

Social Determinants of Health: A Framework for Studying Cancer Health Disparities and Minority Participation in Research

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The theory of social determinants of health (SDH) posits that the health of people and communities is affected by social and economic factors (i.e., economic stability, education, neighborhood and built environment, health and health care, and social and community context). These interrelated constructs may negatively affect minority patients' ability to participate in cancer research. Understanding SDH can help nurse researchers assess and address barriers to research participation, as well as design trials to improve minority patients' cancer-related health.

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Oncology nurses confront health disparity issues in numerous settings and across many roles in their work lives. These health disparity issues are often complex, challenging, and recurrent. Cancer health disparities are defined by the National Cancer Institute (2008) as “adverse differences in cancer incidence (new cases), cancer prevalence (all existing cases), cancer death (mortality), cancer survivorship, and burden of cancer or related health conditions that exist among specific population groups in the United States” (para. 1). Groups affected by health disparities may differ in race, ethnicity, age, sexual orientation, disability, education, income, or geographic location, and they may experience disparities not only in cancer-related health factors but also in representation in cancer-related research.

Background

Individuals from diverse racial and ethnic backgrounds are underrepresented in clinical trials and in cancer research studies (Siegel, Miller, & Jemal, 2015). With the need to provide evidence-based care and to conduct research that is generalizable, the underrepresentation of diverse groups in research compounds the difficulty of adequately understanding, addressing, and reversing health disparities. Data from 2015 indicate that the U.S. population is about 77% Caucasian alone, 13% African

American alone, and 18% Hispanic or Latino (U.S. Census Bureau, n.d.). Therefore, a cancer research study reflecting population-based statistics would include at least 23% non-Caucasian participants. This percentage is rarely achieved.

An organizing framework or theoretical model can be particularly useful for framing, understanding, and addressing the complex issues involved in low research participation rates. The Office of Disease Prevention and Health Promotion (ODPHP) maintains a website, www.healthypeople.gov, which outlines broad health goals and objectives that are part of the federal Healthy People 2020 initiative. The elimination of health disparities is an overarching goal of this initiative. Healthy People 2020 uses social determinants of health (SDH) as its organizing framework for understanding disparities (ODPHP, n.d.). In this article, the authors examine the SDH framework as presented in Healthy People 2020 as a mechanism for understanding health disparities and, importantly, assessing and addressing gaps in minority participation in cancer research studies.

Social Determinants of Health Framework

The SDH framework posits that the health of people and communities is affected by social and economic conditions. These same conditions can negatively influence an

individual's ability and willingness to participate in research, including cancer research. This framework identifies five primary social and economic constructs that can influence cancer outcomes and research participation: (a) economic stability, (b) education, (c) neighborhood and built environment, (d) health and health care, and (e) social and community context.

Economic stability: Factors of this construct include income, employment, expenses, and debt, all of which can have a negative impact on an individual's health and his or her ability to participate in research. For instance, individuals with low socioeconomic status may have poor living conditions that increase their cancer risk and affect their ability to afford quality cancer care (Barrett, 2002; Foley & Moertel, 1991; Holcombe, Jacobson, Li, & Moinpour, 1999; Klabunde, Springer, Butler, White, & Atkins, 1999; Swanson & Ward, 1995). Because some patients of racial and ethnic minorities experience a higher burden of economic instability, their participation in research studies tends to be low. Although explicit costs for participating in research or clinical trials are rare, the implicit costs (e.g., transportation, child care, parking, loss of income from missing work) can be overwhelming to patients who lack economic resources (Sharrocks, Spicer, Camidge, & Papa, 2014).

Education: This construct consists of literacy, linguistic fluency, vocational training, and higher education. Low levels of education can lead to low health literacy. As a result, individuals' ability to access, understand, and act on complex health information, as well as communicate with health team members, fully engage in health-care decision making, and select healthy behavior choices, can become more difficult. Low education levels can also directly contribute to low research participation; many

studies have determined that individuals with low levels of education find information about research trials and informed consent to be complex and difficult to comprehend (Adams-Campbell et al., 2004; Crosson, Eisner, Brown, & Ter Maat, 2001). Individuals who do not have experience with research may not understand research principles or the importance of research participation; consequently, those with more education are overrepresented in research studies (Herndon, Kornblith, Holland, & Paskett, 2013).

Neighborhood and built environment: This construct describes the availability of transportation, safe and modern housing, safe walking paths and sidewalks, and neighborhood infrastructure. Lack of accessible transportation to doctors' appointments can restrict access to health care and can compromise an individual's ability to travel to take part in a research study; similarly, neighborhood factors (e.g., lack of accessibility of academic medical centers, affordable childcare, community outreach from researchers) can contribute to disparities in research participation (Barrett, 2002; Crosson et al., 2001; Foley & Moertel, 1991; Klabunde et al., 1999; Swanson & Ward, 1995).

