Fighting racism in research

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Much has been written about gender, racial and other inequalities, biases, and discrimination, in research in general, especially in psychological research (Roberts et al., 2020; Dupree and Boykin, 2021; Gruber et al., 2021). Recent events such as the murder of George Floyd in the United States and racism toward people of Asian descent, including blaming them for the COVID-19 pandemic, have led to calls for anti-racist action in the scientific community (Wagner et al., 2020; Galán et al., 2021). Most of these calls for action were related to equal rights and anti-discrimination acts. Such issues have also become the focus of studies in palliative care, where research on inequality has led to recommendations for policy makers on improving equality in palliative care (Matsuyama et al., 2011; Brown et al., 2016; Artiga et al., 2020). This includes several recent papers published in our journal Palliative and Supportive Care (Shen et al., 2020; Teresi et al., 2020).

This editorial was inspired by the reaction to a paper that recently appeared in Palliative and Supportive Care on the utility of an algorithm/nomogram developed to identify cancer pain patients at risk for opioid misuse (Yennurajalingam et al., 2021; also see the Letters to the Editor in this issue). Central to the concerns raised is the use of race as a risk factor in this algorithm. What ensued was a discussion of the necessity to closely examine the potential unintended negative consequences of including race as a risk factor, and the necessity to fully discuss the context and the interpretation of results from such a study on risk factors (which include race) that influence the prediction of non-medical opioid use in patients diagnosed with cancer. This study offers an opportunity to discuss issues of vast importance that may have been neglected to date, including data interpretation and racism in medical research. We use the word "opportunity" because an open debate is an important scientific and academic principle that may help promote anti-racist actions.

Responsibilities of Journal Editors, Reviewers, Researchers and Readers to be Anti-Racist

We, the editors of Palliative and Supportive Care, believe that there is a need to act. Action means being “anti-racist” and not simply “not racist.” Without such action and actively debated conclusions, ideas, and data interpretation, research may inadvertently be used for racist purposes. While these ideas may be clear in some areas, such as equal rights for palliative care, they can be more elusive in other areas, such as data interpretation.

We must identify core values that practitioners, researchers, journal editors, reviewers, and readers share. Values such as “first, do no harm” (“primum non nocere”), commitment to the well-being of the patient, and commitment to ethically conducted research are widely accepted in our field. Many research and clinical guidelines can be viewed as derivatives of these principles. For example, the reliance on assessment tools that are not appropriate for a particular population of study, or question of interest, has the potential to undermine an otherwise sound methodology and data analysis approach. Additionally, different data analysis methodologies may lead to different results and conclusions and a debate concerning the right way to analyze the data. Moreover, we are seeing increasingly complicated data analysis approaches that rely on big data and artificial intelligence, and the use of computerized algorithms to help us to identify risk factors and support clinical decision-making. However, such approaches also lead to questions, such as: Should we blindly follow the conclusion of such methods? Should we blindly follow the results of any research? Our call for action is a call for skepticism and critical thinking. Research results and algorithms may give us guidelines, but we must actively apply critical thinking, and confront dilemmas such as: Should we exclude any data or results from publication if we feel uncomfortable about it? Should we conceal results that we suspect might have negative consequences for minority or vulnerable patients? We pose
these questions because debate and conversation are the essence of good clinical research practice.

Researchers should actively seek open discussion and debate of their results. There are valid arguments supporting the idea that “making sense” of quantitative data is not “objective” but has to do with interpretation just as with any other process of interpretation (Kritzer, 1996; Coryn, 2007; Lakew, 2017). It is common to include associations between socio-demographic variables such as gender, race, education, marital status and outcome variables in research analyses. However, the socio-demographic factors that traditionally have been used as a basis for discrimination, may be dangerous because differences in outcome variables may be a direct result of discrimination, and in turn may perpetuate a vicious cycle of racism. For example, if Black people are discriminated against on the basis of race and receive less education than White people, then a researcher can identify gaps in general knowledge and describe it as a race-based outcome without contextualizing the result with discrimination/racism as the potential cause of that finding in the first place. Thus, what should we do if our findings show that being Black is a risk factor for use of non-medical opioid use in patients diagnosed with cancer? Should we ignore this finding fearing that it is likely to promote race-based disparities in opioid use for pain? Or should we use these findings to improve care for Black people and other patients of color?

We believe that medical research journal editors, reviewers, researchers, clinicians, and journal readers must confront the issue of perpetuating racism in medical research. We must face it and discuss it. Such a discussion can follow these steps or actions: The first action should be taken by editors, reviewers, and researchers to identify such potentially racist methodologies and findings and explore the multilayered ecology of the data; debate this openly and honestly understanding that race is a social variable and should be identified as such. The second action is for our readers to be vigilant about racist content in published research and call it out. The third action is for researchers and editors to begin using the results of this debate to counter the potential that inclusion of race as risk factor may be more likely to promote race-based disparities in pain care. Our challenge is to find a way to use race as a variable in medical research that can potentially be the basis for the promotion of better medical care and greater awareness of implicit bias. More than that, further research into race and genetic factors may help to eventually disprove the idea that race is “just genetics.”

Conclusion

We, the editors of Palliative and Supportive Care, are committed to excellence in research, cautious data interpretation, and integrity in interpretation. We are committed to the good of our patients and society, while using honesty, transparency, and open communication. Racism counters all these core values. An anti-racist posture, open discussion, skepticism, and debate promote these values. We are committed to a heightened sensitivity of potential racism in the research submitted, reviewed, and ultimately published in Palliative and Supportive Care.

References


