Psychosocial and Socioeconomic Consequences and Data Needs: Health Equity Considerations

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Disclosures

- Indigenous Land Acknowledgement
  - Presentation recorded on the traditional land/territory of the Monacan Indian Nation

- Scientific Advisory Board Member/Consultant
  - Voluntis

Health Inequity Defined

"A particular type of health difference that is closely linked with social, economic, and/or environmental disadvantage. Health [inequities] adversely affect groups of people who have systematically experienced greater obstacles to health based on their racial or ethnic group; religion; socioeconomic status; gender; age; mental health; cognitive, sensory, or physical disability; sexual orientation or gender identity; geographic location; or other characteristics historically linked to discrimination or exclusion." (Healthy People 2020)

Health Inequity Defined

- Health inequities ≠ Health differences
  - Linked to group-specific oppression, discrimination, and exclusion
- Health inequities are not random or due to chance
  - Systemic and rooted in structural racism/bias*
  - Structural racism
    - Racial differences in access to goods, services, and opportunities
    - Codified in societal institutions of custom, practice, and law
    - Evidenced in action as well as inaction when action is needed

Jones, Camara Phyllis. "Levels of racism: a theoretic framework and a gardener's tale." *American journal of public health* 90.8 (2000): 1212.

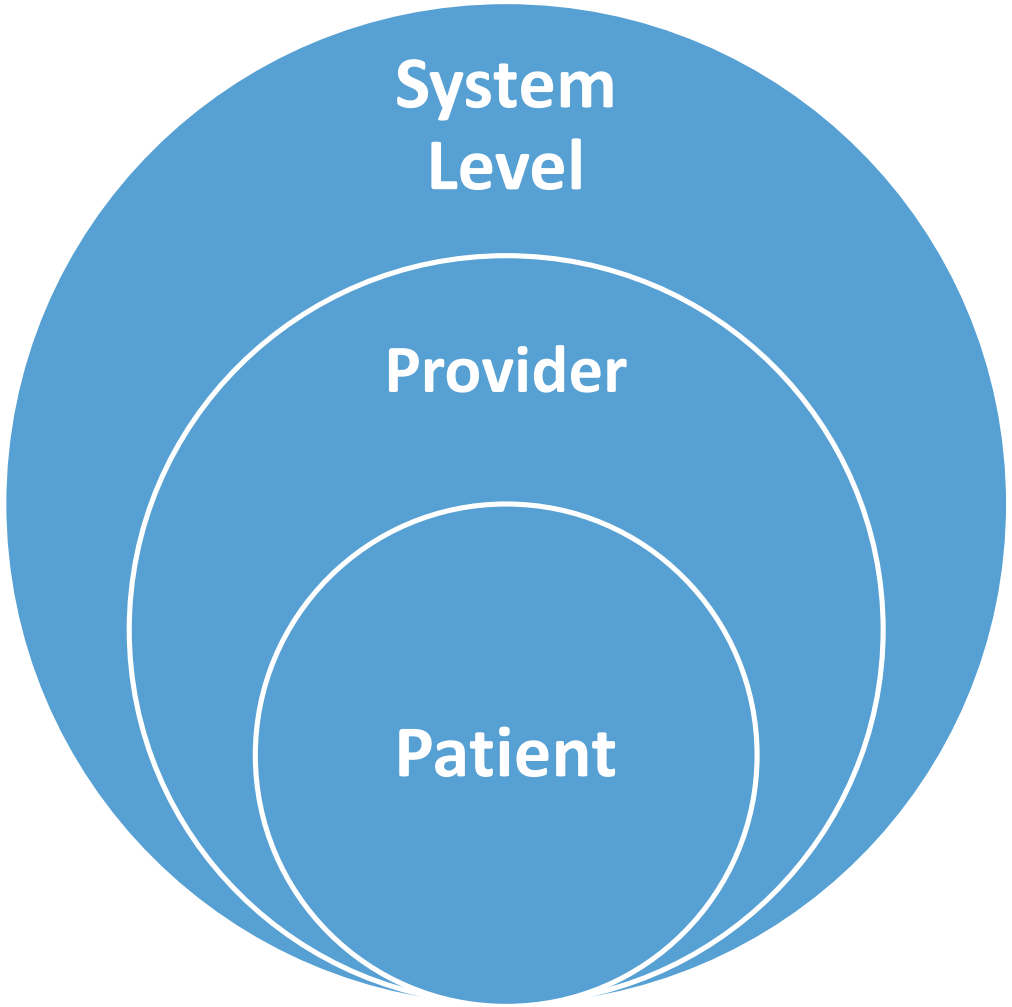
Health Inequity Defined

- Health inequities ≠ Health differences
  - Linked to group-specific oppression, discrimination, and exclusion
- Health inequities are not random or due to chance
  - Systemic and rooted in structural racism/bias*
- Health inequities are not unavoidable
  - Modifiable through systemic change

