Stroke

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Kenton Award Lecture—Stroke Disparities Research: Learning From the Past, Planning for the Future

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ABSTRACT: Inequities in stroke care and outcomes have been documented both within and among countries based on factors, such as race, geography, and socioeconomic status. Research can help us to identify, understand, and address inequities, and this article offers considerations for scientists working in this area. These include designing research aimed at identifying the underlying causes of inequities, recognizing the importance of the social determinants of health, considering interventions that go beyond the individual patient and provider to include policies and systems, acknowledging the role of structural racism, performing community-engaged participatory research, considering intersecting social identities, learning from cross-national comparisons, maintaining the data sources needed for inequities research, using terminology that advances health equity, and improving diversity across the research enterprise.

Key Words: geography ■ health equity ■ mortality ■ social determinants of health ■ social identification ■ stroke

Inequities in health, which may be defined as differences that are "avoidable, unnecessary, and unjust,"[1,2] have been widely documented both within and between countries, revealing tremendous variations in life expectancy, maternal and infant mortality, disease incidence, quality of care and health outcomes based on sociodemographic factors. Examples include the markedly lower life expectancy in the most deprived compared to the least deprived neighborhoods in England, lower quality health care and life expectancy in Black compared with other Americans for a range of diagnoses, and maternal mortality ratios that vary from 3 per 100 000 livebirths in Finland to 1360 per 100 000 livebirths in Sierra Leone.[3–6] Such inequities not only affect the health of individuals and communities but carry a financial cost to societies related to lower productivity, lost tax revenue, and the costs of health care and social supports.[7]

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In the context of stroke, substantial and persistent inequities in incidence, mortality, care, and outcomes have been documented based on race, socioeconomic status, geography, sex, gender, mental illness, and many other factors.[8–16] Improving equity in stroke care and outcomes is therefore a priority for the stroke community.[13,17,18] The annual Health Equity and Actionable Disparities in Stroke: Understanding and Problem Solving symposium is held in conjunction with the International Stroke Conference. This is a collaborative initiative of the American Heart Association and the National Institute of Neurological Disorders and Stroke, with the goal of reducing inequities in stroke, accelerating translation of research findings, and mentoring early-career researchers.[19,20] This article summarizes key points from the Edgar J. Kenton Lecture at the 2022 Health Equity and Actionable Disparities in Stroke: Understanding and Problem Solving Symposium and offers ten considerations for scientists performing research in this area (Table and Figure). Each area is reviewed only briefly despite being the subject of a great deal of scholarly work in its own right, and these considerations should be seen as merely a starting point for reflection and discussion among stroke health equities researchers.

The opinions expressed in this article are not necessarily those of the editors or of the American Heart Association.

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For Sources of Funding and Disclosures, see page 383.

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CONSIDERATIONS FOR SCIENTISTS PERFORMING RESEARCH IN STROKE INEQUITIES

Seek to Understand Why Inequities Exist

Much of the research to date on inequities in stroke has focused on determining whether variations exist in stroke incidence, care, and outcomes based on factors such as race, sex, and socioeconomic status. Such research is an essential first step in identifying differences meriting further study, and there is an ongoing need for descriptive studies that identify inequities and quantify them. However, in areas where inequities have already been documented, new research is needed to cast light on their underlying causes.[49] A population health equity framework can be used to ensure that the focus is not only on individuals and their behaviors and also on the policies, systems, and resource allocation that can create unfair advantages and contribute to health inequities.[21] For research on race and ethnicity, in particular, American Heart Association journals now stress the need for authors to provide a conceptual model that articulates the relationships between race, ethnicity, and the other variables being tested and that considers underlying structural and societal factors.[22] Examples of approaches to studying racial and ethnic disparities in stroke include analyzing data from existing cohorts of people from multiple racial and ethnic groups, using administrative databases that provide information not only on medical care but on exposures, such as socioeconomic status and area of residence, and methodologic strategies, such as mediation analysis.[23,50]

Consider Determinants of Health Beyond Health Care

The social determinants of health may be defined as "the conditions in which people are born, grow, live, work and age … shaped by the distribution of money, power and resources."[24] These include not only health and health care, but also factors such as neighborhood and the built environment, economic stability, education, and the social and community context. Do people have the resources they need to feed, clothe and house themselves? Do they have ready access to parks, schools, clean air, and water? Understandably, most stroke disparities research focuses on the health care system; for example, by identifying gaps and inequities in stroke care access and quality. However, many people are surprised to learn that variations in medical care account for only 10% to 20% of the variation in health outcomes for a population, with