Health and health care: This construct details the availability of health coverage and specialist healthcare providers, as well as the quality of care and the cultural competency of healthcare providers. These vary across healthcare settings and can either improve or compromise an individual's health. Klabunde et al. (1999) observed that lack of access to care, poor quality of care, and low insurance coverage have been given as reasons for some patients' refusal to participate in research studies. In addition, research studies are not always equally promoted or discussed across healthcare settings,

and employees of clinics in lower-income neighborhoods may not know about or have access to clinical trials. Promoting the stereotype that minority patients are difficult to reach and noncompliant could prevent some physicians from referring minority patients to clinical trials (Taylor & Leitman, 2001).

Social and community context: This construct refers to the psychosocial aspects of a community (social integration, community engagement, trust, and social support) that can improve health and reduce health disparities. Certain minority communities may lack social integration and/or may be exposed to discrimination by the majority-dominated society. Exposure to discrimination may lead to difficulty engaging with the broader society, mistrust of elements of this society, and suspicion of health-care systems that have historically exploited minority communities (Mays, Cochran, & Barnes, 2007). Trust has been a concern among minority populations regarding their participation in research studies—and in clinical trials in particular. Some of this mistrust is based on historical precedents of discrimination, as well as unethical research experiments, such as the Tuskegee Syphilis Study (Corbie-Smith, 1999; Green et al., 2000; Shavers, Lynch, & Burmeister, 2002). Taking mistrust into account when designing and promoting research studies in minority communities is essential.

The SDH framework posits that all of these social and economic constructs are interrelated. All are embedded within a broader socio-cultural environment and can interact with an individual's biologic factors (e.g., age, gender, genetics). For example, SDH factors negatively affecting patients in racial and ethnic minorities are the result of a longstanding history of discrimination, prejudice, and institutional discrimination in the United States

(National Institutes of Health, National Cancer Institute, Working Group on Enhancing Recruitment to Early Phase Clinical Cancer Trials, 2004). Individual discrimination involves the unjust actions of an individual or small groups of individuals toward others on the grounds of race, age, or gender. For example, a nurse may provide poor care to a patient because of the color of his skin, his ethnic background, or his sexual orientation. Conversely, institutional discrimination is a discriminatory behavior embedded in important social institutions, such as hospitals. For instance, nurses may provide care to an individual or group of individuals only when they have verified the individual's or individuals' health insurance with the provider. This type of treatment may not be applied to another segment of the population. In turn, these SDH factors are directly associated with health behaviors and outcomes, as well as quality of life (Sharrocks et al., 2014). In the specific context of cancer, low socioeconomic status could result in an individual lacking the education necessary to parse information about cancer risks, as well as sufficient insurance and financial resources to cover cancer screenings or access cancer clinical trials; this individual could also live in a neighborhood with high exposure to carcinogens. These interwoven factors in the context of broader social policies and individual behaviors lead to cancer-related disparities and low participation in cancer research (Wujcik & Wolff, 2010).

Implications for Nursing

Although many oncology nurse researchers have led efforts to enhance participation of minority and underserved patients in research, many challenges and barriers remain. SDH constructs can inform nursing research in three separate

ways: (a) measuring components of SDH in cancer research, (b) accounting for barriers related to SDH in recruitment, and (c) addressing SDH-related disparities through intervention design. In measuring components of SDH, oncology nurse researchers could include questions about social and economic factors in their questionnaires, asking not only about income and education but also about insurance status, living situation, and health literacy. When accounting for barriers related to SDH, researchers can acknowledge that transportation, child care, and reading level may prevent individuals from accessing and understanding research studies. The assumption that all patients read consent forms and understand what they are signing may not be true, and comprehension should be ensured. Taking the time to explain study protocol and informed consent to patients is imperative. Some minority patients are not aware of available studies or clinical trials because they have not been presented with clinical trial options or availability.

Conclusion

One of the major challenges to providing culturally sensitive and appropriate cancer care is the lack of generalizable findings from cancer research; low participation rates of minority patients in research studies contribute to this lack of generalizability. Although many nurses and nurse scientists have made inroads into understanding and studying disparities, much work remains. Cancer research studies reflecting population-based statistics should include at least 23% non-Caucasian participants. The SDH framework offers a way to examine disparities in cancer care outcomes and minority participation in cancer research. Consistent with many socioecologic frameworks, the theory of SDH emphasizes examination of

environmental and social factors that influence health. The current authors propose that the SDH framework continue to be applied by nurse researchers to the issue of recruitment to research studies. Given the complexity of the issues, using an orienting framework, like SDH, can be one strategy for progress.

