Addressing the Need for LGBTQI-Affirming Care: A Focus on Sexual and Gender Minority Prostate Cancer Survivors

A Guide for Health Care Professionals

December 2017

This guide was made possible through a grant from the Association of Oncology Social Work.
INTRODUCTION

This guide serves as a starting point for health care professionals to learn about the unique challenges experienced by individuals who identify as lesbian, gay, bisexual, transgender, queer and intersex (LGBTQI) in the health care setting.

We use the term sexual and gender minorities (SGM). This term is meant to broadly include anyone with prostate cancer who identifies as part of the LGBTQI spectrum. This guide focuses on the impact of a prostate cancer diagnosis among these individuals. Complementary patient education materials for men who have sex with men and transgender or gender non-conforming individuals are also available.

HETERONORMATIVE CARE AND ITS CONSEQUENCES

There is a long history of discrimination and marginalization among SGM in health care. As a result of this approach to care, SGM often report (Burgess, Lee, Tran & Van Ryn, 2015; Institute of Medicine, 2015):

- Low levels of trust in providers
- Fear of discrimination
- Privacy concerns
- Invasive and inappropriate questioning
- Poor patient-provider communication
- Lack of provider awareness and sensitivity
- Unmet needs

Health care professionals and organizations want to provide high quality care to all patients. Yet, data indicates that not all patients in the United States receive the same care.

UNIQUE CARE NEEDS FOR SGM PROSTATE CANCER SURVIVORS

Data for prostate cancer in SGM are limited. It is estimated that 2 to 10 percent of men diagnosed with prostate cancer are gay (Carroll, 2007). Transgender-specific data for prostate cancer is rarely reported.

SGM with prostate cancer have unique needs that have historically been overlooked. These include physical, psychological and social issues that require special attention from the health care team.

For instance, for SGM who were solely the insertive partner prior to a prostate cancer diagnosis, losing the ability to be the insertive partner because of erectile dysfunction or having to explore changing roles with a partner can have a significant impact on their identity. Some SGM are reluctant to become the receptive partner because of what it means in terms of their sexual sense of self and how they relate to their partner’s sexuality (Lee, Breau & Eapen, 2013; Thomas, Wootteen & Robinson, 2013; Ussher et al., 2016). Additionally, sometimes it is not medically possible for partners to switch roles.

When addressing side effects, the needs of SGM may be unique. For example, most sexual rehabilitation is focused on creating an erection sufficient for vaginal penetration. Yet, anal penetration requires a firmer erection than is available from oral treatments for erectile dysfunction (Asencio, Blank, Descartes & Crawford, 2009).
STRATEGIES TO PROVIDE AFFIRMING AND CULTURALLY SENSITIVE CARE

These strategies can help you provide a welcoming environment for SGM:

Organizations should:

- Educate team members and staff about the needs of SGM patients and cancer survivors.
- Tailor conversations/materials so cisgender and heterosexuality is not assumed.
- Create SGM cancer support groups.
- Assess current practices and take steps to address issues you identify.
- Advocate for sexual orientation and gender identity (SOGI) information to be included in clinical and research data.
- Ask SOGI questions on your intake form.
- Post or provide nondiscrimination policies.
- Post pictures and signs that are inclusive of all patients.

Health care providers should:

- Ask all of your patients about their SOGI. The more you practice, the easier it will become.
- Listen to the terms your patient uses to identify themselves and communicate those terms back to the patient. When in doubt, politely ask. This glossary of common terms may help.
- Use the patient's chosen name during interactions, not their birth name.
- Check your assumptions and recognize your own biases (we all have them) including the ways that they may influence how you provide care.
- Avoid microaggressions like name-calling, rudeness, gossiping, refusing care or dismissing past experiences.
- Ask about a patient’s support system, including the important partner(s) for making decisions. This can include support networks like friends, partner(s), paid caregivers and/or coworkers.
- Never discuss a patient’s SOGI with anyone outside the care team.
- Never ask questions to satisfy your own curiosity.
- Ask open-ended questions.
- Acknowledge mistakes and learn from them.

“It’s helpful to find ways to let the patients know that you’re a safe person. That you’re comfortable with diverse populations. That you’re there to help and be an ally and not be judgmental.”

