End-Of-Life and Palliative Care for Lesbian, Gay, Bisexual, Transgender, Queer or Questioning, or Another Diverse Gender Identity Older Adults

Evie Kalmar, MD, MS[a], Jeffrey Mariano, MD[b,*]

KEYWORDS

- Palliative care • Hospice • End of life • LGBTQ

KEY POINTS

- Palliative care is a type of specialized medical care for people living with serious illness.
- A history of trauma or discrimination in life and in health care can lead to avoidance or reluctance to receive care at the end of life.
- Lesbian, gay, bisexual, transgender, queer or questioning, or another diverse gender identity (LGBTQ+) people are more likely to have alternative family structures. It is important to engage in advance care planning to understand their values, clarify surrogate decision makers, and contribute to goal-concordant care at the end of life.
- Clinicians can follow recommendations in this article to ensure they are providing LGBTQ-inclusive palliative and hospice care.

INTRODUCTION

What Is Palliative Care?

Palliative care is a type of specialized medical care for people living with serious illness. Historically, palliative care focused on people with cancer, but it increasingly is available for people with other serious diagnoses such as dementia, heart failure, and chronic obstructive pulmonary disease. The goal of palliative care is to improve quality of life by providing support and relief with both the symptoms related to serious

---

[a] University of California, San Francisco, San Francisco Veterans Affairs Health, 4150 Clement Street, 181-G, San Francisco, CA 94121, USA; [b] Department of Geriatrics and Palliative Medicine, AGSF, Southern California Permanente Medical Group, Bernard J Tyson Kaiser Permanente School of Medicine, Kaiser Permanente West Los Angeles, 6041 Cadillac Avenue Module 150, Los Angeles, CA 90034, USA
* Corresponding author.
E-mail address: Jeffrey.D.Mariano@kp.org

Clin Geriatr Med 40 (2024) 333–345
https://doi.org/10.1016/j.cger.2023.11.004
0749-0690/24/Published by Elsevier Inc.

illness as well as the stress often associated with it. It is sometimes described as an extra layer of support. Unlike hospice care, which is a benefit for people in their last 6 months of life, palliative care can be provided at any stage of illness, including right after diagnosis.

Palliative care is provided by multidisciplinary teams, often including doctors, nurses, social workers, chaplains, and pharmacists. It can be provided to people in their homes, in the hospital, and other settings of care (ie, assisted living facilities, board and care homes). Good palliative care focuses on getting to know patients as people and understanding their values and what makes life worth living. This focus helps provide holistic, comprehensive care that is tailored to the individual. Beyond clinical care, palliative medicine looks to better understand, connect, and support not only the patient but also their support network.

The philosophy of palliative care aligns with providing high-quality, patient-centered, and trauma-informed care to lesbian, gay, bisexual, transgender, queer or questioning, or another diverse gender identity (LGBTQ+) people. As Kimberly Acquaviva[1] wrote in her book *LGBTQ-Inclusive Hospice and Palliative Care*, the goal should be to "shift from providing *special* care to LGBTQ+ people to instead providing *inclusive* care to *all* people, including those who are LGBTQ+." This does not mean treating everyone the same but, instead, means creating space for, respecting, and incorporating differences into care plans using cultural humility.

Locations of palliative care

Palliative care can be provided anywhere, though there distinguishing factors between primary and specialty palliative care. Primary palliative care refers to when palliative care elements such as advance care planning, assessing and management symptoms are completed by the primary care team or specialists.[2] Specialty palliative care refers to when palliative care is delivered by dedicated teams trained in palliative care. Many hospitals have inpatient palliative care consult teams. Increasingly, outpatient clinics offer specialty palliative care in clinic, by phone, and by video, which helps to support people in earlier stages of serious illness. Hospice care, which focuses on comfort and quality of life for people with a prognosis of less than 6 months, can also be provided in many settings.