References

- Adams-Campbell, L.L., Ahaghotu, C., Gaskins, M., Dawkins, F.W., Smoot, D., Polk, O.D., . . . Dewitty, R.L. (2004). Enrollment of African Americans onto clinical treatment trials: Study design barriers. *Journal of Clinical Oncology*, 22, 730–734. doi:10.1200/JCO.2004.03.160
- Barrett, R. (2002). A nurse's primer on recruiting participants for clinical trials. *Oncology Nursing Forum*, 29, 1091–1098. doi:10.1188/02.ONF.1091-1098
- Corbie-Smith, G. (1999). The continuing legacy of the Tuskegee Syphilis Study: Considerations for clinical investigation. *American Journal of the Medical Sciences*, 317, 5–8.
- Crosson, K., Eisner, E., Brown, C., & Ter Maat, J. (2001). Primary care physicians' attitudes, knowledge, and practices related to cancer clinical trials. *Journal of Cancer Education*, 16, 188–192. doi:10.1080/08858190109528771
- Foley, J.F., & Moertel, C.G. (1991). Improving accrual into cancer clinical trials. *Journal of Cancer Education*, 6, 165–173. doi:10.1080/08858199109528114
- Green, B.L., Partridge, E.E., Fouad, M.N., Kohler, C., Crayton, E.F., & Alexander, L. (2000). African-American attitudes regarding cancer clinical trials and research studies: Results from focus group methodology. *Ethnicity and Disease*, 10, 76–86.
- Herndon, J.E., II, Kornblith, A.B., Holland, J.C., & Paskett, E.D. (2013). Effect of socioeconomic status as measured by education level on survival in breast cancer clinical trials. *Psycho-Oncology*, 22, 315–323. doi:10.1002/pon.2094
- Holcombe, R.F., Jacobson, J., Li, A., & Moinpour, C.M. (1999). Inclusion of black Americans in oncology clinical trials: The Louisiana State University Medical Center experience. *American Journal of Clinical Oncology*, 22, 18–21. doi:10.1097/00000421-199902000-00005
- Klabunde, C.N., Springer, B.C., Butler, B., White, M.S., & Atkins, J. (1999). Factors influencing enrollment in clinical trials for cancer treatment. *Southern Medical Journal*, 92, 1189–1193. doi:10.1097/00007611-199912000-00011

- Mays, V.M., Cochran, S.D., & Barnes, N.W. (2007). Race, race-based discrimination, and health outcomes among African Americans. *Annual Review of Psychology*, 58, 201–225.
- National Cancer Institute. (2008). Cancer health disparities. Retrieved from <http://bit.ly/2fDZusl>
- National Institutes of Health, National Cancer Institute, Working Group on Enhancing Recruitment to Early Phase Cancer Clinical Trials. (2004). Enhancing recruitment to early phase cancer clinical trials: Literature review. Bethesda, MD: National Cancer Institute.
- Office of Disease Prevention and Health Promotion. (n.d.) Social determinants of health. Retrieved from <http://bit.ly/1RjVZUH>
- Sharrocks, K., Spicer, J., Camidge, D.R., & Papa, S. (2014). The impact of socioeconomic status on access to cancer clinical trials. *British Journal of Cancer*, 111, 1684–1687. doi:10.1038/bjc.2014.108
- Shavers, V.L., Lynch, C.F., & Burmeister, L.F. (2002). Racial differences in factors that influence the willingness to participate in medical research studies. *Annals of Epidemiology*, 12, 248–256. doi:10.1016/s1047-2797(01)00265-4
- Siegel, R.L., Miller, K.D., & Jemal, A. (2015). Cancer statistics, 2015. *CA: A Cancer Journal for Clinicians*, 65, 5–29.
- Swanson, G.M., & Ward, A.J. (1995). Recruiting minorities into clinical trials: Toward a participant-friendly system. *Journal of the National Cancer Institute*, 87, 1747–1759.
- Taylor, H., & Leitman, R. (2001). Misconceptions and lack of awareness greatly reduce recruitment for cancer clinical trials. *Health Care News*, 1, 1–3.
- U.S. Census Bureau. (n.d.). QuickFacts: United States. Retrieved from <http://bit.ly/1SP0kfl>
- Wujcik, D., & Wolff, S.N. (2010). Recruitment of African Americans to national oncology clinical trials through a clinical trial shared resource. *Journal of Health Care for the Poor and Underserved*, 21(Suppl.), 38–50. doi:10.1353/hpu.0.0251

Authorship Opportunity

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