-SOCIAL WORKER

Invisible Diversity

There is insufficient clinical and research data that highlight the specific experiences of LGBTQI individuals. This leads to a poor understanding of needs and how to best address these needs. The American Society of Clinical Oncology (ASCO) recommends that questions about sexual orientation and gender identity be included in federally-funded health surveys, cancer registries and clinical trials (Griggs et al., 2017).
PROVIDER CHECKLIST

Care Preferences
- Ask about values
- Assess comorbidities (e.g. chronic conditions) for impact on treatment options
- Discuss how side effects may impact work/hobbies
- Ask who should be engaged in care decisions
- Discuss cost of treatments prior to initiation
- Create treatment plan together
- Educate patient on next steps

Sexual Dysfunction
- Assess/treat for:
  - Penile shortening (S)
  - Changes in orgasm (S)
  - Erectile dysfunction (S, R, H)
  - Lack of/less ejaculation (S, R)
  - Loss of libido (H)

Urinary Dysfunction
- Assess/treat for:
  - Incontinence (S, R)
  - Frequency (S, R)
  - Urgency, (S, R)
  - Scarring (S, R)
  - Urethral stricture (R)
  - Hematuria (R)

Relationships
- Ask all patients about sexual orientation, gender identity and relationship status
- Affirm patient support systems
- Discuss social role and relationship changes, refer to social work as indicated
- Ask about impact on dating
- Ask about challenges
- Use open-ended questions

Bowel Dysfunction
- Assess/treat for:
  - Incontinence (R)
  - Frequency (R)
  - Urgency (R)
  - Blood in stool (R)
  - Pain (R)
  - Inflammation of rectum (R)
  - Rectal bleeding (R)

Emotional Changes
- Assess for emotional changes
- Affirm that mood changes are normal
- Refer to social work as indicated

Supportive Care
- Assess for pain/provide palliation
- Document advance care plan
- Assess for psychosocial impacts/refer to social work for:
  - Fear of recurrence
  - Depression
  - Anxiety
  - Pain
  - Body image
  - Financial stress

Other Symptoms
- Assess/treat for:
  - Diabetes (H)
  - Cardiotoxicity (H)
  - Vertigo (H)
  - Loss of muscle/increase in fat (H)
  - Emotional/mood changes (H)
  - Weight gain (H)
  - Swelling of breast tissue (H)
  - Fatigue (H)
  - Sweats (H)
  - Body hair loss (H)

Effects based on modality indicated by S=surgery, R=radiation, H=hormone therapy. Adapted from Skolarus et al. (2014). Access the National Cancer Survivorship Resource Center Provider Toolkit and patient education materials.
RESOURCES

Below are a list of resources to support you and your patients.

<table>
<thead>
<tr>
<th>NAME</th>
<th>SERVICES</th>
<th>WEBPAGE</th>
<th>PHONE</th>
</tr>
</thead>
<tbody>
<tr>
<td>American Bar Association</td>
<td>Legal help; pro bono service directory; helpline</td>
<td><a href="http://www.americanbar.org/">www.americanbar.org/</a></td>
<td>1-800-285-2221</td>
</tr>
<tr>
<td>Association of Oncology Social Work</td>
<td>Resource list for patients and caregivers</td>
<td>bit.ly/AOSWResources</td>
<td>847-686-2233</td>
</tr>
<tr>
<td>CancerCare</td>
<td>Support groups; counseling; financial aid; education; helpline</td>
<td><a href="http://www.cancercare.org/">www.cancercare.org/</a></td>
<td>1-800-813-4673</td>
</tr>
<tr>
<td>CaringInfo</td>
<td>Advance care planning; palliative and hospice care information; helpline</td>
<td><a href="http://www.caringinfo.org/">www.caringinfo.org/</a></td>
<td>1-800-658-8898</td>
</tr>
<tr>
<td>Cancer and Careers</td>
<td>Career coach; legal and financial aid</td>
<td><a href="http://www.cancerandcareers.org">www.cancerandcareers.org</a></td>
<td>646-929-8032</td>
</tr>
<tr>
<td>Fenway Institute National LGBT Health Education Center</td>
<td>LGBTQI related educational programs, resources and consultations for health care organizations</td>
<td><a href="http://www.lgbthealtheducation.org">www.lgbthealtheducation.org</a></td>
<td>617-927-6354</td>
</tr>
<tr>
<td>Lambda Legal</td>
<td>Advance care planning; LGBTQI healthcare rights information</td>
<td><a href="http://www.lambdalegal.org/">www.lambdalegal.org/</a></td>
<td>1-212-809-8585</td>
</tr>
<tr>
<td>LGBT Cancer Project</td>
<td>Support groups; online forums; clinical directory</td>
<td><a href="http://www.lgbtcancer.org/">www.lgbtcancer.org/</a></td>
<td>N/A</td>
</tr>
<tr>
<td>LGBT HealthLink</td>
<td>LGBTQI healthcare rights; LGBTQI related educational resources</td>
<td><a href="http://www.lgbthealthlink.org">www.lgbthealthlink.org</a></td>
<td>954-765-6024</td>
</tr>
<tr>
<td>Malecare</td>
<td>Gay &amp; Bisexual Prostate Cancer Support groups; clinical research information; online forums</td>
<td><a href="http://www.malecare.org/">www.malecare.org/</a></td>
<td>212-673-4920</td>
</tr>
<tr>
<td>National Cancer Institute</td>
<td>Information about prostate cancer treatments, side effects and support</td>
<td><a href="http://bit.ly/NCIPrCa">http://bit.ly/NCIPrCa</a></td>
<td>1-800-422-6237</td>
</tr>
<tr>
<td>National LGBT Cancer Network</td>
<td>LGBTQI-friendly clinical directory; support groups; cancer treatment information</td>
<td><a href="http://www.cancer-network.org/">www.cancer-network.org/</a></td>
<td>1-212-675-2633</td>
</tr>
<tr>
<td>The New York State Department of Health</td>
<td>Best practices for asking patients about SOGI</td>
<td><a href="http://bit.ly/SOGBestPract">http://bit.ly/SOGBestPract</a></td>
<td>N/A</td>
</tr>
<tr>
<td>The Patient Advocate Foundation</td>
<td>Financial aid; case management assistance; helpline</td>
<td><a href="http://www.patientadvocate.org/">www.patientadvocate.org/</a></td>
<td>1-800-532-5274</td>
</tr>
<tr>
<td>The Prostate Cancer Research Institute</td>
<td>Cancer treatment information; clinical research information; helpline</td>
<td><a href="http://www.pcri.org/">www.pcri.org/</a></td>
<td>1-424-261-3727</td>
</tr>
<tr>
<td>Triage Cancer</td>
<td>Cancer survivorship education; access information; legal and financial information</td>
<td><a href="http://www.triagecancer.org">www.triagecancer.org</a></td>
<td>424-258-4628</td>
</tr>
<tr>
<td>University of California, San Francisco Center of Excellence for Transgender Health</td>
<td>Resources for providers and patients</td>
<td><a href="http://www.transhealth.ucsf.edu">www.transhealth.ucsf.edu</a></td>
<td>N/A</td>
</tr>
<tr>
<td>Zero: The End of Prostate Cancer</td>
<td>Free testing center directory; health, screening, and treatment information; financial aid</td>
<td><a href="http://www.zerocancer.org/">www.zerocancer.org/</a></td>
<td>1-844-244-1309</td>
</tr>
</tbody>
</table>
GLOSSARY