The vast majority of people receiving hospice care receive it in their home through a home-visiting interdisciplinary hospice team. There are also options for hospice care in skilled nursing facilities and in dedicated hospice facilities for people whose care or symptom needs are greater than can be managed at home. As people with serious illnesses experience disease progression, they may transition from outpatient palliative care and other alternative home-based palliative/home visit programs to hospice, whetherhome or inpatient. For older LGBTQ+ adults, these transitions often involve meeting and establishing trust with a new health care team and a reluctance to enter long-term care facilities or other settings fearing they would need to conceal their sexual and/or gender identities to prevent discrimination.

Background of lesbian, gay, bisexual, transgender, queer or questioning, or another diverse gender identity people and palliative care

People's experience with serious illness is deeply influenced by their prior experiences with health care. In the case of LGBTQ+ individuals, it is unfortunately common to have experienced discrimination or bias in health care that may make people reluctant to seek needed care. This makes it that much more important to provide LGBTQ+-inclusive palliative care to create an environment where everyone feels safe and able to access palliative care. Even as recently as 2023, there are studies demonstrating that LGBT patients receiving palliative care were faced with inadequate, disrespectful, and even abusive care, even higher amongst transgender and gender diverse people.[3,4]

Family of choice and advance care planning

LGBTQ+ people are more likely to create their own families, choosing their family members in families of choice. A family of choice is one that is inclusive and based on emotional relationships, rather than only on legally recognized or biological relationships. LGBTQ+ older adults are more likely to be unpartnered, not have biological children, and live alone compared to the general population.[5] It was not until 2015 after the Supreme Court overturned the Defense of Marriage Act that marriage was legal for same sex couples in all 50 states. Before this, there was not a legal pathway to be recognized as a family for many LGBTQ+ couples. Historically, this meant many could be denied benefits or even visits from the next of kin who were not legally recognized. The implications of this denial of equality and discrimination faced by older LGBTQ+ adults cannot be overstated, particularly because it influences their interactions with health care to this day.

The fact that LGBTQ+ people are more likely to have alternative family structures highlights the importance of advance care planning and especially designation of a surrogate decision maker. Advance care planning is the process by which an individual can: 1) designate who they would trust to make medical decisions on their behalf if they no longer were able to do so themselves and 2) indicate their values and preferences around health care. This process can be important for everyone with serious illness and especially people who want to designate a nonfamily member to be their decision maker. Though it differs from state to state, most default hierarchies for surrogate decision makers are based on next of kin, prioritizing biological or legal family. Unfortunately, the rate of advance care planning remains low in the LGBTQ+ population, with one study from 2006 demonstrating that fewer than half of the people surveyed had an advance directive or durable power of attorney for health care.[6]

Considerations

LGBTQ+ people face unique challenges while receiving palliative care and hospice services. Studies have shown LGBTQ+ cohort experience lower quality of care and there is a dearth of literature on experience of LGBTQ+ patients and their family members receiving hospice care.[7]

Barriers to care

Systemic barriers occur at the systems level (representing systems, institutions, and services) and the individual level (characteristics directly impacting those seeking care), and combined, they provide a barrier to LGBTQ+ wishing to access end-of-life care. Some examples of these barriers are described in **Table 1**.

Intersectionality

The heterogeneity of LGBTQ+ older adults across populations, countries, and cultures highlights the important role of intersectionality. Intersectionality can be defined as the interconnected nature of social categorizations applied to a given individual or group, that creates overlapping and interdependent systems of discrimination, disadvantage, and marginalization. This can be sociopolitical and personal and, unfortunately, may also lead to internalized negative feelings associated with identity, such as internalized homophobia.

