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INTERSECTION OF OLDER GLBT HEALTH ISSUES

Aging, Health, and GLBTQ Family and Community Life

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Older GLBTQ persons face many age-related challenges and opportunities. Some are shared with their heterosexual counterparts, while others more specifically relate to their GLBTQ status. These occur in the contexts of their personal lives, families, social networks, and community and social milieu. One major challenge is health. This article describes a range of issues at the interface of aging, GLBTQ status, family, community, and well-being related to health, describing aspects of social support, health, and health care systems. Prostate cancer is explored as an example of this nexus of factors illustrating how GLBTQ persons may be affected differently from the married, heterosexual image typically assumed in cancer research and clinical attention.

KEYWORDS GLBTQ, family, social support, health care, chronic illness, prostate cancer, gay men

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INTRODUCTION

Greater attention to aging has included greater recognition of the diversity among older persons including cohort, ethnic and economic diversity, individual capabilities, social support, connectedness to community structures, and the diverse range of health challenges and functional losses as well as opportunities that age may bring. As individuals, couples, families, and communities, GLBTQ (gay, lesbian, bisexual, transgender, and queer) persons face many challenges and opportunities as they age and bring with them varying degrees of resources and needs. Many of the issues and resources of GLBTQ elders are the same as those of their heterosexual peers, but others are specific to their sexual orientation, gender identity, and place in the social structure. These include degree of outness, discrimination, gender identity and performance, sexual behaviors, and cohort-related impact of watershed events such as the Stonewall Rebellion and AIDS crisis. However, the ways GLBTQ older persons and families face the challenges and opportunities of aging are virtually unexplored terrain. The result is a lack of sensitively constructed information and support, and the impact of this may be exacerbated by aging.

One major area of challenge for all persons as they age is health; one particular area is chronic illness. Many develop one or more chronic conditions in young and middle adulthood and carry those with them into the years of aging. Few achieve old age without at least one chronic condition; those who do likely experience advent of a chronic illness in their older years. Some of the health challenges can be life-threatening, such as cancer or congestive heart failure, whereas others are less life-threatening but more debilitating, such as severe arthritis or loss of hearing. As with other areas, we know very little about this domain specific to GLBTQ populations.

In this article, we will explore what is known about GLBTQ family and social support networks and overall health, especially chronic illness, and then turn to a specific example of prostate cancer that illustrates many aspects of GLBTQ aging and health. We draw upon results from focus groups we conducted with 36 men over the age of 40 years who identified as gay or bisexual.

FAMILY AND SOCIAL SUPPORT

There is not a great deal of literature on family and support among midlife and older GLBTQs, especially the BTQ parts of that population. The extant literature largely corresponds to Weston's (1991) findings in her seminal research: families of origin remain integral parts in the lives of many of these communities, but families of choice—non-biologically related

individuals who fill the intimacy and support roles normatively filled by family—are especially important.

Families of Origin and Families of Procreation

Older GLBTQs, coming of age in more repressive eras when homosexuality was classified as a mental disorder, may have suffered ostracization by their families. Hostetler (2004) reported that the single elder gay men in his sample suffered from isolation, likely due in part to alienation from families of origin. Other studies of gay and lesbian elders, however, found ongoing ties to their families (Berger, 1984; Brown, Alley, Sarosy, Quarto, & Cook, 2001; Dorfman et al., 1995; Richard & Brown, 2006; Shippy, Cantor, & Brennan, 2004). Overall, it appears that despite the difficulties of coming out—especially in earlier periods—many midlife and older GLBTQs retain connections with their family of origin.

GLBTQ people, both old and young, also create their own families and households. The couple is a central unit of many of these households. Despite legal barriers, GLBTQ people have persistently formed enduring unions (Peplau, 1991). Black, Gates, Sanders, and Taylor (2000) estimate that 28% of gay men and 44% of lesbians currently live with a partner, and 68% of gay men and 94% of lesbians have lived with a partner at some point in their lives. Same-sex couples face stressors that heterosexual couples do not, such as internalized homophobia, prejudice, and issues of disclosure (Rostosky, Riggle, Gray, & Hatton, 2007). Such stressors likely explain why gay and lesbian couples face a breakup rate twice that of married heterosexual couples (Kurdek, 1998). This is an especially important topic to consider for older GLBTQs and their health, as singlehood is correlated with a variety of negative physical and mental outcomes (Schmitt & Kurdek, 1987; Wayment & Peplau, 1995). Indeed, partnered older LGBs are mentally and physically better off than those who are not (Grossman, D'Augelli, & O'Connell, 2001).

Many GLBTQ families include children as the result of previous heterosexual unions, fostering, adoption, or being born through surrogacy or donor insemination. Black and colleagues (2000) stated that about 28% of lesbians and 14% of gay men have children living in their home. Orel and Fruhauf (2006) estimated that there are 1 to 2 million lesbians and gay men who are or who will soon be grandparents. As elder care is often the provenance of family members (Dwyer & Coward, 1992), these various ties are especially important to understand. GLBTQ families, as noted, often include those not related by blood or legal ties (see also MetLife, 2006). These fictive kin might be friends, former lovers, or members of a partner's family (Weston, 1991). They provide a great deal of support in the lives of GLBTQs, especially for those who are single and/or not close with their biological family (cf. Weinstock, 2004).

Social Support

Like anyone else, GLBTQs exchange time, services, and resources with family and friends. As a minority group, however, social support is particularly important in the lives of GLBTQ individuals, couples, and families. Such support is particularly important during times of illness and in the elder years when individuals may need increasing amounts of help.

