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Compassionate, evidence-based care for patients with HIV/ AIDS at the end of life

Nurses can help patients experiencing HIV/AIDS feel more comfortable and respected, allowing them to receive higher-quality care during the end of life.

By Kiernan Riley, PhD, RN; Megan Lucey; Kaléi Kowalchik, BSN, RN; Lucy Adams, BSN, RN; Logan DeSanto, BSN, RN; Charles C. Robinson, MS, ATC, RN, NREMT, CCRN, CDP; Natalie Faybisovich; Marisa Milton; and Michael M. Evans, PhD, MSEd, RN, ACNS, CMSRN, CNE

Mr. L is an 88-year-old White male who finds himself at the end of life. The nurse arrives at Mr. L's residence for admission to home hospice services. His medical history includes hypertension, dementia stage I, benign prostatic hyperplasia, and HIV, diagnosed 35 years ago. His terminal diagnosis is protein-calorie malnutrition; he's had a significant appetite reduction in the past 3 months and a 10% weight loss in the past 2.5 months. Upon the nurse's assessment, Mr. L is alert and oriented to person, place, and time but dependent in all activities of daily living (ADLs) including eating, dressing, bathing, and ambulation. The nurse notes that his Functional Assessment Staging Tool (which helps determine functional impairment due to dementia) score was

between 3 and 4, which is consistent with stage 1 dementia. He's now sleeping 18-20 hours per day and appears emaciated with cachexia. His extremities are warm to touch with 1+ pedal pulses noted bilaterally. Oral intake has been limited, with 10%-20% of all meals and sips of fluid reported by family members. His skin is intact without the presence of breakdown or lesions. The patient is incontinent of stool. He has an 18fr coude long-term Foley catheter in place to drain scant amounts of clear, yellow urine. His family reports that the patient's last bowel movement occurred yesterday. Vital sign assessment revealed the following: 98.9° F (37.2° C), pulse at 96 beats/minute, 20 respirations/minute and unlabored, 146/88 mm Hg BP, and 93% oxygen saturation on room



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air. Recent lab testing revealed a CD4+ count of less than 100, indicative of the patient's progression to AIDS. Upon assessment, Mr. L's Palliative Performance Scale was determined to be 30 with a Karnofsky Performance Scale (which assesses loss of function in ADLs) score of 20/100. Per Mr. L's partner, Mr. L stopped taking all scheduled oral medications earlier this week.

Mr. L becomes agitated when discussing his AIDS status. When his male partner and identified healthcare proxy mentions his HIV status, Mr. L turns and faces the wall. His partner says that Mr. L can become uncomfortable discussing his HIV status with strangers. Since hospice has been brought up, Mr. L is having difficulty trusting healthcare workers to come into his home. His partner discusses the difficulties they have experienced as gay men and asks the nurse to please be mindful and sensitive when caring for Mr. L during this time.

Background

Over 1 million people in the US were estimated to have HIV in 2019.¹ Of these, 68% were acquired through male-to-male sexual contact.¹ There also exists a racial disparity in HIV diagnoses, with Black individuals accounting for 42% of all new HIV diagnoses in 2020.² HIV was first discovered in the US in the 1970s, and may have originally spread to humans from chimpanzees as a result of hunting for meat.¹ Since its initial spread, HIV has been associated with

gay men due to the initial incorrect belief that HIV was spread solely through male-to-male sexual contact.¹ In addition, it has developed a stigma that has caused discrimination against people with HIV and gay men. The stigmas surrounding HIV can also be internalized by people who are diagnosed, causing them to feel shame and despair regarding their diagnosis.³ Although stigma against individuals living with HIV has improved from what it once was, it still exists across many communities.⁴ It's important to consider the unique nature and history of HIV when caring for individuals who are HIV positive, which includes the history, stigma, and adverse reactions. AIDS is the most advanced stage of HIV and can be considered a terminal diagnosis.³ For the purposes of this paper, HIV/AIDS will be used when discussing barriers and best practices for the end-of-life period; however, it should be noted that HIV itself is not a terminal diagnosis. This paper will explore the methods that nurses can use to provide compassionate, evidence-based care to help these individuals receive high-quality care at the end of life.