Table 1
Potential barriers to palliative and hospice care

Potential Health Care Organization Barriers	Potential Consequences
Heterosexist assumptions of patient's sexual and gender identity	Lack of inclusion of families of choice in decision-making
Lack of provider training about caring for SGM patients	SGM patients' needs may not be understood, and they may experience bias from their provider (conscious or unconscious)
Lack of culturally competent caregiver support and bereavement groups	Higher levels of caregiver strain and disenfranchised grief
Lack of integration and availability of resources for SGM people	Lower levels of satisfaction with care
Potential sexual and gender minority barriers	Potential consequences
Estrangement from family of origin	Incorrect assumptions in regard to surrogate decision-making
Higher rates of mistrust of health care systems	Delayed uptake of medical care
Nondisclosure of SGM status	Higher levels of disease-associated distress
Fear of discrimination by health care providers	Nondisclosure of SGM status and need to distance from friends and community
Complexity of relationship with religious-based organizations	Delayed access to care; reluctance to use pastoral care resources
Isolation and lack of social support	Greater levels of disease-associated distress
Potential societal, health care insurance, and legal barriers	Potential consequences
Variability in and potential fragility of legal protections	Loss of access of SGM spouses or partners to health care insurance
Lack of comprehensive legal protections	Child custody not formalized; burial rights for transgender individuals not observed

Abbreviation: SGM, sexual and gender minority.

From Maingi S, Bagabag AE, O'Mahony S. Current Best Practices for Sexual and Gender Minorities in Hospice and Palliative Care Settings. J Pain Symptom Manage. 2018 May;55(5):1420-1427. https://doi.org/10.1016/j.jpainsymman.2017.12.479. Epub 2017 Dec 27. PMID: 29288882, with permission

By acknowledging intersectionality, we can understand its impact in the experience of receiving health care and palliative and end-of-life care.

One framework for evaluating intersectionality is the ADDRESSING mnemonic, demonstrated in **Box 1**.[8] Intersectionality and cultural humility are reinforced when clinicians are open to attending to the many complexities of intergroup and intragroup differences. Only the patient can tell you which sets of identities are most salient to them and in what ways (for more on cultural humility and affirming care, please see N.M. Javier & R. Noy's, "Affirming Care for LGBTQ+ Patients", in this issue).

To illustrate the point of intersectionality within the LGBTQ+ population, consider the identity "Gay Asian American." This term encompasses numerous religious, geographic, acculturation levels as reflected in the ADDRESSING mnemonic. Thus, there is no such thing as a homogeneous LGBTQ+ Asian American approach to end-of-life decision-making. Culture and intersectionality *inform* decision-making but does not *determine* it.

Serious and progressive illness create priorities at the end of life that may be universal.[9] These include comfort and not being in pain, good communication between

Box 1
ADDRESSING mnemonic for elements of culture and intersectionality

- Age and cohort effects
- Degree of physical ability
- Degree of cognitive ability
- Religion
- Ethnicity and race
- Socioeconomic status
- Sexual orientation and gender identity
- Individualistic life experiences (such as trauma or level of acculturation)
- National origin
- Gender role expectations

patient and clinicians, maintaining hope, honoring spiritual beliefs, fixing relationships, making plans, and saying goodbye. These human values, however, are also colored by a wide array of intercultural and intracultural variations. It is only by asking about culture, identity, and values that we can begin to understand a person and provide patient-centered care.

Case Presentation

Mr S is an 80-year-old male who was recently diagnosed with stage IV non-small cell lung cancer with metastases to brain. He is at his outpatient palliative care clinic appointment.

His chief complaints are worsening memory, pain, anorexia, and weight loss. He is accompanied by Mr P, a 66-year-old Filipinx male, who is his partner of 15 years. The palliative care nurse commented to Mr P, “You are doing such a great job taking care of him. Are you a nurse? Also your English is so good. Where are you from? Is there someone else who makes decisions for him if he were unable?” He did not correct her.

Minority Stress

The case presentation illustrates “minority stress,” the excess stress that individuals from stigmatized social categories are exposed to because of their social minority position. One definition of minority stress widely used is “the chronic, cumulative stress associated with stigma, due to objective events such as discrimination and victimization and psychological responses to these events such as internalized shame.”[10–12] The cumulative stress caused by stigma and social marginalization is a set up for chronic stress and related health problems.

Microaggressions

Microaggressions are brief verbal, behavioral, or environmental indignities, whether intentional or unintentional, that communicate hostile, derogatory, or negative slights and insults. They also can fracture patient-provider relationships and limit the trust that is so important in palliative care relationships.