Research with GLBs shows that social support relates to a variety of positive outcomes such as decreased social anxiety (Potoczniak, Aldea, & DeBlaere, 2007) and increased self-esteem (Yakushko, 2005). Unfortunately, not everyone who would benefit from support has access to it—due to ageism in the gay community and alienation from families of origin, single elder gay men, for example, may lack adequate support (Hostetler, 2004). In gendered counterpoint, a review of research on lesbians (Gabbay & Wahler, 2002) suggested that they may have advantages over heterosexual women as they age, including relationships less reliant upon traditional ideas of attractiveness and a supportive community context that resists ageism.

Caregiving

Gay men in their mid-years and beyond are likely to have been touched by the HIV/AIDS crisis. Research showed that for those who became HIV positive, friends were more likely than family to provide caretaking functions (Bor, du Plessis, & Russell, 2004; Friedland, Renwick, & McColl, 1996). For caretakers such as these, social support may be particularly important in protecting against stress (Wight, Aneshensel, & LeBlanc, 2003).

Beyond the impact of HIV/AIDS, members of the GLBTQ community have performed and continue to perform caregiving for both family and friends (MetLife, 2006). GLBTQs in fact appear to be more likely to be involved in caregiving than their mainstream counterparts (Cantor, Brennan, & Shippy, 2004; MetLife, 2006). Fredriksen (1999) found that 27% of lesbians and gay men were caring for an adult with an illness or disability, primarily friends (61% of recipients).

It should be noted that we find very little literature on the roles of bisexual or transgender people as caregivers (Fredriksen-Goldsen & Hooyman, 2007), although the 2006 MetLife survey did include people who self-identified as bisexual (15%) and transgender (1%). In addition, little research exists that considers racial/ethnic variation in GLBTQ caregivers' experiences (one exception is Evans-Campbell, Fredriksen-Goldsen, Walters, & Stately, 2007).

The formal support services that heterosexuals can draw on are not always easily accessed by GLBT caregivers (Coon, 2007), who also may

experience discrimination while providing care (Dean et al., 2000). Depending on whether they have a legal or blood tie to the person for whom they are caring, GLBTQs may or may not have access to legal rights (e.g., decision-making, information, the ability to use the Family and Medical Leave Act), insurance benefits, or religious resources (Coon, 2003, 2007; Fredriksen-Goldsen & Hooyman, 2007).

Obtaining support services from mainstream venues may be objectionable to some GLBTQs. Richard and Brown (2006) found reluctance in their study of older lesbians to obtain aid from such sources due to fears of bias. Like other researchers, however, they found extensive reliance upon informal sources of support, including members of their families of origin, children, and friends. Correspondingly, Jacobs, Rasmussen, and Hohman (1999) reported a preference in their sample of GLBs to use support services that were specifically oriented toward gay and lesbian clients, in order to be assured of a nonbiased reception.

THE HEALTH AND WELL-BEING OF GLBTQ PEOPLE AND THEIR FAMILIES

Although we can assume that GLBTQs have similar health concerns as the general population, some issues related to sexual or gender identity can affect health and health care issues. For one, the health care system is heterosexist and homophobic in the way that it is structured (Pugh, 2005; Trettin, Moses-Kolko, & Wisner, 2005). In many cases, it does not recognize or acknowledge GLBTQ people, their partners, or their families. It utilizes heteronormative standards that may or may not be appropriate or useful for ensuring the well-being of GLBTQ people and their families. (Please see Witten's paper in this special issue for further discussion on transgender health care issues.)

Studies have found provider bias toward GLBTQ patients and that GLBTQs frequently withhold personal information about their sexual orientation, gender identity, sexual practices, and other behavioral risk factors (Gay and Lesbian Medical Association, 2001), possibly to avoid provider bias or due to internalized homophobia. This may lead to significant delays in obtaining early screening and needed health care that jeopardizes successful treatment options and survival rates. To make matters worse, a few studies note the lack of training in American medical schools on GLBTQ issues and sexuality in general. The average medical school spends less than half a day within the four-year curriculum on GLBTQ issues (Bonvicini & Perlin, 2003, p. 117). That limited training extends to mental and other clinical health providers. Unfortunately, for older GLBTQ patients, medical and clinical training on aging is also limited.

According to Bonvicini and Perlin (2003), GLBTQ patients face five major barriers at the clinical encounter:

1. Health care providers seem oblivious to the fact that they may have GLBTQ patients and address their health concerns as if they were heterosexual;
2. health care providers may lump all GLBTQ people together, making assumptions about their sexual behaviors and lifestyles, and may not take accurate and appropriate sexual histories;
3. the clinical setting and the support staff may give verbal and nonverbal cues to the patient that this is an unwelcoming or non-GLBTQ friendly practice environment;
4. health providers likely lack knowledge of the diversity of GLBTQ family structures. They may not be able to access the support networks of patients and provide appropriate access to GLBTQ families, which may include friends or other non-traditional supports, and;
5. legal constraints frame GLBTQ relationships and families and affect everything from a partner's medical insurance coverage, hospital visitation, and medical decision-making, to having non-biological or non-adoptive parental rights over their child's health care, to taking care of an older, non-biological, non-adoptive parent.

Another barrier noted by Silvestre (2003) was that when clients in therapy do disclose their sexual orientation, their presenting problem may be redefined by the therapist or clinician as stemming from their sexual identity. Also, homophobia by caregiving professionals and nurses may decrease the level of empathy and care given to GLBTQ individuals (Albarran & Salmon, 2000). Medical students with greater exposure to GLBTQ patients, however, tend to perform more comprehensive histories, hold more positive attitudes toward GLBTQ patients, and possess a greater knowledge of GLBTQ concerns than those students with little to no clinical exposure (Sanchez, Rabatin, Sanchez, Hubbard, & Kalet, 2006). The recruitment and support of GLBT-identified health and social services providers as part of the diversification of the health care delivery system is a strategy that can be adopted to improve the current situation (Maccio & Doueck, 2002).