Inequities in Psychosocial and SES Consequences

- Black, Indigenous, and People of Color (BIPOC) with cancer experience substantial psychosocial and socioeconomic burden
- Blacks: poor physical and functional well-being; post-traumatic distress; financial burden and job disruptions; infertility and sexual dysfunction
- Latinx: poor psychological, physical, and social well-being; financial burden and job disruptions; sexual dysfunction
- Limited data on psychosocial and socioeconomic consequences for American Indians, Alaskan Natives, Asians, Pacific Islanders, Native Hawaiians
  - However, documented inequities in financial burden and employment status

Contributors



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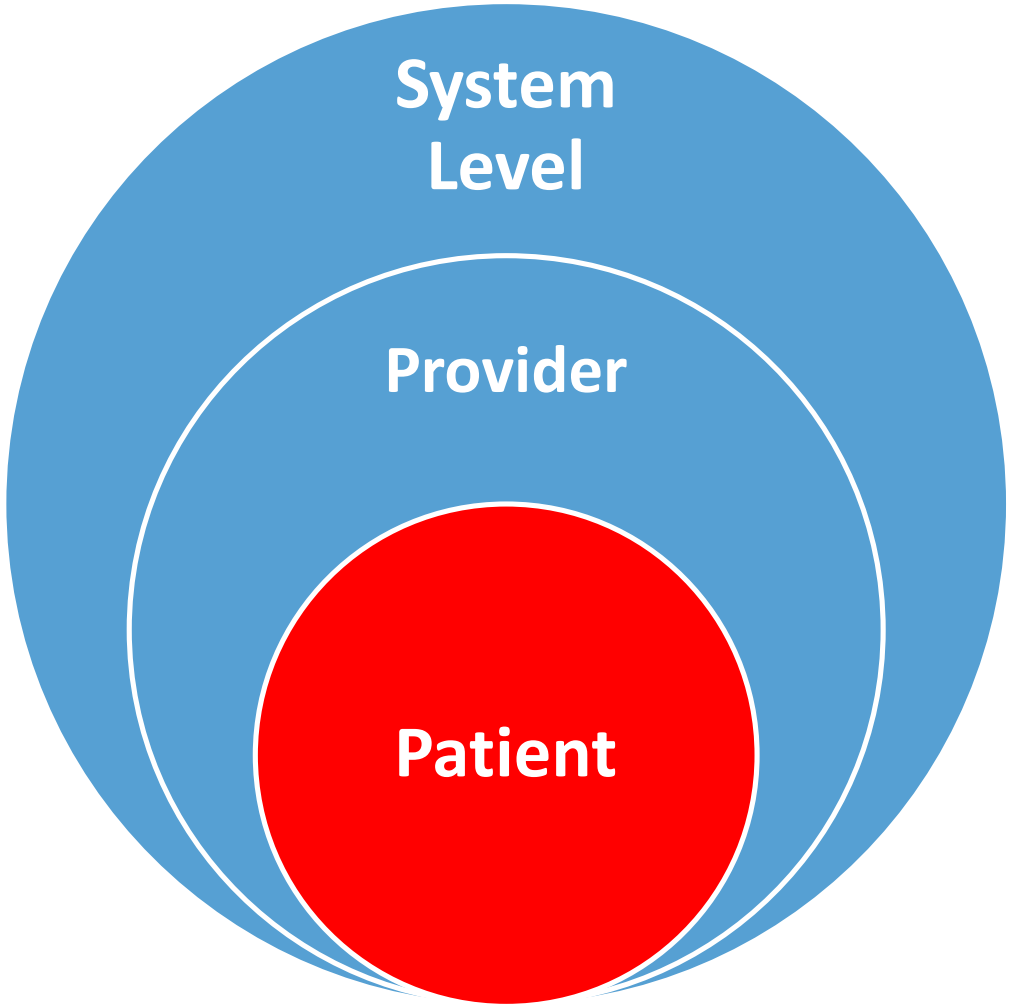

