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THE FUTURE OF LGBT CANCER CARE: PRACTICE AND RESEARCH IMPLICATIONS

DAVID RICE AND MATTHEW B. SCHABATH

<u>OBJECTIVES</u>: To synthesize state of the knowledge collected in this volume and propose future directions for lesbian, gay, bisexual and transgender (LGBT) cancer practice, education, research, and advocacy.

DATA SOURCES: Current and extant literature.

<u>CONCLUSION:</u> Health care disparities that are known but not yet fully elucidated in the LGBT population carry into the cancer arena. Substantially more effort is required in the domains of patient care, nursing practice, nursing and patient-facing services provider education, patient education, nursing and interprofessional research, governmental commitment, professional organization action, and patient advocacy.

<u>IMPLICATIONS FOR NURSING PRACTICE:</u> Professional nurses are committed to the uniqueness of each individual and respect and value the health and wellbeing of each individual. To that commitment, oncology nurses are positioned to advance the research in the field, which will help to clarify the issues and concerns related to LGBT cancer, address the health care inequities in this important population, and lead to improved outcomes for all.

KEY WORDS: health care disparity, LGBT, cancer, nursing research, education, practice, advocacy.

al and transgender (LGBT) and cancer, throughout the cancer continuum, including survivorship and end-of-life care. The articles discussed in this issue include barriers to care, social determinants that may increase cancer risk to LGBT populations, and legal bioethical features of care. Authors reviewed cancer screening and early detection in LGBT people and have offered considerations for high-risk screening. With the

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Nursing provides a synthesis of the

knowledge base of lesbian, gay, bisexu-

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voices of patients and families, the personal experiences of patients with cancer were illuminated. This article provides a framework for future directions for nursing practice and nursing research with regard to the care of LGBT patients and families with cancer.

The National Institutes of Health (NIH)commissioned report from The National Academies of Sciences, Engineering, and Medicine "The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding" demonstrated substantial health disparities within the LGBT population and inadequate funding of research for LGBT people.¹ This ultimately led to the formal recognition of sexual and gender minorities (SGMs) as a health disparity^{2,a} population for NIH research by the National Institute on Minority Health and Health Disparities in 2016.³ The NIH's stated goal of health disparities research is to gain a "... greater scientific knowledge about the influence of health determinants, understanding the role of different pathways leading to disparities, and determining how this knowledge is translated into interventions to reduce or eliminate health disparities."4 In addition to SGMs, health disparity populations also include racial and ethnic minorities, rural residents, and less privileged socioeconomic status (SES). A recent position statement on cancer health disparities research jointly published by the American Association for Cancer Research, the American Cancer Society, the American Society of Clinical Oncology, and the National Cancer Institute states the goal is to: . . . promote cooperation among investigators in all areas of the cancer health disparities research community, to ensure that cancer research benefits all populations and patients regardless of race, ethnicity, age, gender identity, sexual orientation, socioeconomic status, or the communities in which they live.⁵

According to the National Institute on Minority Health and Health Disparities, a health disparity is defined as a health difference that adversely affects disadvantaged populations, based on one of more of the specified health outcomes:

- Higher incidence and/or prevalence of disease and/or disorders;
- Premature and/or excessive mortality in diseases where the populations differ;
- Greater burden of disease demonstrated with metrics such as reduced quality of life or disability-adjusted life years; or
- Poorer daily functioning.⁴

The National Academies report committee members framed their investigation on the state of LGBT health in the following conceptual viewpoints:

- The *life-course framework*: One's age and historical context shapes the individual and experience; events at each stage of life influence subsequent stages:
 - o *Linked lives* (interdependence, social ties, families, relationships)
 - o *Life events* as part of an overall trajectory (differential impact of events/experiences)
 - Personal decisions (social context influences choices)
 - o *Historical context* (era, generation, context of forces and factors that shape experience).^{6,7}
- The minority stress model: LGBT people experience chronic stress because of stigmatization, which influences health and behavior; distal objective stressors (actual experiences of violence and discrimination); proximal subjective stressors (internalized homophobia); and perceived stigma (that one will be rejected) lead to a state of chronic stress and negatively impact health and well-being.⁸
- *Intersectionality* places the individual in the context of the many identities in which they live and interact:
 - o Race as a social construct;
 - Historical and social experiences of LGBT people regarding class, gender, race, ethnicity, and geography;
 - Economic and social positioning (institutional practices and policies);
 - o Representation (social, structural, political, historical, and geographic).⁹
- The social ecology perspective: Effects of environment on individuals' health. We are

^aIn Healthy People 2020, a health disparity is defined as "a particular type of health difference that is closely linked with social, economic, and/or environmental disadvantage. Health disparities 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.": http://www.healthypeople.gov/sites/default/ files/PhaseI_0.pdf.²

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