One major challenge in meeting the health needs of this population is the limited research available. Many major national and statewide health data collection surveillance systems that track the nation's health, including cancer, do not ask about sexual orientation or gender identity. Therefore, we cannot determine if the GLBTQ population is doing better or worse than their heterosexual counterparts in their health status at a point in time or over time. Instead, we must rely on smaller-scale studies and occasional limited inclusion in national surveys to access the health status of GLBTQ individuals. These studies are limited in many ways, including sampling and methodological issues.

As an extreme case, the research on sexual orientation and mental health historically was based on a conception of non-heterosexual orientation as a mental health disorder and a sexual deviance (Boehmer, 2002). This "sexual deviance" was assumed to cause physical health problems, deformity, and disabilities (Gibson, 2003). Most of the current research has moved away from that model (McMahon, 2003), but it can be argued that remnants of this pathologizing trend remain within the health care system and providers.

Current mental health research focuses on stress and its effect on the health and well-being of sexual minorities who have to cope with the chronic stress of homophobia and heterosexism (Trettin et al., 2005). Researchers tend to agree that it is not sexual orientation that causes psychological distress but rather belonging to a stigmatized group (Smith & Ingram, 2004). In a study of Latino gay and bisexual men, those who identified as effeminate, non-gender-conforming men had higher levels of mental distress than those who did not. This distress was attributed to more exposure to homophobia (Sandfort, Melendez, & Diaz, 2007). This brings up an important issue about the health experiences of those who are visibly perceived as GLBTQ versus those who pass as heterosexual in appearance or behavior. Future research should incorporate gender nonconformity and visibility as a factor in health. The psychosocial stresses caused by creating and maintaining a closeted life or managing the outcomes of self-disclosures frame GLBTQ mental health issues (Schope, 2002). Interestingly, the failure by GLBTQ individuals and other marginalized people to recognize or acknowledge discrimination may also have a negative impact on physical health (Huebner & Davis, 2007).

Much of the research, as reviewed here, emphasizes negative aspects of GLBTQ populations based in the very real impacts of discrimination and the complexity of managing one's identity brought on by minority status or is designed to counter the negative stereotypes that dominate the understanding of these populations. However, we should remember and note the importance of attending to strengths and resilience among GLBTQs as well (Hunter, 2005). Partly because of the difficulties attendant to dealing with discrimination, older GLBTQ persons may be very self-sufficient, independent, and able to manage crises generally and the processes of aging specifically (Berger & Kelly, 1986; Brown et al., 2001; Friend, 1991; Fassinger & Miller, 1996; Kimmel, 1978; Quam & Whitford, 1992), although we also note Lee's (1987) and Hostetler's (2004) cautions about over-interpreting data from primarily well-to-do, very fully out GLBTQ persons in many of the studies to state with assurance that this sort of resilience is uniform across the population. Reid (1995) specifically addresses how negotiating coming out may produce personal growth. Likewise, some evidence shows that as they age, older GLBTQ persons may find it easier to cross gender-based roles and tasks and, thus, cope with changes in relationships (Brown et al., 2001; Fassinger & Miller, 1996; Friend, 1991). Active participation in community and an affirmative sense of self and identity are related to high levels of life satisfaction

among many GLBTQs as they age (Adelman, 1990; Kertzner, 1999). Thus, it is likely that some sub-groups within the aging GLBTQ population are psychologically and socially worse off than their heterosexual counterparts, others are better off, and still others are essentially the same. This once again strengthens the argument for including maximum diversity in understanding aging in the GLBTQ context.

In reviewing the public health research, Boehmer (2002) noted that only 0.1% of published literature found through the search engine Medline included GLBTQ issues, and of that, 85% omitted participants' race/ethnicity. Most studies that exist are still framed by pathological or risk-taking models primarily due to the HIV/AIDS and sexually transmitted infection (STI) research on men who have sex with men. Most present research involves HIV/AIDS among men, and, to a lesser extent, breast cancer among lesbians (Gay and Lesbian Medical Association, 2001). What is strikingly lacking is a focus on chronic diseases, access to health care, health and disability concerns, and well-being. In fact, some research suggests that even when HIV-negative gay or bisexual males present with symptoms stemming from a chronic illness, the specter of HIV/AIDS may frame the medical encounter. As Charles Isola (2004) wrote about his own medical experience as someone who had a chronic illness and was HIV negative, "My being homosexual required punishment somehow: a doctor would surmise that a spot on a lung X-ray must be PCP, or repeatedly order T-cell counts because I just had to be HIV positive" (p.109).

GLBTQ Health and Issues of Aging

The findings from the Women's Health Initiative survey of women aged 50 to 79 suggest that lesbians within this age cohort were more likely to be obese; suffer depression; have a higher incidence of certain cancers (e.g., breast cancer among lesbian and bisexual women and cervical cancer among bisexual women); and a higher rate of myocardial infarction compared to heterosexual women (McMahon, 2003; see also Bonvicini & Perlin, 2003, concerning the relationship between non-child-bearing and certain cancers). The limited data on lesbians suggest that lesbians may smoke, drink alcohol, and use certain illegal drugs at higher rates than heterosexual women (Ryan, Wortley, Easton, Pederson, & Greenwood, 2001; Tang et al. 2004; Trettin et al., 2005). These health behaviors have consequences for an increased risk among lesbians of cancers, lung diseases, liver diseases, and other chronic and life-threatening health problems as they age. Among older gay and bisexual males, HIV/AIDS continues to be a major health concern because HIV-positive individuals are aging and those over 50 are also at risk for infection (McMahon, 2003). Elderly GLBTQs who survive a long-term same-sex partner are not recognized in federal programs such as Social Security, and the vast majority cannot receive health benefits from partners. If proper

estate planning was not done, surviving partners may find themselves in financial difficulties and lose their property and financial resources to a late partner's biological family.