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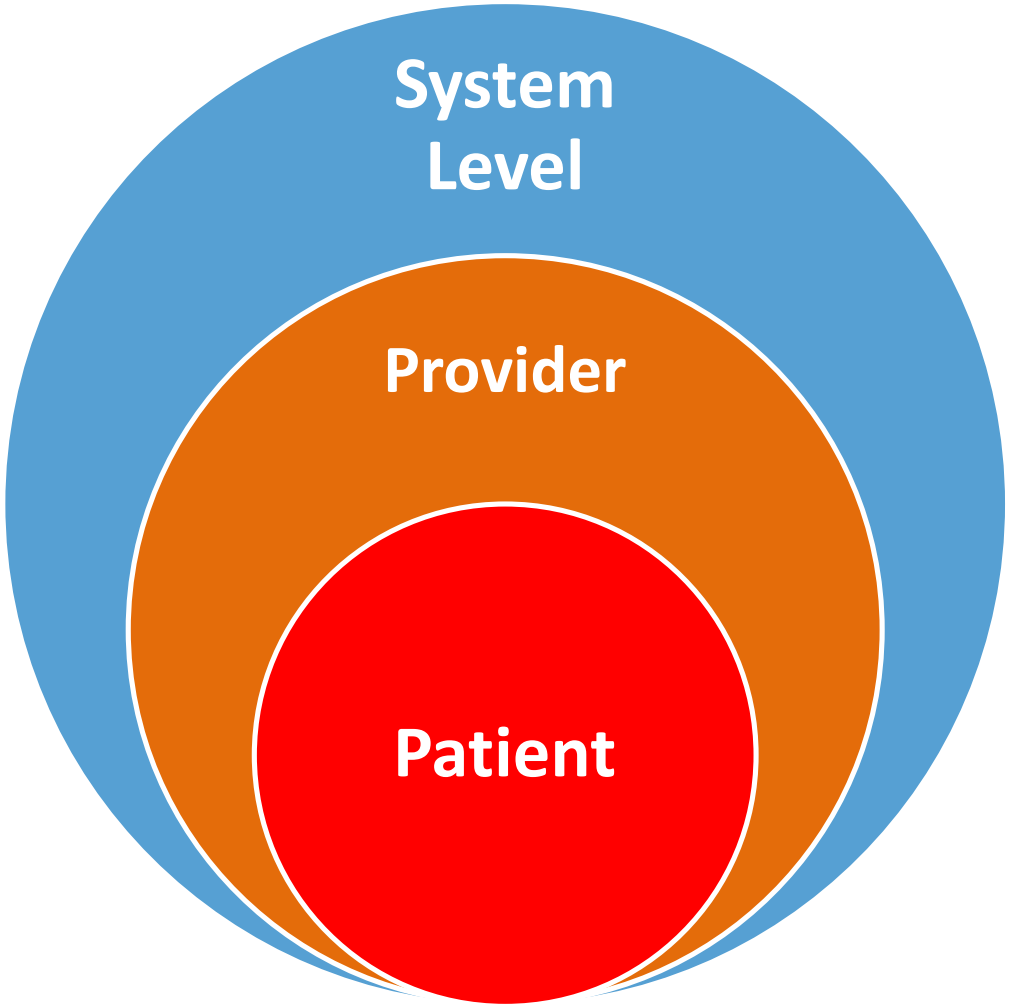