Table. Considerations for Researchers Studying Inequities in Stroke

1. Seek to understand why inequities exist	Consider a population health equity framework[21]
	Use a conceptual model for studies of race and ethnicity[22]
	Methodologic approaches can include mediation analyses[23]
2. Consider determinants of health beyond health care	Other social determinants of health include economic stability, neighborhood and the built environment, education, and the social and community context[24,25]
3. Move from descriptions to solutions	May include community-centered, culturally tailored initiatives[26]
	Policy, systems, and environmental interventions are often needed[27]
	Collaborate with other sectors and support advocacy efforts[28]
4. Acknowledge the role of structural racism	Recognize that race is a social construct rather than a biological variable, and incorporate a consideration of structural racism into the design and interpretation of studies on racial health inequities[29,30]
5. Involve affected people and communities	Community-based participatory research involves collaborative partnerships between researchers and community members[31]
	Research with Indigenous communities requires recognition of Indigenous data sovereignty[32]
6. Consider intersectionality	Intersectionality theory provides a framework for understanding people's experiences based on their intersecting social identities[33]
	Research should be based on a conceptual framework, and a variety of quantitative methods may be used[23,34]
7. Learn from cross-national comparisons	Comparisons with other countries and health care systems can provide insight into the structural factors that influence health[35]
	Global disparities in stroke and health care must also be addressed[36]
8. Improve the availability of data	Invest in data sources that provide information on social determinants of health[37]
	Ensure that trials include representative participants[38]
9. Use appropriate terminology	Use language and narratives that advance health equity[39]
	Follow best practices regarding the reporting of race and ethnicity[40–42]
10. Diversify the research enterprise	Adopt strategies to improve the hiring, retention and promotion of people who have been historically excluded from academia[43,44]
	Diversify grant and guideline panels and editorial boards[45–48]

 Stroke. 2023;54:379–385. DOI: 10.1161/STROKEAHA.122.039562

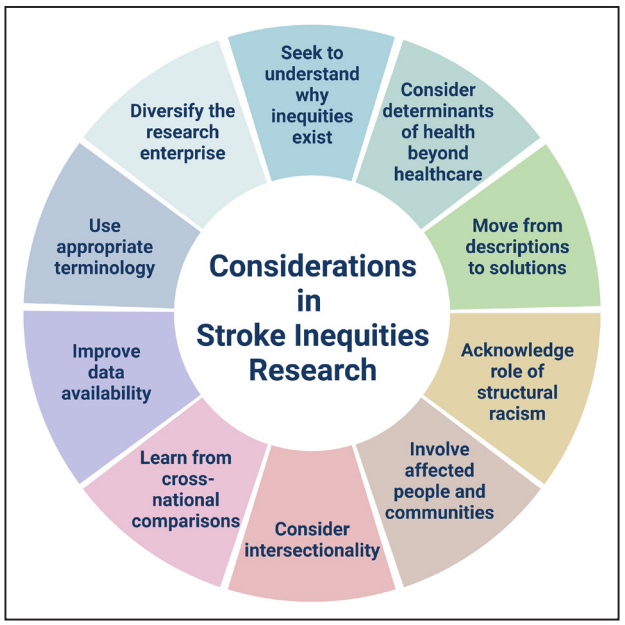

Figure. Considerations for researchers studying inequities in stroke.
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the remaining attributable to the other social determinants of health.[51] This is not to say that ongoing research on inequities in stroke care delivery is not necessary or important. Rather, it is a reminder that if the other social determinants of health are not also addressed through research and policy interventions, we won't make as much of a difference in improving health outcomes as we would like.[25]

Move From Descriptions to Solutions

Despite decades of research documenting inequities in stroke incidence, care, and outcomes based on sociodemographic factors, there has been relatively little study of potential solutions, and there are few examples of successful interventions. As health care researchers, our focus is often on interventions designed to improve stroke care at the level of the patient or provider, with promising examples including management, education, and behavioral change initiatives that are community-centered and culturally tailored to reach specific populations.[26,52] This work aligns with our clinical expertise, and it remains critical to addressing the quality and delivery of clinical health services. However, since the causes of disparities extend beyond the biomedical system, the solutions must as well, with population-level policy, systems, and environmental interventions that address the structural determinants of inequities likely to have the greatest impact on health.[21,27] As health care researchers we may not have the expertise to study or implement such interventions, but we can collaborate with social scientists, public health experts, and community groups to identify potential solutions, and it is encouraging to see interdisciplinary work being valued by granting agencies. We can change the types of research questions we ask to promote a health equity perspective: rather than asking how individuals can reduce their risk of health problems, we can ask, "What kind of public collective action is necessary to address health inequity across identifiable populations?"[39] We can support other sectors to address deficiencies in social services, living conditions, education, and resource allocation, and we can join advocacy efforts and lend our voices to social movements that are likely to effect policy change.[13,28,30,53,54]