GLBTQ elderly are more likely than heterosexuals to live alone, which itself is correlated to "increased risk of lower income, poorer nutrition, poorer mental health, and risk of institutionalization" (McMahon, 2003, p. 591). This connects to the previous discussion on the openness and ability of health and caregiving institutions to serve this population. Although more GLBTQ specific institutions and organizations are developing (e.g., Senior Action in a Gay Environment [SAGE] and GLBTQ retirement communities), the needed amount of services and housing for this aging population cannot be provided by the limited resources available (see, for example, Marech, 2005, specifically concerning GLBTQ retirement communities). Also, the GLBTQ community, in particular the gay male community, has been described as youth-oriented, with many activities, events, and services targeted toward younger members. Two factors can make older gay individuals and couples doubly invisible: being gay in the world of non-GLBTQ services and being older in the GLBTQ community (Genke, 2004; Herdt & deVries, 2004).

For transgender people and their families, many of the issues previously discussed may be even more extreme, since gender nonconformity and transgenderism is still highly stigmatized, pathologized, and less accepted than GLB sexual orientation, yet research is even more lacking. What research exists has focused more on MTF than FTM individuals. According to Williams and Freeman (2007), the limited health-related studies available suggest that transgender people are significantly more likely to have no regular source of care and to be underinsured or uninsured compared to other populations. Insurance companies exclude coverage for transgender-specific health procedures such as hormone therapy and sex reassignment surgery and exclude transsexuals from treatment for health problems that may be categorized as arising from being transsexual even if they are not related. Hormone treatments present specific problems. Hormones can interact with other prescription drugs and are associated with increased risk for certain health problems such as diabetes, cardiovascular disease, thromboembolic events, and liver abnormalities (Williams & Freeman, 2007). Further, transsexual women who maintain their prostates and transsexual men who have ovaries, uteruses, and cervixes may not be screened for health concerns of these organs.

In summary, as a diverse community, it is obvious that adult GLBTQs experience the same range of family and health issues that confront all people across the life span and the changes associated with aging that confront all people within various socioeconomic classes and race/ethnicities. It is also clear that GLBTQs face specific concerns that frame those experiences. However, the literature on chronic diseases (except HIV/AIDS) and sexual

minorities is seriously lacking. As a result, we simply do not know even the rudiments of the extent of those health issues within the GLBTQ population or the difference (or lack thereof) in incidence and prevalence as compared to heterosexual people, nor do we know the degree to which GLBTQs experience the confluence of chronic conditions and aging in their lives differently from what is portrayed in the heteronormative literature. We need to be planning ahead much more aggressively in ensuring a health care system that is responsive to the needs of GLBTQ adults and older persons. A part of the pursuit of this goal is to conduct more high-quality studies to understand GLBTQ health and aging in general but in particular those chronic diseases that remain under- or unresearched. Toward this end, we turn now to an example of the issues facing GLBTQ individuals and their families as they age.

PROSTATE CANCER AS AN EXAMPLE OF A GLBTQ HEALTH ISSUE

We use prostate cancer (PCa) for our example because it is both common among middle-aged and older men and yet its significance for gay and bisexual men (and MTF transgendered persons) has been ignored in the research and health service communities (Blank, 2005). Because of the nature of its impacts, it typifies many of the questions and issues faced by aging gays and lesbians, even though it is specific to men. In addition, although the impact of gynecological cancers and breast cancer on lesbians is also underresearched, we find at least some data in that area (Boehmer, 2002; Dibble & Roberts, 2002; Fobair et al., 2004; Gay and Lesbian Medical Association, 2001; Meyer & Northridge, 2007—the latter of which has a specific chapter on cancer and lesbians but no corresponding one on cancer and gay men). We will provide a very brief overview of PCa and its treatments, discuss the nature of issues that are likely to confront all men dealing with prostate health issues, highlight how those may differentially affect gay men in some ways, and, then, describe results from focus groups we have recently conducted that illustrate how gay men view those issues.

Prostate Cancer in General

First, a brief overview of PCa is in order (for more details readers can consult books such as Marks [2003] and online resources such as http://www.malecare.org). There are an estimated 230,000 new cases of PCa each year in the United States alone (Jemal et al., 2007), and over 2 million PCa survivors. Average age at diagnosis is in the later sixties; many men who were diagnosed and treated earlier grow old in their subsequent survivorship. Thus, to a large degree, PCa is a disease of older men, although

they can be diagnosed as young as in their thirties, and younger often have more intensified impacts (Blank & Bellizzi, 2006, and others).

Prognosis after treatment is excellent (IOM/NRC, 2006; Jemal et al., 2007; Marks, 2003). Primary treatment modalities for early-stage disease range from radical prostatectomy (surgery) and two forms of radiation to actively watching very slowly developing cancers without medical intervention, the latter because many men die of something else without the PCa ever becoming lethal. Treatment for advanced, that is, metastatic, disease is much less likely to be curative (five-year survival about 34%) and consists primarily of androgen (testosterone) deprivation.

