

INTRODUCTION

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Gay and bisexual men, and other men who have sex with men (GBM) have always been part of the population of men who experience prostate cancer. Until relatively recently their needs and experiences have not been acknowledged in prostate cancer research, clinical practice, or policy, which has led to the description of GBM with prostate cancer as a “hidden population”¹ or an “invisible diversity.”² This book makes visible that which has been neglected for too long—the specific needs and concerns of GBM and their partners living with prostate cancer. This book provides an overview of research and practice, interweaving the personal narratives of GBM who have experienced prostate cancer. Our intention is twofold. By providing insight into the unique experiences and concerns of GBM, we seek to inform future research, clinical practice and supportive care, and policy, ensuring that GBM are recognized and included on the prostate cancer agenda. We also seek to provide a frame of reference that normalizes the experiences of GBM and their families who are facing a prostate cancer diagnosis, undergoing treatment, or living with the aftermath of both. Knowing that you are not alone, and having information about how others in a similar situation have responded and coped, is central to coping with and surviving cancer.^{3, 4}

Prostate cancer is a serious concern for all men.⁵ It represents 26% of all new cancer diagnoses in men,⁶ has the highest incidence of any cancer (aside from non-melanoma skin cancer), and is the second leading cause of cancer death after lung cancer.⁷ Approximately 14% of men will be diagnosed with prostate cancer at some point in their lifetimes,⁸ a similar incidence to breast cancer in women.⁹ No precise estimate of the number of GBM and transgender women (TGW) with prostate cancer exists, as sexual orientation is rarely and inconsistently recorded in medical records,¹⁰ the result being scarce information about cancer disparities in sexual minorities.¹¹ Population estimates suggest that a considerable number of GBM are affected. Take the case of the United States, where 2,795,592 men were known to be living with

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prostate cancer in 2012.⁸ The Centers for Disease Control and Prevention (CDC) estimates 3.5–4.4% of U.S. men have had sex with a man in the last five years,¹² of whom 40–60% are in sexual relationships.^{13,14} By extrapolation, between 97,845 and 123,006 GBM are living with a diagnosis of prostate cancer, including 39,138 to 73,804 men in male couples.¹⁵ One in six GBM and one in three male couples in the United States will receive a prostate cancer diagnosis in their lifetimes. In Australia, where 94,114 men were living with a prostate cancer diagnosis (2012 data),¹⁶ using similar estimates for the size of the gay community, between 3,293 and 4,141 GBM are prostate cancer survivors, and 700 to 880 new cases are diagnosed in GBM each year.

But these are broad estimates. Because some men refuse to acknowledge their same-sex behavior to researchers, and because social research systematically usually excludes men in same-sex populations (e.g., prisons, armed forces), these are probably underestimates. On the other hand, over half a million GBM have died of HIV/AIDS in the United States alone, which has significantly reduced the size of the older gay community. For TGW, it is impossible to estimate the prevalence of prostate cancer. Because the development of prostate cancer after orchidectomy is rare,¹⁷ the number of TGW with prostate cancer in a country is probably a function of the availability of gender-reassignment surgery and hormone therapy.

While prostate cancer treatments have had a dramatic positive effect on five-year survival rates, which currently stand at between 84% and 92%,^{18,19} such treatments can have a long-term negative influence on men's sexual functioning, quality of life, and psychological well-being. These negative effects include erectile difficulties, non-ejaculatory orgasms, and decreases in desire and sexual satisfaction,²⁰ often accompanied by bowel and urinary incontinence.²¹ These sexual changes have been associated with anxiety and depression,²² as well as threats to masculine identity²³ and relationships.²⁴ Until recently, research examining the effects of prostate cancer has focused on heterosexual men or has not asked about sexual identity or orientation, assuming heterosexuality and heterosexual coital sex to be the norm.²⁵ There have been calls for health promotion and education to acknowledge that GBM with prostate cancer may experience health concerns differently from heterosexual men.^{1,26,27} However, recent reviews of prostate cancer educational resources and lesbian, gay, bisexual, and transgender (LGBT) primary care guidelines report a dearth of such information,^{28,29} with a

few notable exceptions,^{30, 31} and an absence of research to inform its future development. The failure of science to conduct studies specifically on LGBT populations results in health disparities in some diseases, including prostate cancer.³² Clearly, clinicians cannot practice evidence-informed medicine without the studies being conducted to inform their practice.