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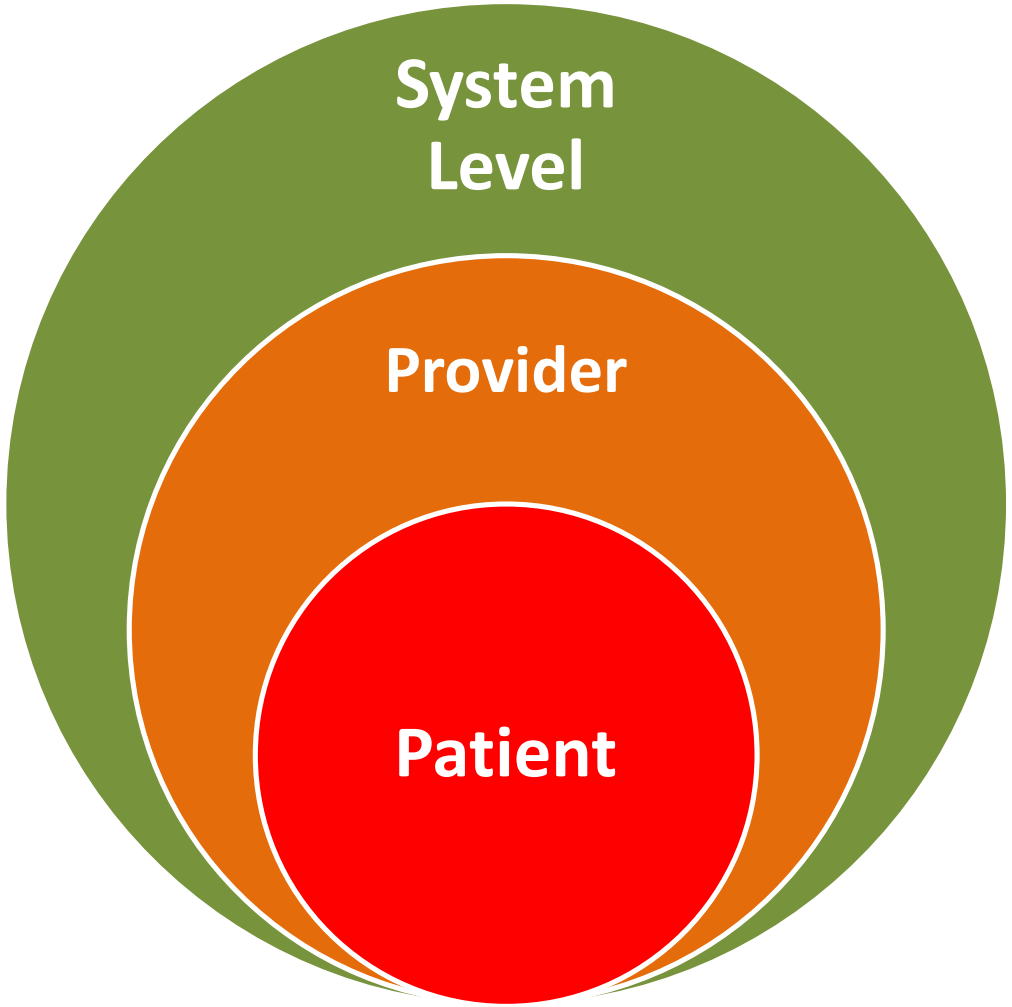

