

Foreword

In 1999, a group of us worked on a white paper that was to provide background information to Health and Human Services (HHS) investigators who were considering the inclusion of LGBT populations in Healthy People 2010 (1). Research on cancer in LGBT populations was limited—mostly addressing HIV/AIDS -related cancers in men and breast cancer in women. The section of the white paper that reviewed knowledge then available about cancer started and ended with notes on the need for further research to help in understanding cancer in LGBT populations. Fifteen years later, this book, which comprises 19 chapters edited by Boehmer and Elk, is an important response to the call for knowledge on cancer in LGBT populations. This book provides an indispensable resource for information about the many aspects of cancer.

The chapters assembled for this book cover impressively broad areas of research and practice, with authors providing diligent analysis and integration of research conducted on the epidemiology, clinical care, and policy of LGBT cancer. Part I discusses risks for cancer, with careful analysis addressing women and men, including transgender individuals, separately. Chapters address risk related to infection in LGBT men and women and lifestyle risks, related to obesity and nutrition, substance use and smoking, and physical activity. Part II addresses cancer prevention by focusing on issues related to early screening. Again the authors avoid generalizations by carefully covering issues of concern to GBT men (e.g., HPV) and LBT women (e.g., breast, reproductive organs) separately. Part III provides a review of the epidemiology of cancer in LGBT populations and addresses clinical issues, treatment and survivorship. The unique issues of LGBT people in cancer are made especially clear here as authors discuss issues such as disclosure of one's sexual orientation to care providers, sensitivity to special concerns of LGBT individuals (e.g., sexual performance after prostate cancer treatment, Chap. 10), and social support and, specifically, the inclusion of expanded definition of family that is so important to LGBT people (e.g., inclusion in care-giving of ex-lovers of a lesbian entering hospice, Chap. 12). Of course, cultural competence in providing cancer care, including in support groups, is crucial for providers to be able to address these issues sensitively (Chap. 13).

Although authors of all the chapters are sensitive to including concerns of transgender individuals and to address, as possible, issues affecting diverse LGBT populations, Part IV takes a special look at concerns of transgender populations and LGBT people of color. For example, authors highlight the combined impact of social, economic, and cultural factors that place barriers to screening, health care services, and engagement in risk behaviors (Chap. 16). Also addressed in all chapters are implications of the research findings and observations to healthcare policy but the editors address this important issue specifically in Part V where authors review implications of new U.S. policies and how they have impacted healthcare for LGBT populations, as well as discuss challenges, and suggest a roadmap for LGBT cancer health.

One question that emerges from the pages of the book, sometimes implicitly, is whether LGBT disparity in cancer outcomes is the main reason for studying LGBT populations in cancer. Authors review data to try to understand cisgender/heterosexual vs. LGBT cancer disparities. The focus on health disparities is an important topic for the U.S. Health and Human Services, as described in Healthy People 2010 and Healthy People 2020. It is a key motivation for studying social epidemiology because health disparities reveal important structural inequities that ought to be addressed. But as Boehmer notes in the context of breast cancer (Chap. 9), the “absence of a disparity must not be interpreted as lack of need for programs for and interventions with sexual minority women who live with breast cancer” (p. 155). Although understanding health disparities is important, it is not the only reason to study LGBT people and cancer and should not be the only topic of study. As many chapters demonstrate, even where there are no differences in rates of disease or screening, special attention ought to be paid to LGBT issues. For example, Blank, Descartes, and Asencio (Chap. 7) ask not only whether screening rates in gay and bisexual men and transgender people differ from screening rates of cisgender heterosexual men, but also whether there are specific factors related to these populations that may merit screening guidelines being different. These authors, like most of the book’s authors, explore these and other distinctions among LGBT and cisgender heterosexual populations and reveal important areas for research and intervention.

Indeed, the book is impressive in the broad perspectives taken by the authors in discussing cancer in LGBT populations. For example, although risks for cancer are often discussed at the individual genetic and behavioral levels, authors in this volume have incorporated a broader health equity perspective that identifies larger structural factors (e.g., Chaps. 4, 16). Indeed, by the very act of focusing on LGBT populations in cancer, all authors adopt a social-cultural view of medicine, where one’s identity and position in society are as important determinants of health as are biological and behavioral factors. In weaving these social-cultural factors together with individual lifestyle risks and vulnerabilities, the book enlightens us not only about cancer in LGBT populations but also about the many ways that cancer is affected by seemingly non-medical factors. One of the research respondents in Margolies and Kamen’s chapter noted this connection when he talked about the importance of support: “My partner IS MY FAMILY and when [health care providers]

treat him as such my [health] outcomes are much better. He is my advocate and can remember everything I can't. Good [health] outcomes depend on his involvement as does my emotional well being" (p. 208). Behind this observation is a profound realization, explicated by authors throughout the book, that LGBT identity matters because it is connected with a host of structural factors related to stigma, prejudice, and access to resources, which determine health outcomes.

Despite the great progress in knowledge about LGBT cancer since the 2000 white paper, as chronicled here in the book reveals important continuing challenges for researchers, clinicians, and policy makers. For example, several authors have noted that cancer registries still do not include information about sexual orientation or gender identity, making vast invaluable information about cancer unusable with regard to issues that may be specific to LGBT populations (Chap. 3, Chap. 8). As Tracy noted: "If we are to enhance our understanding of basic epidemiology of STI-associated cancers in LBT women, we must start by integrating data collection of sexual identity and gender identity into our national surveillance systems as crucial demographic variables, and we must urge members of the scientific community to adopt standards for collecting demographic variables related to sexual identity, sexual behavior and gender identity so that results can be compared meaningfully across studies" (p. 32). Several authors noted that the recent decision by HHS to include sexual orientation questions in the National Health Interview Survey, like the inclusion of sexual orientation questions in other state-based surveys, is an important first step in improving knowledge on LGB health. Still, as Fredriksen-Goldsen, Hoy-Ellis, and Brown (Chap. 4) remind us, to date only one survey—the Massachusetts Behavioral Risk Factor Surveillance System—includes information about gender identity.

Another challenge for cancer in LGBT population is the paucity of specialized targeted programs and culturally competent care in general. As several authors noted, there are too few evaluations of both primary interventions to reduce risk for cancer and secondary and tertiary interventions with LGBT people with cancer (Chaps. 4, 13). It may not be apparent to service providers, but even when the information provided to a cancer survivor is the same regardless of sexual orientation and gender identity, an LGBT person can be alienated when services are not tailored and culturally sensitive to the him or her. As Margolies and Kamen (Chap. 13) said: "LGBT survivors ... may feel most comfortable and most supported when talking to another LGBT survivor who shares their concerns and experiences." The authors report on one of their research participants, who said "Without knowing other lesbians who had had breast cancer who helped me through the process, I am not sure how I would have fared" (p. 215). Fredriksen-Goldsen, Hoy-Ellis, and Brown concluded "it is imperative that tailored community-based prevention efforts and interventions be designed and tested to improve health and promote health equity in these communities" (Chap. 4., p. 54).

Thanks to the editors, this book goes a long way toward providing knowledge, ideas, and resources that can help researchers, clinicians, and policy makers achieve

the goal of improving health and promoting health equity in LGBT communities. It also points to challenges ahead which, hopefully, will encourage researchers to study the topics covered in the book and bring about more progress in the study of LGBT cancer.

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References

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Cancer and the LGBT Community
Unique Perspectives from Risk to Survivorship
Boehmer, U.; Elk, R. (Eds.)
2015, XVII, 331 p. 4 illus., Hardcover
ISBN: 978-3-319-15056-7