LGBT communities have been described as experiencing an “ignored epidemic”³³ and characterized as a “growing and medically underserved population”³⁴ in the area of cancer care. Research on cancer in sexual minorities is an emerging field of study;³⁴ existing evidence, though limited, suggests that LGBT cancer survivors have unique needs and greater levels of distress on most variables. These unique needs include greater stigma associated with cancer in LGBT communities, limited support from family, challenges to sexual identity, and higher cancer-related distress,^{34, 35} all of which compound the higher rates of distress found generally in the LGBT population.³⁶ Health and access to healthcare services are adversely affected by social marginalization: up to 30% of LGBT adults do not seek healthcare services or lack a regular health service provider, compared with 10% of the non-LGBT population.³⁴ LGBT individuals often delay or avoid health screening, which results in later-stage cancer detection and a worse prognosis.³⁷

LGBT cancer survivors also report difficulties in disclosing their sexual identity to cancer care providers, lower satisfaction with healthcare, and difficulties in accessing support services.^{34, 35} When sexual identity is not disclosed to healthcare providers, there are poorer health outcomes.³⁸ This lack of disclosure promotes “invisibility” of LGBT cancer survivors and neglect of LGBT-specific needs and health risks.³⁹ Same-sex partners can also feel or be excluded from health consultations, which leaves many LGBT individuals to face difficult and stressful situations alone.⁴⁰ Fear of discrimination⁴⁰ or internalized stigma on the part of LGBT individuals⁴¹ may prompt this lack of disclosure. Lack of knowledge or embarrassment about LGBT concerns by cancer health professionals can also make disclosure difficult.^{40, 42}

There are significant gaps in knowledge about LGBT cancer survivorship and care. Previous research has been small-scale, with an emphasis on documenting disparities in diagnoses or health outcomes, and little attention has been paid to LGBT experiences of survivorship and cancer care.^{34, 35} In recent years, research on GBM with prostate cancer has started to address many of these limitations, as evidenced by the

many contributions to this book and the growing body of published research that is referenced and discussed throughout the chapters.³⁵ Leading international researchers, differing in their approaches and methods, have examined GBM's and TGW's experiences of prostate cancer from a variety of perspectives, and they provide new insights into the experience of living with prostate cancer as a sexual or gender minority.

The first section of the book provides an overview of the current research evidence base, beginning with a detailed review of published research on GBM and prostate cancer (chapter 1). We then examine in detail the consequences of prostate cancer treatment on GBM's sexual relationships and identity, drawing on a series of qualitative studies (chapters 2 and 6). We present a model of understanding psychological adjustment (chapter 5) and examine couple dynamics and coping (chapters 3 and 4).

In the second section, we examine cancer care and support, including identity disclosure and heterocentrism in clinical encounters (chapter 8), as well as treatment decision making for GBM in relation to sexual modes and functioning (chapter 9). We consider the specific effects of radiation treatment on GBM (chapter 13) and examine the range and utility of medical and sexual aids to address changes in sexual functioning (chapters 10 and 11). A model of social support and the influence of illness intrusiveness are explored in chapter 12. This section concludes with the presentation of a comprehensive model of prostate cancer care for GBM and TGW (chapter 14) and the case of a GBM support group and network, Malecare (chapter 15).

The final section of the book shares the personal experiences of GBM who are living with or have had prostate cancer. These chapters include Gary W. Dowsett's account, "Losing My Chestnut" (chapter 16), reflecting on diagnosis and treatment ten years later; Ross Henderson's question "What about Me?" (chapter 17), in which he recounts his experience as a gay man with prostate cancer; and Perry Brass describing his experience of prostate cancer as "An Invader in the Pleasure Dome" (chapter 18). In 2005 Gerald Perlman and Jack Drescher published an edited book, *A Gay Man's Guide to Prostate Cancer*,⁴³ the first substantive publication in this field. Today Gerald Perlman reflects on his own experience of prostate cancer and of leading a support group for GBM (chapter 19). Finally, Simon Rosser, William West, and Badrinath Konety explore a shared decision-making approach to assessing prostate cancer risk through the account of the senior author's own diagnosis (chapter 20).

We are aware that we have not included the experiences of bisexual men and transwomen with prostate cancer. There is scant research on these populations, as we note throughout the book, and unfortunately we were not able to obtain personal narratives.

We hope that this book will inform, inspire, and provide insight into the needs, concerns, and challenges facing GBM with prostate cancer and their families. It may no longer be the case that GBM with prostate cancer can be described as an “invisible diversity,”² as the contributions to this book demonstrate the growing body of research in this field. There is still very little knowledge of this research and its implications, however, outside the group of pioneering researchers we are privileged to include as contributors to this book. Our intention is for this book to redress this imbalance through making public and accessible our collective research findings, insights into GBM-centered clinical practice and supportive care, and reflections on the experience of GBM who live with and have survived prostate cancer. We also identify future research directions, highlighting the need for prostate cancer treatment and rehabilitation tailored to address the needs of GBM and TGW. If this book encourages future research on GBM and TGW with prostate cancer, we will have succeeded in our endeavors.

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