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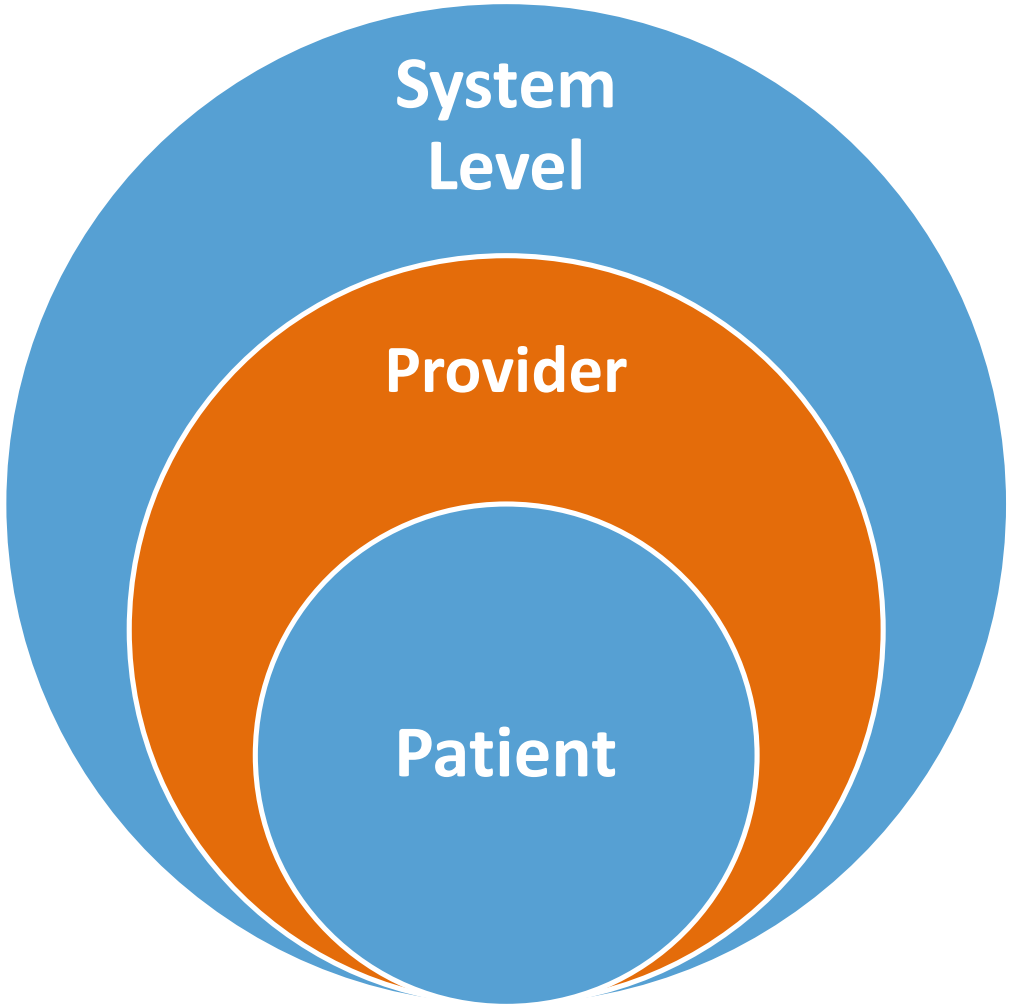
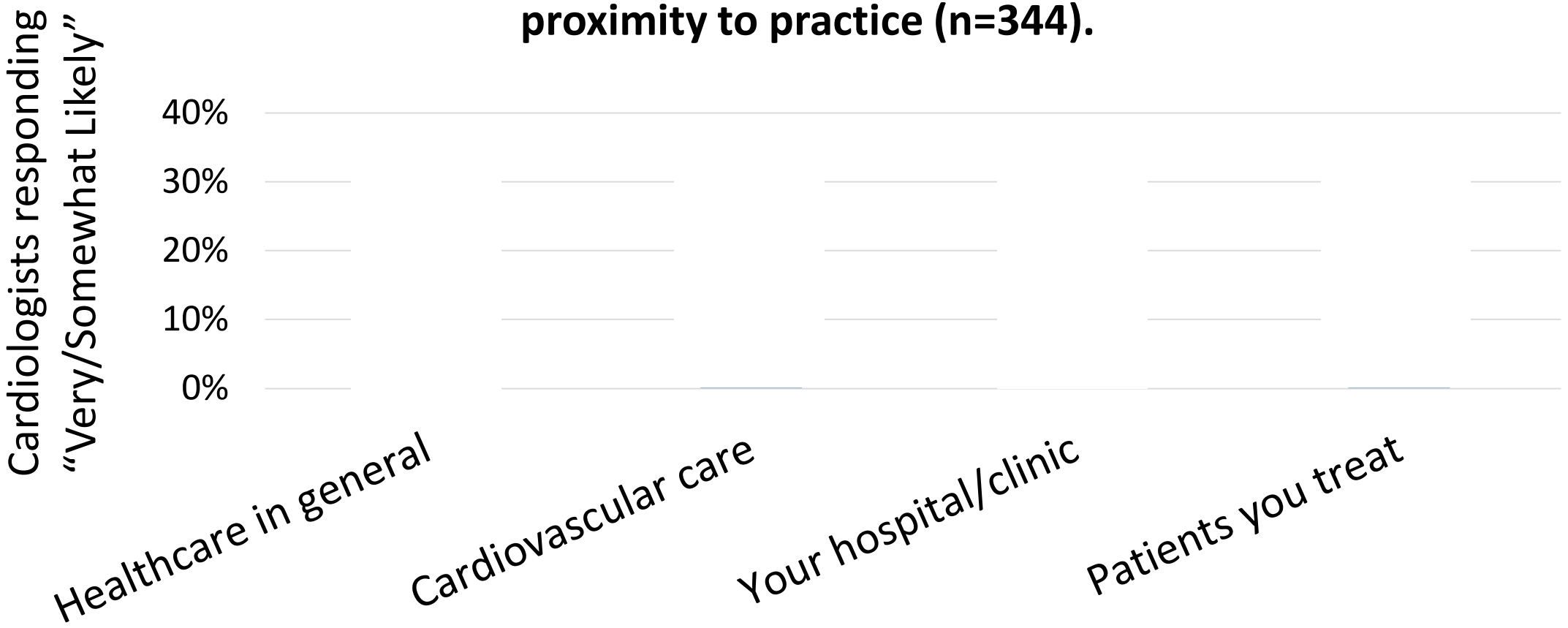


Provider Level Factors

- Implicit bias
- Lack of awareness and ownership of the problem among clinicians

Lack of Awareness and Ownership of the Problem

Proportion responding that they believe that clinically similar patients receive different care on the basis of race/ethnicity by proximity to practice (n=344).