Acknowledge the Role of Structural Racism

Racial and ethnic inequities in stroke incidence, risk factors, mortality, care, and outcomes have been documented in the United States and internationally, with, for example, Black Americans having the highest stroke mortality compared to any other group in the United States, Indigenous people having higher stroke incidence compared to non-Indigenous people in Canada, the United States, Australia, and New Zealand, and Black and South Asian people having a higher stroke incidence compared with White people in the United Kingdom.[8,30,55–59] Until recently, however, race was often incorrectly considered a biological variable rather than a social construct, with disparities attributed to genetic differences or individual behaviors rather than systemic and structural factors.[60,61] The increased prevalence of vascular risk factors, stroke incidence, and stroke mortality in Black communities is to a large degree the downstream effect of slavery and racist policies, laws, and judicial biases which in turn have led to inequitable distribution of resources, limited economic opportunities, poor access to health care, and neighborhoods with few resources and poorly funded schools.[30,62] The elevated risks of cardiovascular disease in Indigenous communities are likewise the legacy of colonization, oppression, residential schools, and anti-Indigenous racism.[63] It is not race itself but rather structural racism that is the underlying cause of racial health inequities,[29,30] and we must provide this context as we interpret the health inequities identified in our research and ensure that our questions and interventions are informed by a consideration of structural racism.[60,64–66]

Involve Affected People and Communities

It only makes sense that research on stroke inequities would benefit from the perspectives of people and communities with lived experience, particularly when aiming to identity the underlying mechanisms or develop interventions. Community-based participatory research involves collaborative partnerships between researchers and community members who ideally participate in all aspects of the research process from conception to implementation.[31] Research with Indigenous

communities requires recognition of Indigenous data sovereignty, or "the right of Indigenous peoples and nations to govern the collection, ownership, and application of their own data,"[32] often expressed as "Nothing about us without us." Guidelines exist that cover partnerships, research priorities, Indigenous ethical processes, involvement of Indigenous stakeholders and researchers, and methods to incorporate the context of colonization and social injustice.[66] It can be challenging for an individual researcher to create partnerships for community-based participatory research, but an increasing number of academic institutions and research organizations are facilitating this through the creation of patient panels and community advisory boards.

Consider Intersectionality

Studies of stroke inequities often focus on a specific sociodemographic factor of interest, such as race or sex. However, people's experiences and health will vary based on their intersecting social identities, which will include not only race and sex but also gender, age, nationality, socioeconomic status, immigration status, geography, and other factors.[33,67] For example, the health experience of a young professional female living in a high-income neighborhood will differ from that of an older female living in a rural area or an immigrant female employed as a shift worker, yet all may be categorized as women and analyzed as a homogeneous group. Rooted in Black feminist activism, intersectionality theory provides a framework for understanding "the unique experiences at the nexus of multiple social positions of power" with the goal of advancing social justice.[68,69] Intersectionality theory has been widely used in qualitative research and the social sciences but has only recently been applied to quantitative research studies, in part because it is challenging to quantify the complexities of intersectionality.[33] Intersectional studies should include a conceptual framework to identify the intersections of interest and how these reflect social power.[70] Ideally, such studies will avoid a narrow focus on certain measures of intersectionality (eg, race and sex alone), consider a range of explanatory mechanisms (eg, discrimination, adversity, health-promoting factors, such as personal resources, and contextual factors, such as neighborhood characteristics), and incorporate a life-course perspective that recognizes that the role of early life experiences.[23] Specific quantitative methods for studying intersectionality are beyond the scope of this article but can include regression with interaction terms or stratified analyses, structural equation modeling and mediation approaches, decomposition methods, decision tree methods, χ^2 automatic interaction detection analysis, and multilevel regression application for large numbers of intersections.[34,68,70]

Learn From Cross-National Comparisons

Stroke inequities research typically focuses on populations within a single country, region, or even institution. However, we can learn from cross-national comparisons and different health care systems, especially where different policy interventions have already been implemented. For example, a 2013 report from the National Research Council and Institute of Medicine documented a health disadvantage for the United States compared with other high-income countries and outlined the many potential explanations for this, especially differences in policies, resource investments, and infrastructure that support the health of the entire population.[35] And as we focus on the important disparities that exist within high-income countries, we cannot neglect the tremendous global disparities that exist in stroke and health care, and the burden of preventable morbidity and mortality from non-communicable diseases in low-income and middle-income countries.[24,36,71,72]