It is important to recognize that by the time a person is engaging with palliative care, they likely have a long history of experiencing microaggressions and this can impact their openness to care.

Clinical Pearl

Microaggressions often occur toward people of sexual and gender minorities and can negatively impact people's openness to care, even at the end of life.

These include

- Endorsement of heteronormative or gender normative culture and behaviors (eg, assuming someone of the opposite sex is a patient's partner in a family meeting rather than asking for introductions and relationship to the patient)
- Discomfort or disapproval of LGBTQ+ experiences
- Assumption of a universal LGBTQ+ experience (eg, assuming an LGBTQ+ patient on hospice does not have any children or that sexual orientation is a big part of who they are)
- Exoticization
- Denial of the reality of heterosexism and genderism (eg, not asking about someone's experience of prejudice or trauma related to their identities)
- Assumption about someone's sexual orientation or gender identity based on appearances (eg, assuming someone who has a partner of the opposite gender is heterosexual when in fact they may be bisexual)

Case Continued

Mr S was hospitalized after a seizure and the inpatient palliative care team was consulted. The inpatient team recommended discharge to a skilled nursing facility for rehabilitation. Mr S discussed this with Mr P and their friends. They recognized that he was weaker and might need more care than at home, but he ultimately declined referral to the skilled nursing facility based on the negative experience of a friend who died in a nursing facility during the acquired immune deficiency syndrome (AIDS) epidemic.

Social Safety

Social safety refers to reliable social connection, inclusion, protection, and degree of social belonging, which are core human needs that are imperiled by societal and interpersonal stigma. Lack of social safety exacerbates the chronic threat vigilance of minority stress and compounds the negative long-term effects on cognitive, emotional, and immunologic functioning.[13,14] Many LGBTQ+ individuals may have both minority stress and lack of social safety creating cumulative effects in their experience with serious illness. Taking a patient-centered approach, palliative care teams view the person beyond the disease and can help address social safety concerns, improve their quality of life, and empower families of choice.

Recommendations

In order to best serve LGBTQ+ older adults, the authors recommend a trauma-informed care approach and better understanding the biases in end-of-life care.

Trauma-Informed Care

Trauma-informed care is an organizational approach to care that assumes that everyone who encounters the system might have had a past traumatic event. The goal is to enact practices to avoid retraumatization.[15] This approach is critical in palliative and end-of-life care because past trauma plays a role in how people react to and cope with pain, serious illness, change in function, and loss.

Utilizing the ADDRESSING model in Table 1, clinicians can explore individualistic life experiences that might contribute to trauma including childhood and adult physical abuse, emotional abuse, sexual abuse, neglect, intimate partner violence, and community violence, as well as structural violence in our society including racism, sexism, xenophobia, homophobia, and transphobia.

Maladaptive responses to trauma experiences that lie dormant for long periods may emerge later in life or when facing serious diseases. The possibility of death itself is a trauma and a history of psychological trauma can make managing the symptoms of end of life more challenging. This challenge arises from the association of trauma history with post-traumatic stress disorder (PTSD) and higher levels of chronic pain. Also, life review is a common practice that focuses on meaning-making and closure among people who are dying, and this may include the integration of past traumatic events which may retraumatize the individual. Prior trauma can also resurface in family members or even the care team. For palliative care and hospice providers, such experiences may be particularly difficult due to repeated exposure to death and reactivation of prior trauma.

Clinical Pearl: Look for Markers of Trauma

- Certain conditions that are highly correlated with recent and past trauma include heart, lung, and liver diseases; obesity and diabetes; substance abuse and overdose; and mental health issues such as depression, PTSD, and anxiety.
- If these are on a patient’s problem list, consider screening further for a history of trauma.

Trauma-informed care can help mitigate disparities and create a space of safety and support. For LGBTQ+ older adults, histories of trauma, including minority stress/discrimination and adverse childhood events, are strongly associated with future burden of physical and mental illnesses. This means that past or present trauma may be an active factor in decision-making for any patient facing a serious illness and more so when the serious illness is combined with other societal experiences as in LGBTQ+ older adults.