Because of the treatment effects, however, many survivors with excellent prognoses have varying degrees of permanent changes in their bodies and bodily functions. By far the most common are negative effects on erectile function (30 to 70% or more affected), and small amounts of urinary incontinence (Marks, 2003). Radiation treatments can affect bowel function and produce rectal irritation and scarring. Men treated with androgen deprivation experience loss of muscle tissue, loss of libido, bone loss and osteoporosis, and breast tenderness and/or enlargement. All these treatment effects may have significant and enduring impacts on men's senses of themselves, their masculinity, and their relationships to others, especially sexual partners (Blank, 2008). Correspondingly, considerable research exists, with well over 40,000 articles about PCa, its treatment, and resulting effects. The thousands of studies on quality of life after PCa reveal several clear patterns (Eton & Lepore, 2002; Litwin, Melmed, & Nakazon, 2001; Penson & Litwin, 2003): PCa survivors maintain high general and health-related quality of life with comparability to national norms of non-cancer groups attained within six months to a year after treatment. The only exceptions to high quality of life concern functional losses due to treatment and not to the cancer as such.

As we have already demonstrated, little attention in any area of health and chronic illness has been paid GLBTQ populations (e.g., Boehmer, 2002), and PCa is no exception. In fact, the literature is essentially devoid of studies that consider the range of masculinities and sexualities in middle-aged and older men, which includes many men who are not exclusively heterosexual (Berger, 1982; Blank, 2005; Herdt & deVries, 2004; Kimmel & Messner, 2003; Perlman & Drescher, 2005a, 2005b). Even if only 2 to 3% of the male population is gay (Black et al., 2000; Laumann, Gagnon, Michael, & Michaels, 1994), at least 5,000 gay men are diagnosed each year and 50,000 or more are living after PCa treatment; the numbers are probably considerably larger. Millions of gay men in or beyond their forties must deal in some way with the prospect of PCa entering their lives. As with gynecological cancers and breast cancer with lesbians, gay men in committed relationships with other men are obviously twice as likely as heterosexual men to have to deal directly with PCa within their couple. As with all men facing PCa, this population needs appropriate and accessible information about screening and

prevention, treatment options and their effects, and support related to prevention, treatment, and survivorship.

Yet, as described in Blank (2005), to date there have been no systematic studies specific to gay men in this exclusively male disease. A major report on the importance of survivorship research (IOM/NRC, 2006) only mentions gay men once and cites only that *Journal of Clinical Oncology* commentary (Blank, 2005). Most of the extant articles related to the subject are in one special issue of the *Journal of Gay and Lesbian Psychotherapy* (Perlman & Drescher, 2005a), subsequently published as a book, *A Gay Man's Guide to Prostate Cancer* (Perlman & Drescher, 2005b). These edited volumes are important as a resource for gay men and provide interesting illustrative material, but these are primarily a collection of autobiographical narratives from one support group of gay men with PCa in New York City. Added to these sources is a limited amount of information specific to gay men on the Web site http://www.malecare.org.

Both Perlman and Drescher (2005a, b) as well as Blank (2005) detail a number of ways in which the PCa experience may be quite different for GBTQ men compared to heterosexuals, ranging from sexual activity to social and personal relationships as well as relationships to the medical profession—areas that have been noted already in our review. These differences make the lack of attention distinctly problematic. We address those briefly in the following paragraphs. As far as we know the medical community has paid no special attention to the particularly problematic situation of MTF transgender persons, who still have intact prostates despite the changes to their external genitalia and may not even be aware of that fact or its implications.

Echoing what we said earlier about the reliance on heteronormative standards for determining care, what is known about the impact of PCa on men and those who love them is based almost exclusively on an explicit or at least implicit image of a man dealing with PCa as being an older heterosexual man in a very long-term (at least three to five decades), monogamous, marital relationship (Blank, 2008). That normalized version indeed reflects the majority of men, but easily leads to research, interventions, self-help guidance, and provision of service in a constricted way that disenfranchises significant sets of men who, for one or more reasons, violate the norms. As a result, both problems and complications that may be specific to subgroups, such as gay men, as well as potentially positive outcomes that may result from being part of such a group, are ignored.

All men who are middle-aged and aging should consider prostate health and the prospect of PCa, and all men who have had PCa face similar potential for impact on their physical functioning, psychological well-being, and social relationships. Thus, the distinctiveness of impacts on gay men are worthy of much further investigation, but so is the commonality of their experience to non-gay men. Both Slevin (2007) and we, in a workshop conducted two

years ago at the national conference of SAGE and in our recent focus groups, found few differences in reporting problems and issues between gay and heterosexual PCa survivors. Also, gay men sometimes went to considerable lengths to downplay differences between themselves and heterosexual men in this area. The men emphasized that the prostate is the same for every man, and that if cancer is found the goal for everyone is the same: Get it out! To some degree, they stressed their commonality to heterosexual men with PCa by specific reference to aging. While this deemphasizing of difference may be adaptive, it may also be related to the negative impacts noted earlier and delineated in Huebner and Davis (2007), in that it may lead to inadequate attention in care to aspects that are, in fact, specific to gay men. We believe it is critical to gain a better understanding of the impacts of PCa on GBTQ men, especially those that may differ from the heteronormative and marriage-centric model. We will briefly mention a few of those; it is noteworthy for this special issue that every one of the differences, even ones that are individual to a significant degree, are really social and interpersonal in nature, and each can have an impact beyond the individual to those with whom he has relationships—those whom he considers family.