Improve the Availability of Data

Research on stroke inequities can only be performed with data sources that provide information on the variables under consideration. We have benefited from cohorts with information on race, ethnicity, and other social determinants of health, with examples including the REGARDS study (Reasons for Geographic and Racial Differences in Stroke), NOMAS (Northern Manhattan Study), BASIC (Brain Attack Surveillance in Corpus Christi), GCNKSS (Greater Cincinnati and Northern Kentucky Stroke Study), and the South London Stroke Register.[37,73–77] Administrative databases, electronic health records, surveys, and geographical data can also be valuable sources of population-level information on risk factors, medical care, vital statistics, socioeconomic status, and regional, neighborhood, and environmental variables, and can be particularly useful for stroke inequities research when linked with clinical registries or cohorts.[78–82] We need to ensure that trials recruit representative participants and communities so that we can know whether the results apply to all populations. Funders should establish policies that support diverse trial enrollment, researchers should enhance recruitment to ensure representation of understudied groups, and journals should require authors to provide information on the representativeness of their study participants.[38,83,84] Finally, since most of our research is based on data sources that were never intended to be used to study inequities, we need to advocate for new studies that are specifically designed for this purpose. The American Neurological Association's blueprint on organizational diversity recommends the collection of data on social determinants of health and other key variables at both the individual and neighborhood level, the incorporation

 Stroke. 2023;54:379–385. DOI: 10.1161/STROKEAHA.122.039562

of behavioral and social science methodologies to identify and address the underlying causes of inequities, and the use of cross-institutional studies to facilitate recruitment and improve generalizability.[85]

Use Appropriate Terminology

Language frames our thinking, and the use (or avoidance) of particular phrasing can influence the way research on stroke inequities is conceptualized, interpreted, and used. For example, use of adjectives such as "underprivileged" or "vulnerable" can imply that the condition is inherent to the group rather than due to underlying structural factors. The term "disparities," while frequently used to refer to differences linked to economic, social, or environmental disadvantage, may not accurately characterize differences that are unjust; "inequities" is preferable in many contexts. The American Medical Association and the Association of Medical Colleges Center for Health Justice have created a document that provides recommendations not only for specific terminology but also on how to articulate questions and narratives that advance health equity.[39] The Journal of the American Medical Association and The *BMJ* have published guidance on the reporting of race and ethnicity and on the classification of countries.[40–42] Of course, language evolves, norms change, context matters, and consensus is sometimes elusive. Those who are involved in research on stroke inequities will need to stay abreast of updated guidance in this area.

Diversify the Research Enterprise

Innovation and research productivity can be improved with the inclusion of diverse perspectives, and so improving representation among researchers is an important mechanism for producing high-quality stroke research.[86] However, many groups have been historically excluded from academia and still face barriers to recruitment, retention, promotion, compensation, publishing, and funding. For example, only 1% of US medical school faculty at the level of professor are Black women.[87] Specific strategies to diversify academic medicine can include the provision of anti-racist training to leaders and mentors, ensuring structural supports and resources for new faculty members from underrepresented groups, establishing nontraditional funding opportunities to counterbalance inequities in traditional funding, holding institutions accountable for adopting practices to address inequities, improving recruitment through formal searches, enhancing retention through equity in pay and resources, and using data to drive improvement.[43,44] Professional societies, funders, and journals can correct practices that perpetuate inequities and institute policies that diversify grant review panels, guideline panels, and editorial boards, and many have committed to do so.[17,45–48,85,86]

CONCLUSIONS

Identifying, understanding, and addressing inequities in stroke care and outcomes requires high-quality research that is grounded in an understanding of the underlying determinants, structures, and policies that affect health. The considerations for researchers outlined in this paper are presented from a position of learning and humility, recognizing that there are important areas that have not been addressed and concepts that have not been explored to the depths they deserve. We have much work to do, but the stroke community is rising to the challenge, and I am optimistic that together we will engage in research and action that improves health outcomes for all.

ARTICLE INFORMATION

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Acknowledgments

The author is grateful to Drs Amy Y.X. Yu and David N. Juurlink for helpful comments on earlier versions of this article.

Sources of Funding

Dr Kapral holds the Lillian Love Chair in Women's Health from the University Health Network and the University of Toronto.

Disclosures

None.

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