Background  The end-of-life care needs of lesbian, gay, bisexual, and transgender/transsexual (LGBT) patients are in many ways identical to those of non-LGBT patients. However, health care providers should recognize that some unique considerations exist. This Fast Fact discusses the issues of advance care planning and partner and family involvement, as they pertain to LGBT patients. It ends with a discussion about open communication regarding sexual orientation, and how this may be facilitated by providers. While there is minimal literature on the end-of-life care needs specific to transgender individuals, we feel that the summary and recommendations presented below, though based largely on data regarding lesbian, gay, and bisexual patients, apply to the transgender population as well.

Advance Care Planning  The inclusion of same-sex partners in decision-making and treatment planning has been repeatedly shown to be a priority for LGBT patients facing life-limiting illness (1).

- Those who desire their same-sex unwed partner to be their health care representative (“health care power of attorney” or “health care agent/proxy”) must complete an Advance Directive (AD) formally making such a designation. Without such documentation, a same-sex partner may have limited or no rights regarding the medical decision-making and treatment planning for his or her partner, especially if there has been a history of non-acceptance of the same-sex relationship by the patient’s biological family members (2,3).

- One study suggests that while a majority of LGBT patients are knowledgeable about ADs and the appointment of health care proxies, only 49% of those who desire a same-sex partner to be their surrogate decision maker have completed the necessary documentation (3). Clinicians should educate patients about the importance of completing such documentation, such that medical and end-of-life wishes can be met.

- After a 2015 Supreme Court ruling (Obergefell v Hodges), same-sex marriage has been legal throughout the US. Regardless, even legally married LGBT individuals who want their spouse to be their surrogate decision makers are advised to complete legal ADs designating that.

Partner and Family Involvement  LGBT patients may receive support from unique social circles, sometimes referred to as “lavender families” or “families of choice,” with whom they find acceptance. Such families may be comprised of heterosexual friends, other members of the LGBT community, co-workers, and biological relatives, all of whom may provide support at the end-of-life (2,4).

- The end-of-life can be a time of reunion and reconciliation with estranged family and friends, and this may be especially true for LGBT patients who may have experienced isolation from these individuals in the past due to their sexual orientation (2). Providers should be sensitive to the potentially complex family and social dynamics that these reunions can create for both the patient and his or her partner. For instance, a patient’s family may initiate some reconciliation with a patient, but in a way that denies the role of the partner or family of choice. Additionally, when such reunions do not occur, feelings of grief, loss, and abandonment experienced by an LGBT individual at the end-of-life may be magnified.

- Clinicians should ask the patient whether his or her biological family knows that his or her surrogate decision maker is the patient’s LGBT partner. Trouble-shooting with the patient on how to proactively communicate this may help avoid conflicts as the patient is actively dying.

- Partners facing the loss of their same-sex loved one may experience disenfranchised grief – grief which is not acknowledged or viewed as legitimate, owing to the relationship not being fully recognized by one’s family or community (5,6). Such disenfranchisement may limit the partner’s ability to grieve openly, result in a lack of bereavement support from health care professionals, and augment feelings of isolation (2,5). Clinicians should be sensitive to this when monitoring the grief reaction and proactively offer bereavement support services as indicated.

Discussion of Sexual Orientation
• The decision of LGBT patients to discuss their sexual orientation with clinicians may be affected by past negative reactions to disclosure and, in some cases, discrimination concerns (1).
• As sexual orientation is intrinsic to a patient's social history, its recognition and acceptance by clinicians is essential to the provision of holistic and patient-centered palliative care. Additionally, an appreciation of a patient's sexuality and sexual orientation is pertinent to end-of-life care by facilitating meaningful engagement in life review and reflection (1).
• Clinicians should use inclusive language that does not presume a sexual orientation or relationship status when meeting with patients and/or their significant others (1). If unsure about how to address an individual, clinicians should let the person guide them. A good approach is to ask the patient to introduce significant others in the room and their role in his or her life. Once established, clinicians should generally use the term patients themselves use to describe their significant relationship, e.g., "boyfriend," "girlfriend," "wife," "husband," "partner," "roommate."
• When inquiring about a patient’s social history and support network, consider asking one or more of the following: Who is family for you? Whom do you most rely on for support? Do you currently have a significant other or partner? These questions avoid assumptions and allow patients to respond openly about their sexual orientation and those who may play an important role in their end-of-life care.

Resources
LGBT patients and their health care providers may find more information on advance care planning and other pertinent health care topics at the following websites:
• National Resource Center On LGBT Aging http://www.lgbtagingcenter.org
• Human Rights Campaign © (Section on Health & Aging) http://www.hrc.org/issues/health-and-aging

References

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