Common Impacts of PCa and Potential Relationships to GBTQ Men

Loss of sexual capability, in terms of erectile dysfunction, is clearly the most ubiquitous life-altering side effect of treatment for PCa (Eton & Lepore, 2002; Litwin et al., 2001; Marks, 2003; Schover et al., 2002; Walsh & Worthington, 1997). This basic area of life is also distinctively different between exclusively heterosexual men and men who have sex with men at least some of the time and among different subpopulations of the homosexual population with different sexual activity preferences. Erections and their role in homosexual activity vary from the vaginal penetration criterion that is either explicitly stated or implicit in studies of erectile dysfunction from PCa in an obvious definitional way, but also erectile function suitable for oral or anal penetration is different from that for vaginal intercourse (an aspect also relevant for subgroups within heterosexual segments of the population). For example, gay men who are predominantly or entirely anal receptive or anal penetrating may have different perspectives on treatment decisions and outcomes, with surgery more likely to affect erectile function and radiation more likely to impact bowel function and rectal pain (Perlman & Drescher, 2005a, b). The impact of treatment effects related to sexual activity are often quite profound for heterosexual, gay, and bisexual men alike (Blank, Bellizzi, Murphy, & Ryan, 2003; Fergus, Gray, & Fitch, 2002; Oliffe, 2005, 2006; Perlman & Drescher, 2005a, b). Some men, however, may feel less impact in this area primarily in relation to age-related declines that were already present (Fergus et al., 2002). (For further discussion of impacts of erectile dysfunction on sense of masculinity, see Blank [2008].)

Broader patterns of sexual behaviors and the relationships in which they are embedded are also often different between heterosexual and GBTQ men in a more relational way (Berger, 1982; Laumann et al., 1994; McWhirter & Mattison, 1984), including different likelihoods of a long-term, monogamous relationship as the exclusive venue for their sexual lives (Berger, 1982; McWhirter & Mattison, 1984; Jacobson & Grossman, 1996; Peplau, Veniegas, & Campbell, 1996). Yet, books about dealing with PCa and erectile dysfunction impacts on relationships are specifically framed in terms of a heterosexist marital/wife relationship (Alterowitz & Alterowitz, 2004; Howe, 2002; Laken & Laken, 2002; Wainrib & Haber, 2000; Walsh & Worthington, 1997).

The difference in the likelihood of a current long-term relationship leads directly to the important variations between gay and heterosexual men in terms of another aspect helpful in dealing with PCa: social support. The same discussions that take the wife point of view in discussing erectile dysfunction also characterize the primary social support from involvement in screening and prevention to developing a treatment plan to dealing with recovery and survivorship in terms of explicit assumptions that the man's wife is his primary social support.

Thus, most heterosexual men with wives sharing their experience have a distinctly different set of experiences and perspectives from both single heterosexual men (McCarthy, 1992) and the majority of GBTQ men, who are not living with long-term partners. We have already discussed that indeed most gay men do have social support to rely on (Berger, 1982; Hostetler, 2004; Jacobson & Grossman, 1996; Peplau et al., 1996). However, the specific character and center of that support is different and less likely to be primarily a marital or marriage-like partner but more likely to be a network of friendships (see de Vries & Megathlin in this special issue) and the broader GLBTQ community. Both understanding how those who are not in a long-term relationship or who are in a partnered relationship with a man are similar to or different from those in heterosexual marriages and getting a much clearer picture of the alternative sources of support from friends, family, and former or current lovers—the networks of fictive kin or chosen families we have already delineated—are critical.

One interesting issue addressed by both heterosexual men and gay men in our studies concerns whether partnership or singlehood is more problematic. Discussions in the broader literature framed in heterosexual terms and discussions which we will note below in our focus groups indicate that different men see this as cutting either way in terms of the importance of sexual functioning after PCa treatment. The difficulties of being single and wanting to play the field but having performance issues are contrasted to the feelings of letting one's partner down or having one's partner have to deal with the complications of cancer (or any health challenge) in their relationship. Finally, as we have detailed about GLBTQ aging persons, gay men are more likely to have difficulty dealing with the medical community of mainly

heterosexually oriented urologists and oncologists (Cole, Kemeny, Taylor, & Visscher, 1996; Gay and Lesbian Medical Association, 2001; Silvestre, 2001). Many providers may indeed be biased, by prejudice or sheer lack of knowledge or attention. On their parts, GLBTQ persons may be wary of a real or feared homophobia and heteronormative focus of clinicians. The potential for the chronic stress of managing outness with health providers we noted previously can add to both psychological and physical problems related to being a PCa survivor. Several contributors to Perlman and Drescher's (2005a, b) work relate, in strong terms, their difficulties negotiating health care as a gay man. On the other hand, many of the men in our focus groups were fully out and comfortable with their providers. Still, that is clearly not true for many, and some, especially those without adequate health insurance, had experienced significant difficulties accessing sensitive health service.

Preliminary Focus-Group Data

In order to investigate some of these issues further and gain a better understanding of the views of GBTQ men about prostate health and, specifically, PCa, we conducted focus groups with middle-aged and older gay men (who have not had PCa themselves). We conducted five focus groups, with a total of 36 participants. The average age was 49.3 years old, and average education was "some college." One focus group (seven men) was entirely composed of Latino men and conducted primarily in Spanish, and another (six men) was all African-American men (while racial/ethnic differences will not be a focus of this report, it is important to realize the range of men in the groups). The remaining groups were mixed, primarily non-Latino white. Occupations ranged broadly from clerical and non-skilled labor to professional (e.g., lawyer, teacher); six reported themselves as disabled. Almost all had some form of health insurance, more or less equally divided between private employer-paid, Medicaid, and Medicare.

Half of the men were currently partnered. All but six had had sex in the past six months; for the previous year, 26% reported no male sexual partners, 39% one, and the rest from two to five (one outlier had 20 contacts). Types of sexual activities ranged very broadly with most men participating in multiple forms of sexual expression. For importance of sex, the men were almost equally divided as it being important, not important, or in between.