Several evidence-based approaches to trauma-informed care have been developed. An important element in all of these approaches is the initial screening for histories of trauma, which ideally should be done as early as possible. Universal screening reduces the risk of providers making assumptions about burdens of trauma merely because of a patient’s racial, ethnic, and/or sexual identity.

For palliative care, the authors recommend using the 5 principles of trauma-informed care that include providing safety, establishing trust, enabling patient choice, facilitating collaboration, and empowering the patient. Utilizing the framework of trauma-informed care, there has been an important shift from considering “what is wrong with you?” which can trigger past trauma or lead to shame to “what has happened to you and how can our team best support you and your family of choice?” Open-ended, nonjudgmental questions in a safe, affirming clinical space can prove crucial in learning about a patient’s trauma history. To set this stage, one might share, “Difficult life experiences, like growing up in a family where you were hurt, or where there was mental illness or drug/alcohol issues, or witnessing violence, can affect our health. Do you feel like any of your past experiences affect your physical or emotional health?” After experiences are shared, make sure to support the patient and acknowledge the bravery of sharing.

For palliative medicine patients experiencing progressive and serious illnesses on top of normal aging, an awareness of the presence of psychological trauma is important. Traumatic events including engagement in the health system (ie, ICU, hospital, clinic), interpersonal and intrapersonal stigma (ie,internalized homophobia), historical events (ie,the AIDS epidemic and survivorship), and other serious illness end-of-life experiences can compound the expression and experience of total pain (ie,physical, psychological, social and spiritual) and symptom burden. This reality highlights the importance of adopting affirming care, since these elements of someone's health may be unknown and unaddressed unless they are screened (see N.M. Javier & R. Noy's, "Affirming Care for LGBTQ+ Patients", in this issue).

Recognizing Bias and Earning Trust

Trust is the cornerstone of a successful clinical relationship with a patient facing a serious illness. Yet stigma and the multitude of isms and phobias (ageism, racism, transphobia, homophobia) are ubiquitous within society as well as within medical institutions. These forms of historical and present discrimination perpetuate health disparities and contribute to worse health outcomes.[16,17] As discussed earlier, this is especially true for sexual and gender minority people and bias can show up and create barriers to care. The SEEDS model describes different forms of bias that might show up in palliative or end-of life care, including 1) similarity bias where people have differential responses to people who are more similar to them, 2) expedience or confirmation bias such as a lack of openness to hearing from something from a patient that goes against what the provider expects or believes, 3) experience bias where people may project their own assumptions about quality of life on their patients or may assume they know about the patient because of past interactions with similar patients, 4) distance bias where priority may be given to the most vocal family member over what has been documented about a patient's longstanding values, 5) safety bias such as favoring choices based on risk aversion or sunk cost, or based on misleading way of framing (eg, "Should we do everything for your loved one or should we switch to comfort care?").[18–22]

Being aware of bias, the presence of microaggressions, and the impact of verbal and nonverbal language is essential. This is especially true when an individual is confronted with a serious illness, letting us view their coping through the lens of minority stress and social safety. A nonjudgmental, culturally humble approach is recommended to best support the individual being cared for at the intersection of their identities and their illness.

Approach Decision-Making with Cultural Humility

What are the specific ways in which specific LGBTQ+ cultural identities inform decision-making at the end of life? Because there is no one-to-one correspondence between cultural identity and decision-making style, here the authors will highlight the patterns of decision-making themselves. These are some of the main questions and possibilities to assess with each individual patient and family.

First, who makes the medical decisions? In Western bioethics and legal systems, if a patient has mental capacity and legal competence to make medical decisions, that is their unassailable right. Yet patients of different cultures choose to involve families of choice or community in their decision-making to a lesser or greater extent. Studies have shown that the majority of participants across all demographic groups preferred an approach of shared decision-making.[20]

Second, how much information should be disclosed to the patient? Once again, Western bioethics and legal systems have 1 clear approach: it is the patient's right to know everything. Yet some patients will prefer **not** to know all their diagnostic and prognostic information, and that is also their right. In some communities, there is a belief that bad news or discussing death will hasten death.[21]

Third, what are the health disparities and associated barriers to care? How can they be addressed? As cited earlier in the article, challenges with access to care, acceptance, and stigma can create barriers seen more commonly in LGBTQ+ communities.