Barriers to care and cultural context

Individuals with HIV/AIDS are often misunderstood regarding their goals for end-of-life care. Person-centered care can't be achieved when a society renders the person invisible, either through failure to collect sexual orientation and gender identity information, or refusal

to acknowledge their identity at all.⁵ Those in the LGBTQ+ community often experience discrimination from health-care providers, which impedes the patients' ability to clarify their end-of-life care plans, such as treatment options, and wishes.⁵ For example, cultural differences in the LGBTQ+ community such as family definition must be a vital consideration when providing care to this population as the meaning of family is subjective. This is important when determining power of attorney, next of kin, etc. A history of absence of legal marriage and documentation, limited access, lack of support, and cultural differences have all proven to be barriers to end-of-life care for individuals with HIV/AIDS in the LGBTQ+ population.⁶

Culture intersects with aging, sexuality, and health status to adequately describe how disparities affect this community.⁷ Implementing mandatory training for medical personnel regarding biases specifically directed to the LGBTQ+ community will aid in providing culturally considerate care to the population. Without proper understanding of an individual's background, including sexual orientation and gender identity information, a medical professional cannot provide the same level of care as they might with a more complete picture.⁵ Older adults who identify as LGBTQ+ may experience having their wishes disregarded by healthcare staff, less involvement in decision-making, mistreatment, isolation, and abuse, all of which contribute to poor-quality healthcare.⁸ These factors lead to mistrust in medical professionals and the fear of being judged or dismissed.

Access to hospice care may be limited for individuals with HIV/AIDS for multiple reasons. Many individuals living with HIV/AIDS are not presented with education regarding the services hospice care provides.⁹ There's a lack of understanding of the differences between

Medication considerations for physical symptoms

Management of diarrhea

- Antibiotics (if desired by patient and permitted under hospice operating guidelines)
- Loperamide (PO; first line)
- Octreotide (IM; second line or for refractory diarrhea)
- Skin barrier ointment (protect perianal region)

Management of fever

- Acetaminophen (PO, PR)
- Naproxen (PO)
- Ibuprofen (PO)
- Aspirin (PO)

Management of anxiety

- Lorazepam (PO, SL)
- Diazepam (PO, PR)

Management of delirium/agitation

- Haloperidol (PO)
- Quetiapine (PO)
- Olanzapine (PO, SL)

palliative and hospice care, along with the transition from one to the other.⁶ Palliative care includes treatment of a disease long-term, including symptom management, whereas hospice care is implemented when death is imminent.⁶ In addition, communication regarding care goals for individuals living with HIV/AIDS may be limited. A multidisciplinary approach is necessary to integrate knowledge and align care goals between palliation for debilitating symptoms and support at the end of life.⁶ Providers may not assess for clear treatment goals, leading to individuals experiencing prolonged aggressive treatment when hospice may have been more appropriate.⁹ Additionally, individuals with HIV/AIDS may live in under-resourced areas with limited hospice care facilities in general.⁹ There have been instances of partners in these settings not being recognized as legal spouses, thus affecting financial and medical care rights, leading to difficulties in receiving adequate healthcare or appropriate services.⁶ In addition, individuals may have



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feelings of hesitancy in confiding in providers due to fears of judgment, discrimination, or homophobia.⁹

Best practices

Physical symptom management

Individuals with HIV/AIDS who are at end of life can face a multitude of physical symptoms for which hospice services can provide relief. While common symptoms such as pain and dyspnea are present, individuals face other symptoms that are unique to the disease process, including but not limited to diarrhea, fever, and neurologic changes.¹⁰ (See *Medication considerations for physical symptoms.*)

Diarrhea

Diarrhea is common and can be an adverse reaction of antiviral therapies such as highly active antiretroviral therapy or the direct result of opportunistic infections that are common in this population, typically due to a CD4 lower than 200 cells/mm.^{3,10} Managing the underlying cause when infectious in nature typically involves the use of antimicrobial therapy, which may be controversial given the perceived life-sustaining nature of these medications when used in hospice care.¹¹

Nonpharmacologic methods of managing diarrhea include the promotion of adequate fluid and nutrition intake as tolerated by the patient.¹² Further, skin barrier ointments may be necessary to protect the perianal regions to prevent

breakdown and additional discomfort, especially if the patient becomes immobile as the disease progresses.¹² If pharmacologic intervention is desired, oral loperamide should be considered as first-line treatment; however, caution should be taken as there are opioid agonistic effects.^{10,12}

Fever

Fever is common at end of life, especially in patients with HIV/AIDS where it is likely indicative of infection.¹⁰ Nonpharmacologic methods of managing fever include the promotion of adequate oral fluid intake, as tolerated, along with the use of cool sponges and fans.¹⁰ For pharmacologic methods, acetaminophen and naproxen should be considered first-line treatment, but other nonsteroidal anti-inflammatory medications such as aspirin may also be considered.¹⁰

Neurologic symptoms

Common hospice medications such as lorazepam for anxiety and haloperidol for delirium, agitation, and other associated changes in mood, along with medical cannabinoid-based products should be considered.¹⁰