**Bisexual:** Refers to people who have romantic ties to people of the same gender and different genders (Laumann, Gangnon, Michael & Michaels, 1994).

**Cisgender:** Individuals whose gender identity aligns with sex assigned at birth. “Cis” stands for “consistent in sex.”

**Gay:** Refers to men who have primary sexual, romantic and relational ties to other men. Some cultures don’t identify with the term “gay.” “Same gender loving” may be a preferred term for some men. Researchers tend to use the term “men who have sex with men” or MSM, but this term is not typically used by patients.

**Gender identity:** An individual’s self-concept as male, female or neither.

**Genderqueer or Gender Non-Conforming:** Individuals who may not adhere to strict gender categories.

**Heterosexual or Straight:** People who do not identify as a sexual minority.

**Intersex:** Refers to people who have differences in anatomy (reproductive or sexual) that do not fit into typical definitions of male and female.

**Lesbian:** Refers to women who have primary sexual, romantic and relational ties to other women. Not all women who are primarily attracted to women identify with the term “lesbian.” You may hear the term “women who partner with women” or other terms.

**Queer:** A more fluid sexual orientation term referring to someone who does not identify as straight.

**Sexual orientation:** A complex idea that includes a combination of sexual and romantic attraction, behavior and identity.

**Transgender:** Individuals who have a gender identity that does not align with the sex they were assigned at birth (GLAAD, n.d.).
SAMPLE SEXUAL ORIENTATION AND GENDER IDENTITY QUESTIONS

These are currently what research has shown to be the best ways of wording these questions on a survey.

Do you think of yourself as:
- Straight
- Lesbian, gay or homosexual
- Bisexual
- Something else
- Don’t know

What is your current relationship status?
- Married
- Partnered
- Single
- Widowed
- Divorced
- Other

What is your current gender identity?
- Male/man
- Female/woman
- Trans male/Female-to-male
- Trans woman/Male-to-female
- Genderqueer
- Other

What sex were you assigned on your original birth certificate?*
- Male
- Female
- Intersex

*When interviewing a patient verbally, you might reword this question to the following: “Knowing your medical history helps me provide the best care to you. Also, insurance may require your sex assigned at birth for certain procedures. Can you tell me what sex you were assigned on your original birth certificate and anything I should know about body changes you have had as a gender non-conforming person?”
REFERENCES