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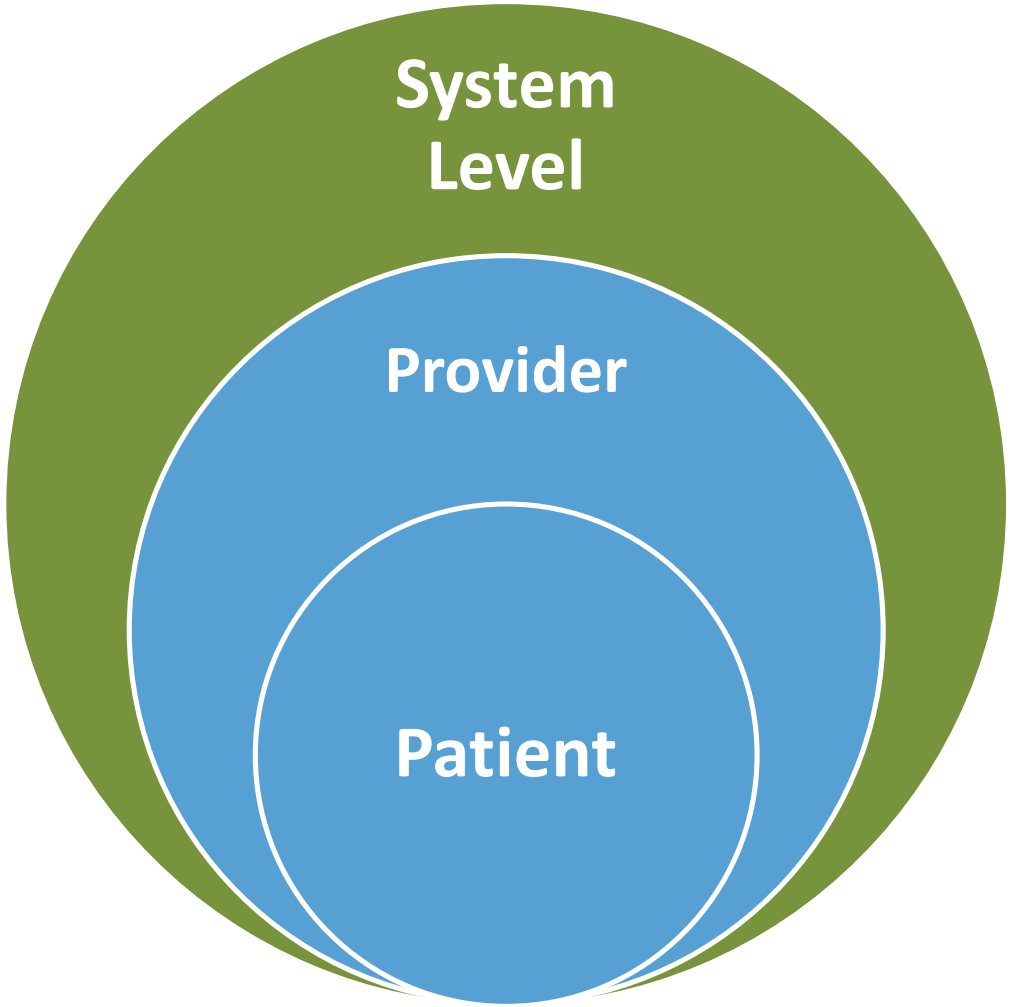

System-Level Factors

- Lack of institutional awareness and commitment to culture of equity
- Lack of transparency in data collection and reporting by race/ethnicity
- Lack of equity accountability in education/training, accreditation standards, payment models
- Lack of workforce diversity
- Variability in access to and coordination of supportive care services

STRUCTUAL RACISM
INACTION WHEN ACTION IS NEEDED

Solutions

- Institutional assessment and planning for culture of equity
  - A Diversity, Equity and Cultural Competency Assessment Tool for Leaders
- Real-time data collection and monitoring of psychosocial and socioeconomic concerns by race/ethnicity*
  - Facilitated through patient-reported outcomes and real-time registries (e.g., ACCURE Study)
- Incorporating equity domains into oncology practice certification programs (e.g., ASCO QOPI, CoC)
- Payment models that prioritize disparities reduction and equity