Fourth, what are the meanings ascribed to suffering, to dignity, and to death? How do these differing meanings translate into differing priorities for end-of-life treatments and trajectories? What takes priority: struggle or comfort?

In sum, these domains of difference give a sense of the great heterogeneity both across and within the LGBTQ+ community. The clinician must, therefore, adopt an open and nonjudgmental approach to respond appropriately to the cultural nuances in the decision-making process and help create a patient-centered care plan.

To reduce bias and stigma, the authors recommend incorporating standardized assessments of such preferences into the care of every patient, instead of attempting to guess when particular patients or families of choice might have divergent perspectives. In **Box 2**, the authors describe best practices for addressing LGBTQ+-inclusive decision-making or advance care planning.

DISCUSSION

The authors emphasize that any clinician, not just those working in palliative care, can and should use an approach to shared decision-making that is informed by cultural humility and structural competency.

Communication in serious illnesses and end-of-life care should be regarded as a procedure that improves with practice and a standardized, patient-centered approach. Studies show that patients wish to speak with clinicians frankly to receive

Box 2
Recommendations for addressing decision-making in serious illness

1. Adapt existing best practices around value-based, shared decision-making to mitigate bias and foster person-centered care.
    a. Resources: Prepare For Your Care (https://prepareforyourcare.org/), ACP videos (https://acpdecisions.org), Respecting Choices (https://respectingchoices.org), Vital Talk (https://vitaltalk.org).
    b. Techniques: Scripting, using in-person interpreters in settings of language nonconcordance, drawing on cultural brokers within the health system or from the patient's community.
2. Clarify the different types of decision-making to the patient.
    a. Include the family members of choice to the degree that the patient desires.
3. Acknowledge mistrust and stigma in the health care system.
    a. Ask open-ended questions to determine whether the patient has experienced discrimination or breaches of trust from any past or current providers.
4. Evaluate, acknowledge, and make strategies to address social determinants of health and barriers to care, including but not limited to
    a. Transportation options
    b. Insurance needs
    c. Documented versus undocumented status

as much information as possible and to feel that they have been heard as people rather than patients. Yet clinicians use medical jargon, fail to recognize that the patient or family is not following, miss cues that patients are experiencing emotions that affect information absorption, or block patient questions and concerns. The result is divergence in illness understanding between what physicians believe they have communicated and what patients believe they have heard.[22]

There are numerous evidence-based approaches to communicating with patients with serious illnesses to achieve goal-concordant care. In this article, the authors will refer to the SUPER^3 model created by the Clinician Patient Communication and Life Care Planning group of the Southern California Permanente Medical Group (**Fig. 1**). This model incorporates ADDRESSING intersectionality, evaluating bias, and trauma-informed care (Refer **Box 3** for how to use the model).

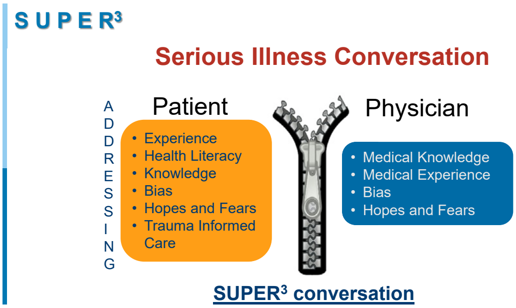

Fig. 1. The SUPER^3 model (*Adapted from* the original content developed by the Southern California Permanente Medical Group Life Care Planning Program)

