User Engagement in Research as a Tool for Dismantling Ageism

The World Health Organization (WHO; 2020) declared 2020–2030 the Decade of Healthy Aging. This year, 2020, is also the WHO Year of the Nurse and Midwife, which offers an excellent opportunity to redouble our efforts as nurse scientists to ensure healthy aging for all. Robust evidence suggests that ageism is profoundly deleterious to health (Chang et al., 2020). The reality of ageism and associations between this form of discrimination and negative consequences are empirically well established. Nonetheless, nurse scientists hold a distinctive position, allowing them to help dismantle ageism in the research they conduct. In this editorial, I review ageism, highlighting the ambivalent form of this discrimination, and go on to argue that nurse scientists may employ user engagement in gerontological nursing research to mitigate ageism and thus improve healthy aging.

Somewhat counterintuitively, ageism is often unintentional and frequently protective in intent. Cary et al. (2017) use the term ambivalent ageism to describe ways in which good and bad thoughts about older adults often coexist and influence behavior. For example, viewing older adults as warm but incompetent may lead to patronizing behavior that is positively intended but discriminatory (Cary et al., 2017). Nursing, as a profession, continues to struggle with overcoming ageism. Our ageism is often expressed with the intent of respect but is quickly understood as ambivalent discrimination. Such respect sees risk before opportunity and weakness before strength. A view of the older adult as vulnerable and under threat results. Thus, associated attitudes and actions are typically entangled with ambivalence about aging and older people. Hence, a tendency to usurp older adults’ appraisal, autonomy, and action becomes the inadvertent consequence.

Our role, as nurse scientists, beyond being aware of and sharing awareness of ageism is frequently unclear. Do we address ageism ourselves by studying it? Or do we support other scholars who specialize in it? Ageism—from antecedents and attitudes to actions and consequences—along with the related domain of elder abuse demand our attention. Adequate science necessary to redress ageism requires the commitment of dedicated researchers maintaining strong programs of investigation sequenced over years. Ageism is, however, no different from many other phenomena in gerontological nursing. All require high-quality evidence accrued through application of well-suited methods to advance health and social care. The resulting dilemma, then, seems blankly dichotomous—join the ageism science cadre, seeking to dismantle the source of so much inequity in health and well-being, or not?

We miss a powerful opportunity if we view only those studying ageism as their primary research topic as the ones who are able to address this phenomenon. Each gerontological nurse scientist holds the power, with each study undertaken, to take apart ageism. Our power lies in user engagement. Engaging older adults as our native partners achieves two important goals, one scientific and the other societal. The first is obvious. Older adults who partner with us to conceive, design, implement, and evaluate our studies can make our science better. The second goal is less evident. Partnering with older adults on research projects provides, rather than depletes, older adults of their autonomy and agency. Such partnerships create activism that contributes to curtailing ageism.

Engaging users in research looks different depending on the project, discipline, and society in which the science takes place. The United Kingdom, for example, mandates engagement of those people who are the intended users or consumers of research in development and conduct of that research. This mandate emerged as a result of funders coming together to endorse a policy edict in a public–private partnership. That edict, made public by United Kingdom Research and Innovation (UKRI; n.d.), stands today as a mandate for researchers, educators, and others. User engagement is essentially a standard of practice for most researchers in the United Kingdom. Such a broad policy perhaps risks pro forma performance rather than genuine engagement. Nevertheless, the principles at hand suggest possibilities for American scientists and specifically for gerontological nurse scientists.
User engagement is bigger than community-based participatory research (CBPR). CBPR, in keeping with its name, emphasizes community. User engagement, seen in UKRI guidance (access https://www.ukri.org/public-engagement/research-council-partners-and-public-engagement-with-research/embedding-public-engagement), goes beyond settings for research, such as a specific community, and requires broader representation and participative voice. This breadth implies utility for gerontological nurse scientists and their collaborators to see older adults as partners and collaborators in research conducted in institutional settings and focus on individuals seeking health and social care.

Gerontological nurse scientists conduct research across phenomena, situations, and settings. Engaging with a residents’ council from a continuing care retirement facility or the leadership of a village model program looks much like the familiar precepts of CBPR. Conversely, imagining user engagement in a project aimed at improving delirium detection by clinical nurses might seem less feasible. However, engaging former patients who experienced delirium along with their family and friends creates new possibilities for consideration in approach to the topic, methodological design of the study, and interpretation of findings.

Regardless of the specific aims in a study, user engagement in gerontological nursing research has the potential to achieve valuable ends. User engagement moves people from vulnerable older and passive recipients to active partners and knowledgeable collaborators. User engagement becomes the means to make any research a tool for dismantling ageism. Respect moves out of the realm of directing and doing for older adults into a place of dialogue, leading to a range of new ways of working in research. Those new ways span older adult advisement and consultation, on the less intensive end of the range, to co-design and co-direction in a more intensive model. Regardless of the level of engagement selected by any given research team, including its older adult users, clinicians, and academicians, all can benefit in the process. Intergenerational conversations become commonplace, misapprehensions and stereotypes are broken, and new roles and models are created. Importantly, older adult users gain advantages in overcoming negative age-related self-stereotyping as they contribute to research beyond the role of participant. Limiting this insidious and socially acceptable form of ageism is especially valuable in improving health and showcasing roles for older adults that inspire others to do the same.

Moving forward as each of us plans our next study, achieving user engagement is easier than it seems. First, consider who exactly is the user for the study and define the key characteristics and experiences of that person. Second, identify whether that user is more likely someone who lived the phenomenon under study, supported someone living it, or holds other connections to it. Consider those whose experiences, conditions, concerns, and situations reflect the aims of the study at hand. Next, review contacts within the research team and the setting for the study, identifying people in that network able to inform prospective user representatives. Finally, develop conversations with those prospective user representatives to explore interest, delineate parameters for the role, and pilot engagement.

Our liberty here in the United States is the absence of a mandate for engagement. However, our privilege is freedom to learn from and to interpret principles and practice from the United Kingdom to inform how we advance the conduct of our science as much as we do the science itself. User engagement provides a distinctive tool by which to achieve advancement in both spheres, simultaneously taking ageism down one study at a time.

Hope for a world free from ageism grows each time we decide to ensure that user engagement is genuine, improving our research in content, methods, and message. Older adults should and must contribute to all facets of our society, including research. Ageism, as discrimination against people perceived as older, threatens health, well-being, and science along with many other essential functions in our society. By engaging users in every study we conduct, we possess greater power to dismantle ageism and move toward age equity in the United States and around the world.

REFERENCES

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