. (Eds.), *Partners in palliative care: Enhancing ethics at end of life* (pp. 82-97). New York: Routledge.

Cadet, T., Burke, S. L., Naseh, M., Grudzien, A., Kozak, R. S., Romeo, J., Bullock, K., & Davis, C. (2021). Examining the Family Support Role of Older Hispanics, African Americans, and Non-Hispanic Whites and Their Breast Cancer Screening Behaviors. *Social work in Public Health*, 36(1), 38–53. https://doi.org/10.1080/19371918.2020.1852993

#### References

Laurencin CT, Walker JM. A Pandemic on a Pandemic: Racism and COVID-19 in Blacks. Cell Systems, 2020: 11, 9-10.

Hauer, K. E., Park, Y. S., Bullock, J. L., & Tekian, A. (2023). "My Assessments Are Biased!" Measurement and Sociocultural Approaches to Achieve Fairness in Assessment in Medical Education. *Academic Medicine: Journal of the Association of American Medical Colleges*.

Bullock, K., & Allison, H. (2015). Access to medical treatment for African American populations: The current evidence base. In Christ, G., C. Messner & Behar, L. (Eds.), Handbook of oncology social work (pp. 293-298). New York, NY: Oxford University Press.

Morrison, R. S., Meier, D. E., & Arnold, R. M. (2021). What's Wrong With Advance Care Planning?. JAMA, 326(16), 1575–1576. <a href="https://doi.org/10.1001/jama.2021.16430">https://doi.org/10.1001/jama.2021.16430</a>

Nedjat-Haiem, F. R., Cadet, T. J., Parada, H., Jr, Mishra, S. I., & Bullock, K. (2022). A National Survey of Social Workers Focusing on Attitudes, Knowledge, and Practice Behaviors for Educating Patients About Advance Directives: Implication During COVID19. *American Journal of Hospice & Palliative Care, 39*(6), 737–744. https://doi.org/10.1177/10499091211038503

Nwando Olayiwola, J. et al., Making Anti-Racism A Core Value in Academic Medicine, Health Affairs: Blog (Mar. 25, 2021), https://www.healthaffairs.org/do/10.1377/hblog20200820.931674/full/.

#### Resources

Cain, C., Surbone, A., Elk, R. & Kagawa-Singer, M. (2018). Culture and palliative care: Preferences, communication, meaning, and mutual decision making. Journal of Pain and Symptom Management. 55:5.

Center to Advance Palliative Care. https://www.capc.org/

Faulkner, A. (1998). ABC of Palliative Care: Communication with patients, families, and other professionals. British Medical Journal. 316:130.

Ferrell, B., Twaddle, M., Melnick, A., Meier, D. (2018). National consensus project clinical practice guidelines for quality palliative guidelines, 4th edition. Journal of Palliative Medicine. 21:12.

Hawley, P,H. (2014). The Bow Tie Model of 21st Century Palliative Care. Journal of Pain and Symptom Management. Retrieved from <a href="http://dx.doi.org/10.1016/j.jpainsymman.2013.10.009">http://dx.doi.org/10.1016/j.jpainsymman.2013.10.009</a>

Huddleston, P. (2004). Culture and quality: An anthropological perspective. International Journal for Quality in Health Care. 16:345-46. Retrieved from: https://academic.oup.com/intqhc/article/16/5/345/1822533

Hudson, P., Aranda, S., & Kristjanson, L. (2004). Meeting the supportive needs of family caregivers in palliative care: Challenges for health professionals. Journal of Palliative Medicine. 7(1).

#### References

Elbaum A, Black Lives in a Pandemic: Implications of Systemic Injustices for End-of-Life Care. *Hasting Center Report.* 2020; 50: 58-60.

Rikard, R. V., Hall, J. K., & Bullock, K. (2015). Health literacy and cultural competence: A model for addressing diversity and unequal access to trauma-related health care. *Traumatology*, 21(3), 227.

Paradies Y, Ben J, Denson N, et al. (2015). Racism as a Determinant of Health: A Systematic Review and Meta-Analysis. *PLoS One,10*(9):e0138511-e0138511.

Boucher, N. A., & Johnson, K. S. (2021). Cultivating Cultural Competence: How Are Hospice Staff Being Educated to Engage Racially and Ethnically Diverse Patients?. *The American journal of hospice & palliative care*, 38(2), 169–174. <a href="https://doi.org/10.1177/1049909120946729">https://doi.org/10.1177/1049909120946729</a>

Rhodes, R. L., Barrett, N. J., Ejem, D. B., Sloan, D. H., Bullock, K., Bethea, K., Durant, R. W., Anderson, G. T., Hasan, M., Travitz, G., Thompson, A., & Johnson, K. S. (2022). A Review of Race and Ethnicity in Hospice and Palliative Medicine Research: Representation Matters. *Journal of Pain and Symptom Management*, *64*(5), e289–e299. <a href="https://doi.org/10.1016/j.jpainsymman.2022.07.009">https://doi.org/10.1016/j.jpainsymman.2022.07.009</a>

Bullock, K., Gray, T. F., Tucker, R., & Quest, T. E. (2022). Race Roundtable Series: Structural Racism in Palliative Care. *Journal of Pain and Symptom Management*, S0885-3924(22)00038-0. <a href="https://doi.org/10.1016/j.jpainsymman.2022.01.015">https://doi.org/10.1016/j.jpainsymman.2022.01.015</a>