Box 3
Sample scripting using the SUPER^3 model

1. Setup
   a. Assess decision makers, awareness of clinical circumstance, and evaluation of family:
      i. "Who is someone you trust to make decisions for you if you are very sick?"
      ii. "I'd like to talk about some decisions that people with your health conditions often face—is that OK?"
      iii. "How are health care decisions made in your family or support system?"
   b. Ensure shared understanding of the decision maker role:
      i. A person who knows your values, wishes, and what is important to you.
      ii. A person who agrees to be your decision maker.
      iii. A person who is able to make decisions in difficult situations
      iv. A person who agrees to follow your wishes even if different from their own
2. Understanding
   a. Assess patient's or decision maker's understanding of the situation and address gaps:
      i. "What do you understand about your illness?"
      ii. "What have the doctors told you about that?"
      iii. "Do you feel that you have a good understanding of what to expect over time?"
3. Past experiences
   a. Assess prior hospitalizations, prior treatments, and context and experience with the condition (eg, family members who went through a similar illness):
      i. "Do you know anyone else with this condition?"
      ii. "What did you learn from your last treatment? Last hospital stay?"
      iii. "Have you had experiences with family members who were very sick? Family members who were in the ICU? Who were on life support?"

4. Elicit values
    a. Assess personal goals, spiritual/religious affiliation, and other cultural influences:
        i. "What abilities matter so much to you that you can't imagine living without them?"
        ii. "What do you look forward to each day?"
        iii. "What does quality of life (living well) mean for you?"
        iv. "Do you have spiritual or religious beliefs that might inform your medical decisions?"
5. Review/Recommend/Record (R3)
    a. Review—recap the discussion to ensure agreement. You may need to provide additional information to bridge any misunderstanding.
        i. "It sounds like..."
        ii. "What I heard was..."
    b. Recommend—seek to align patient's goals and values with the treatment options being offered, asking permission to provide your own clinical recommendation:
        i. "Based on what we know about your health condition, and what I heard you say is important, I have some recommendations. Would that be OK?"
        ii. If the patient's values lead you to recommend do-not-resuscitate (DNR) status:
            1. "I recommend a natural dying process. We'll make sure to prioritize your comfort and support your children. In medical language, this is a DNR order."
            2. "I wish intubation and tube feeding would cure the underlying ________."
        iii. "If you were to receive _______ what would you expect?"
        iv. "What concerns, if any, do you have about making this decision?"
    c. Record—make note of the information you have learned in the discussion somewhere it will be easily accessible. It is essential to document any changes for treatment course or code status.
6. Repeat as many times as necessary, as the disease and the situation evolve.

SUMMARY

Palliative care focuses on improving the quality of life for people with serious illnesses and their loved ones. This article introduces considerations including barriers to care, intersectionality, minority stress, microaggressions, and social safety that may impact the experience and openness of people to receive this care. The authors outline tools to address these challenges including trauma-informed care and how to recognize bias and earn trust. The authors conclude by offering a model for incorporating these assessments and tools with sample scripts to provide patient-centered and holistic palliative care. Though this article focuses on palliative and hospice care for LGBTQ+ patients, the themes and tools can be extended to a broader patient population to provide high-quality and inclusive palliative care. When possible, the authors recommend connecting LGBTQ+ patients with teams and resources known to support the LGBTQ+ community. The use of out lists or tips for finding LGBTQ+ affirming care (https://www.lgbtagingcenter.org/resources/resource.cfm?r=4) can help to ensure appropriate and sensitive care for serious illnesses, end-of-life, and postmortem planning and care.

Further Learning

The authors recommend the following resources for people and organizations wishing to improve the quality of palliative and hospice care provided to LGBTQ+ people:

- Acquaviva, Kimberly D., "LGBTQ-Inclusive Hospice and Palliative Care: A Practical Guide to Transforming Professional Practice" (2017). *Faculty Bookshelf*. 107. https://hsrc.himmelfarb.gwu.edu/books/107

- Maingi S, Bagabag AE, O'Mahony S. Current Best Practices for Sexual and Gender Minorities in Hospice and Palliative Care Settings. J Pain Symptom Manage. 2018 May;55(5):1420-1427. https://doi.org/10.1016/j.jpainsymman.2017.12.479. Epub 2017 Dec 27. PMID: 29288882

ACKNOWLEDGMENTS

The authors would like to thank Masil George for her contributions to the article.