Solutions

- Clinical decision support to interrupt implicit bias
- Incorporating equity competencies into GME and CME requirements
- Greater investment in pipeline programs to diversify clinical and administrative staff
- Integration of patient navigators, community health workers, and financial counselors in cancer care delivery

Closing Remarks

- Inequities in the adverse consequences of cancer treatment are not unavoidable
- System-level change is needed
  - Institutional awareness
  - Transparency
  - Accountability
  - Workforce diversification
  - System redesign with equity prioritization

References

1. Jones, C. P. (2000). Levels of racism: a theoretic framework and a gardener's tale. *American journal of public health*, *90*(8), 1212.
2. Samuel, C. A., Pinheiro, L. C., Reeder-Hayes, K. E., Walker, J. S., Corbie-Smith, G., Fashaw, S. A., ... & Wheeler, S. B. (2016). To be young, Black, and living with breast cancer: a systematic review of health-related quality of life in young Black breast cancer survivors. *Breast cancer research and treatment*, *160*(1), 1-15.
3. Pinheiro, L. C., Samuel, C. A., Reeder-Hayes, K. E., Wheeler, S. B., Olshan, A. F., & Reeve, B. B. (2016). Understanding racial differences in health-related quality of life in a population-based cohort of breast cancer survivors. *Breast cancer research and treatment*, *159*(3), 535-543.
4. Vin-Raviv, N., Hillyer, G. C., Hershman, D. L., Galea, S., Leoce, N., Bovbjerg, D. H., ... & Valdimorsdottir, H. (2013). Racial disparities in posttraumatic stress after diagnosis of localized breast cancer: the BQUAL study. *Journal of the National Cancer Institute*, *105*(8), 563-572.
5. Letourneau, J. M., Smith, J. F., Ebbel, E. E., Craig, A., Katz, P. P., Cedars, M. I., & Rosen, M. P. (2012). Racial, socioeconomic, and demographic disparities in access to fertility preservation in young women diagnosed with cancer. *Cancer*, *118*(18), 4579-4588.
6. Samuel, C. A., Mbah, O. M., Elkins, W., Pinheiro, L. C., Szymeczek, M. A., Padilla, N., ... & Corbie-Smith, G. (2020). Calidad de Vida: a systematic review of quality of life in Latino cancer survivors in the USA. *Quality of Life Research*.
7. Samuel, C. A., Spencer, J. C., Rosenstein, D. L., Reeder-Hayes, K. E., Manning, M. L., Sellers, J. B., & Wheeler, S. B. (2020). Racial differences in employment and cost-management behaviors in patients with metastatic breast cancer. *Breast Cancer Research and Treatment*, *179*(1), 207-215.
8. Nelson, A. (2002). Unequal treatment: confronting racial and ethnic disparities in health care. *Journal of the National Medical Association*, *94*(8), 666.
9. Arrow, K. J. (1972). Some mathematical models of race discrimination in the labor market. *Racial discrimination in economic life*, 187-204.
10. Phelps, E. S. (1972). The statistical theory of racism and sexism. *The american economic review*, *62*(4), 659-661.
11. Lurie, N., Fremont, A., Jain, A. K., Taylor, S. L., McLaughlin, R., Peterson, E., ... & Ferguson Jr, T. B. (2005). Racial and ethnic disparities in care: the perspectives of cardiologists. *Circulation*, *111*(10), 1264-1269.
12. John, D. A., Kawachi, I., Lathan, C. S., & Ayanian, J. Z. (2014). Disparities in perceived unmet need for supportive services among patients with lung cancer in the Cancer Care Outcomes Research and Surveillance Consortium. *Cancer*, *120*(20), 3178-3191.
13. American Hospital Association (2018). Equity of Care Toolkit. Accessed at: http://www.equityofcare.org/resources/resources/2018%20EOC%20Toolkit.pdf.
14. Neuss, M. N., Desch, C. E., McNiff, K. K., Eisenberg, P. D., Gesme, D. H., Jacobson, J. O., ... & Simone, J. V. (2005). A process for measuring the quality of cancer care: The Quality Oncology Practice Initiative. *Journal of Clinical Oncology*, *23*(25), 6233-6239.

Questions? Comments?

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