In a questionnaire distributed prior to the focus groups, men indicated that they felt they had a moderate level of knowledge about prostate issues. Almost half had been tested using the digital rectal exam and/or PSA (Prostate Specific Antigen blood test) within the past year and a third not in the past year but at least once. Most anticipated a fairly high likelihood for prostate problems and prostate cancer specifically (50% likelihood was the highest

choice for each of those). However, most correctly indicated that someone diagnosed with PCa was more likely to die of something else. Most rated both their level of knowledge and their worry about prostate issues as moderate. As we report below, to some degree their confidence in their knowledge was obviated by what they said in the focus groups, which indicated significant lack of appropriate knowledge in a number of different areas.

In the group discussion we explored four general areas in detail: (1) knowledge of prostate and PCa; (2) knowledge of PCa diagnosis and treatments; (3) experiences with medical care; and (4) available support. These domains arose out of a combination of sources. Our initial literature review of articles that dealt (virtually exclusively) with heterosexual men and their knowledge of and activities toward PCa pointed toward these major areas, as did a small set of interviews conducted by the senior author of this article several years ago with heterosexual men. This facilitated comparison of insights by GBT men to those already noted with heterosexual men. Also of relevance were Blank's (2005) commentary about the absence of attention to GBT men in literature on PCa and the reactions he received from other researchers concerning topics raised therein as well as the first-person accounts of gay PCa survivors included in Perlman and Drescher's (2005a, 2005b) compilation. We structured our focus group guide to reflect these categories. The senior author moderated the focus groups (except for the Spanish-speaking), and the second co-author took detailed notes on content and group dynamics. These notes and the transcriptions of the focus groups were used by the authors to identify group trends and individual concerns related to those four domains, generating the following information.

Knowledge of the Prostate and Prostate Cancer

Despite indicating a moderately high level of knowledge about the prostate in the pre-group questionnaire, what was most striking in the four focus groups was the very limited or complete absence of knowledge about the prostate itself (exact location, function), screening tests for PCa (digital rectal exam and PSA), and PCa and its treatments. Several men in two different groups noted that the prostate is seen by some men as the G-spot of the anus in terms of sexuality, but again this description of the prostate was formulated with little understanding of anatomy and function. One participant was not aware that only men had prostates. A transgender participant who is living her life as a woman only recently realized that she still has a prostate. Consequently, the men asked numerous questions that the moderator tried to answer after getting a sense of their level of knowledge.

Even the half of the men who stated that they had received a prostate exam were unaware about the location and purpose of the prostate as well as the purpose of the exam. This raises issues about the communication between these men and their doctors and the level of health education

on the issue within the GLBTQ community. Areas of misinformation existed as well. Some believed that the prostate has something to do with or is contained within the colon or anus. Therefore, some had confusion between a colon exam and a prostate exam. Men were also interested in what causes PCa, but their own beliefs about that varied. Some believed it had to do with receiving anal sex. Others thought it to be hereditary. They wanted certain areas of concern addressed, such as "What is the risk for prostate cancer among gay men as compared to heterosexual men?" and "Does HIV increase the risk for prostate cancer?" Of course, the answers to such questions are unknown because of the lack of research on PCa and gay men.

Diagnosis and Treatments

When asked how they would react to and how they would deal with PCa if they had it, the majority of men named their primary care physician as the primary person who would help them understand both the diagnosis and treatment. They reported wanting the physician to tell them what to do as well as what the next steps would be or should be. Some did talk about using the Internet or finding the best doctor to treat it (interestingly, this was observed among the men who insisted they had very inadequate insurance), but they generally had limited enthusiasm for being proactive. We should note that very little information about PCa on the Internet (except some on http://www.malecare.org) is specific to gay men.

Most of the men talked about treatment for PCa in terms of what they knew about cancer in general versus prostate treatment in particular. For example, several mentioned chemotherapy, which is not routinely used in prostate treatment. Also, only a small number of the men knew of the side effects of treatments, especially sexual dysfunction, or were under the impression that medications such as Viagra and Cialis are effective treatments for that but were unaware of the limits and side effects associated with those drugs. Although treatment options may have differential effects related to preferred sexual activities (e.g., radiation may cause bowel problems and pain that impede anal-receptive activities, and surgery is more likely to cause erectile dysfunction), the men were unaware of those possibilities or about how to address them.

Medical Care

There was a variation in responses to coming out to one's medical provider, although most of the men had done so and were adamant that it was important to do so. While most did not discuss coming out to a physician as a major issue or concern, some simply did not feel the need to tell their

doctors about their sexual orientation, saying they did not see the relevance of providing this information. It is difficult to say how much of that was motivated by concerns about their medical treatment or rejection. Several wanted gay-friendly doctors and clinics to be identified or made available. It is clear that the lack of systematic identification of sexual orientation in cancer registries and research makes this population invisible to their practitioners and inaccessible to researchers. Not sharing sexual orientation may be seen as unimportant or irrelevant or leading to potential discrimination against gay men, but, in fact, it has relevance for practice as well as research.

Each focus group had at least a few HIV-positive men. This subgroup raised important questions. Since the primary focus of their health care was HIV, other health and aging concerns tended to be regarded as less significant. One man noted that if a problem is not seen as HIV related, it is ignored by his HIV doctor. A related issue was coordination of care when one has multiple health problems when HIV-positive status is such a major focus. Another man wanted to know if HIV increased the risk of PCa. The fact that we have no extant data on the risks of PCa among HIV-positive men means that such questions cannot be answered.

Health insurance plays an important role in the medical care and screening tests available. Although most of the participants were covered by some insurance, those with government health insurance or who were unemployed, in particular, reported not getting adequate health care. Also, those with insurance but limited incomes spoke about co-pays for doctor visits and other costs associated with medical care as creating obstacles. While this is true for non-gay individuals as well, gay men are more likely not to have access to a partner's insurance or other benefits.