DISCLOSURE

The authors have no disclosures.

REFERENCES

1. Acquaviva K. LGBTQ-inclusive hospice and palliative medicine: a practical Guide to transforming professional practice. New York, NY: Harrington Park Press; 2017.
2. Quill TE, Abernethy AP. Generalist plus specialist palliative care–creating a more sustainable model. N Engl J Med 2013;368(13):1173–5.
3. Berkman C, Stein GL, Godfrey D, et al. Disrespectful and inadequate palliative care to lesbian, gay, and bisexual patients. Palliat Support Care 2023;1–6. https://doi.org/10.1017/S1478951523001037. Published online July 12.
4. Berkman C, Stein GL, Javier NM, et al. Disrespectful and inadequate palliative care to transgender persons. Palliat Support Care 2023;1–7. https://doi.org/10.1017/S1478951523001104. Published online July 14.
5. de Vries B. Persons in the second half of life: the intersectional influences of stigma and cohort. LGBT Health 2014;1(1):18–23.
6. de Vries B, Mason AM, Quam J, et al. State recognition of same-sex relationships and preparations for end of life among lesbian and gay boomers. Sex Res Soc Policy 2009;6(1):90–101.
7. Kemery SA. Family perceptions of quality of end of life in LGBTQ+ individuals: a comparative study. Palliat Care Soc Pract 2021;15. https://doi.org/10.1177/26323524211997153. 26323524211997153.
8. Hays P. Addressing cultural complexities in practice: assessment, diagnosis and therapy. American Psychological Association; 2008.
9. Clark K, Phillips J. End of life care - the importance of culture and ethnicity. Aust Fam Physician 2010;39(4):210–3.
10. Meyer IH. Prejudice, social stress, and mental health in lesbian, gay, and bisexual populations: conceptual issues and research evidence. Psychol Bull 2003;129(5):674–97.
11. Sue DW, Capodilupo CM, Torino GC, et al. Racial microaggressions in everyday life: implications for clinical practice. Am Psychol 2007;62(4):271–86.
12. Nadal KL, Whitman CN, Davis LS, et al. Microaggressions toward lesbian, gay, bisexual, transgender, queer, and genderqueer people: a review of the literature. J Sex Res 2016;53(4–5):488–508.
13. Diamond LM, Alley J. Rethinking minority stress: a social safety perspective on the health effects of stigma in sexually-diverse and gender-diverse populations. Neurosci Biobehav Rev 2022;138:104720.
14. American Psychiatric Association. Diagnostic and Statistical Manual of Mental Disorders. 5th ed.; 2013.

15. Harris M, Fallot R. Using trauma theory to design service systems. Jossey-Bass; 2001.
16. Institute of Medicine (US) committee on understanding and eliminating racial and ethnic disparities in health care. In: Smedley BD, Stith AY, Nelson AR, editors. Unequal treatment: confronting racial and ethnic disparities in health care. National Academies Press (US); 2003. Available at: http://www.ncbi.nlm.nih.gov/books/NBK220358/. Accessed August 30, 2023.
17. Spencer K, Grace M. Social foundations of health care inequality and treatment bias | annual review of sociology. Annu Rev Sociol 2016;42:101–20.
18. Lieberman MD, Rock D, Halvorson HG, Cox C. Breaking bias updated: The seeds model. Neuroleadership J 2015;6:4–18.
19. Kripke C. Patients with disabilities: avoiding unconscious bias when discussing goals of care. Am Fam Physician 2017;96(3):192–5.
20. Chiu C, Feuz MA, McMahan RD, et al. “Doctor, make my decisions”: decision control preferences, advance care planning, and satisfaction with communication among diverse older adults. J Pain Symptom Manag 2016;51(1):33–40.
21. Colclough YY, Brown GM. End-of-life treatment decision making: American Indians’ perspective. Am J Hosp Palliat Care 2014;31(5):503–12.
22. Back AL, Fromme EK, Meier DE. Training clinicians with communication skills needed to match medical treatments to patient values. J Am Geriatr Soc 2019;67(S2):S435–41.