It is noteworthy that the level of anticipated emotional distress caused by both a diagnosis of cancer and the treatments made some wonder if a gay man may become suicidal. As such they would be at high risk of mental health problems and would need care.

Seeking Support

None of the men in these focus groups had been diagnosed with PCa. When asked whether they would seek support groups if they had been offered, some, but not all, said they might. Those who said they would uniformly said it did not matter if the groups were gay or not. Some believed that men going through PCa would be welcoming of any other man in the same situation. This echoes our earlier discussion of the common de-identification of health issues from one's sexual orientation and gender identity. Quite a few participants felt that created families or families of origin were important for social support. In a few cases, the men said they would seek family support even though their family wasn't aware of their sexual orientation.

Unlike letting family know about being HIV positive, PCa is seen as a men's health issue rather than a gay issue. Therefore, seeking family support does not necessitate disclosure.

Many participants expressed romantic notions and expectations that if they were in a solid relationship, their partners would be with them and support them through the cancer and treatment. However, as noted earlier, some men felt that being in a partnered relationship would be disadvantageous to adjustment while others felt it would be advantageous. Clearly, that depends on their view of what constitutes a strong partnered relationship. One interesting interchange in one of the focus groups indicated the complexity of this issue. A man in a long-term relationship stated that a relationship would make having prostate cancer-related problems worse because of the inability to fulfill expectations to hold up one's part of the sexual relationship, while another, also in a long-term relationship, indicated how it would be easier to deal with the disease because of the partner. He framed it in two important ways, one specifically related to aging: (1) His partner would understand and not let it get in the way of the broader intimate relationship; and (2) because of aging they had already decreased the frequency and intensity of their sexual activities, and so this could just close the book on that aspect of their lives. Thus, we find considerable disagreement about the advantages or disadvantages of obtaining social support from a long-term partnered relationship. Some participants pointed to the gay male community as possibly more intolerant of sexual dysfunction and therefore indicated that if a man were single, he could be isolated and alone.

CONCLUSION

The data from the focus groups and the specific issue of PCa illustrate and reinforce many of the points made in the first part of this paper about health, aging, support, and GLBTQ populations. These include

1. The invisibility of GLBTQ people within the health care system (Blank, 2005; Boehmer, 2002; Pugh, 2005; Trettin et al., 2005);
2. the lack of effective doctor-patient communication;
3. the lack of openly GLBTQ clinical providers;
4. the need for GLBTQ-affirming physical and mental health services that are sensitive to the unique issues affecting GLBTQ individuals and their families;
5. the need for health insurance benefits for same-sex couples; the lack of understanding of the types and meanings associated with sexual practices within the GLBTQ community reflected in medical education; and
6. the predominance of HIV/AIDS over other chronic health issues in gay men's lives.

Beyond the general confirmation of many of the points made in the overall review, specific issues raised in the focus groups bear upon some of the aspects of dealing with health and aging in a GLBTQ context we reported above. For example, there has been considerable discussion about the relative merits of being in a partnered relationship or being single and of having a range of fictive kin to rely on (Grossman et al., 2001; Haas, 2002; Potoczniak et al., 2007; Weinstock, 2004). Most of that research has emphasized the positive aspects of being partnered for dealing with health issues, and that is paralleled by some of our participants. Yet, other participants strongly emphasized the potential problems of being partnered; the degree to which this is specific to GLBTQ populations or specific to PCa (in terms of dealing with treatment-induced sexual problems) is not known at this time. In a similar vein, whereas Jacobs and colleagues (1999) reported a preference to use support groups specific to GLBTQ populations, men in our focus groups seemed much more amenable to any focus group in which they shared the common bond of PCa regardless of sexual orientation of other members of the group.

All of the focus group participants seemed very enthusiastic about learning more about health issues and what role sexual orientation plays in health and aging. Therefore, an eager community is waiting to be approached and educated. The interest and need for knowledge is valuable news for health educators and GLBTQ leaders. Also, if GLBTQ populations can be made aware of how important it is for the future of GLBTQs' health to open up about sexual orientation, we would have many more opportunities to increase the research that could answer the kinds of questions addressed in our groups and the amount of tailored information that could become available. Correspondingly, researchers on cancer and other diseases and conditions related to aging can be made aware of the value of gaining access to and understanding of GLBTQ populations.

In all this, of course, it must be stressed that many aspects of preventing, treating, and dealing with psychological and social impacts of PCa or other chronic diseases are likely to be sexual-orientation neutral. However, the dearth of information currently means that the degree of differences and similarities of heterosexual and gay populations dealing with PCa are simply unknown. Open discussion can provide the initial grounding for all the populations of concern, enhancing the sensitivity to diversity in prevention and screening, treatment, and survivorship. The diversity of orientations, knowledge, and behaviors in the members of our focus groups graphically illustrates the necessity of giving all men who may deal with PCa their voices so that commonality and difference can both be recognized.

Due to wide variations and diversity in what men bring to their diagnosis of PCa, where they live, whom they interact with, and their care providers, each person is on his own partly unique trajectory. Often these trajectories

combine the impacts of personal and social resources and liabilities, and they often include both elements of loss and of gain, of distress and growth. The more that our models of persons dealing with PCa and other chronic diseases—and our understanding of families and of aging—reflect the diversity of experiences, explicitly including sexual orientation and gender identity, the better equipped we will be to provide support and information that will enable them to integrate their disease experiences into their senses of themselves and their relationships with partners, families, communities, and the health care system.

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