Mental health management

Hospice services for an individual living with HIV/AIDS focus on the quality of life, as well as comfort measures of end-of-life care.¹³ Management and relief of the physical symptoms associated with HIV/AIDS are only one part

of the services provided. The mental well-being of individuals with these conditions, as well as the support system and caregivers of those individuals, is a major point for concern due to its high burden on mental, social, and physical health.¹⁴

Depression

The prevalence of depression among individuals with HIV/AIDS ranges from as low as 22% to as many as 61% of cases.¹⁵ Antiretroviral treatment can mimic symptoms of depression such as fatigue, disrupted sleeping patterns, and weight loss associated with a decreased appetite.¹⁶ Selective serotonin reuptake inhibitors, such as sertraline, citalopram, and escitalopram may provide the most benefit in hospice care as they have the fewest adverse reactions and interactions with other medications.¹⁷

Anxiety

Stigmatization and healthcare interactions can cause anxiety in patients with HIV/AIDS. Anxious emotions may prevent open communication between the patient with HIV/AIDS and their interdisciplinary team of healthcare workers and may impede any comfort care measures that can be customized to their individual needs. Further, without proper communication due to anxiety, the patient at the end-of-life stages of HIV/AIDS may not be provided with the appropriate therapeutic resources or medications and may experience unnecessary pain and symptoms, which interferes with the quality of life that hospice is meant to provide.²

Like depression, pharmacologic therapies are the suggested anxiety management regimens of end-of-life care.¹⁰ Typically, low doses of benzodiazepine lorazepam can be used in hospice care to alleviate anxiety and stressors, with an increase in dose if necessary.¹⁰ Haloperidol, an antipsychotic, may be given to

address mood changes such as hostility and agitation that are commonly experienced among individuals in hospice care.¹⁰ Healthcare providers play an important role in the treatment and prevention of these anxieties by improving therapeutic communication and constantly working to remain culturally competent toward the HIV-positive population.³

Family support

A critical part of hospice care for an individual in the final stages of their HIV/AIDS illness is a support system. End-of-life care for patients with HIV/AIDS extends beyond the individual to include a sphere of loved ones.⁶ It's necessary to first determine what the patient defines as family. Establishing stress management interventions together with family benefits the individual living with HIV/AIDS and the support system around them. These coping skills can also be useful for family support during all phases of the HIV/AIDS illness, as the death and dying stages do involve grief and bereavement of their loved one(s).⁶

Inclusive and affirming patient-provider communication

While providing end-of-life care to LGBTQ+ patients or individuals with HIV/AIDS, it's imperative for healthcare providers to provide affirming communication to patients and their families. Inclusive and affirming communication can be centered around direct patient-provider communication during care as well as the use of appropriate and inclusive language through documentation or patient education materials. Providers must effectively communicate and obtain the necessary skills and knowledge to deliver culturally competent care.⁸ Developing clinicians' knowledge, sensitivity, and communication skills can improve

patient-care experiences for underserved populations.⁸

It's equally important for healthcare staff to create a safe and inclusive environment to provide care and establish a rapport with their patients and families. To uphold inclusive and affirming care for vulnerable populations, clinicians and their healthcare organizations need to regularly reflect upon their own implicit biases that may negatively impact care provided to patients.¹⁸ Reducing providers' biases and enhancing organizations' documentation, resources, and recruitment materials can allow patients and their families to feel comfortable and confident in the care they receive from their healthcare providers.^{8,18}

Case study update

Over the next 2 weeks, Mr. L's condition continues to decline. He receives daily personal care from the same home health aide, and the same RN makes home visits to assess the patient, collaborate with the interdisciplinary team, and manage the plan of care, including ordering oxygen at 3 L via nasal cannula to help with labored breathing. During Mr. L's time in hospice care, he begins to feel comfortable and respected by his care team. He confides to his healthcare team about the difficulties he faced during previous healthcare encounters and thanks them for caring for him. On the 15th day in home hospice care, Mr. L. stops eating and drinking, and urine output decreases to 10 mL/h with a subsequent worsening of his vital signs. The following day Mr. L dies peacefully with his partner by his side.

Conclusions

Patients with HIV/AIDS can significantly benefit from compassionate and evidence-based care at the end of their

lives. Nurses can have an impact in this regard by working to eliminate the identified barriers such as discrimination, lack of support, and disregard. Additionally, nurses can improve care by implementing the identified best practices including physical symptom and mental health symptom management and inclusive, affirming patient-provider communication. As demonstrated in this case study approach, nurses can help LGBTQ+ individuals and those experiencing HIV/AIDS feel more comfortable and respected, allowing them to receive higher-quality care during end-of-life care. ■

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Kiernan Riley is an assistant professor of nursing at Fitchburg State University in Fitchburg, MA. At Pennsylvania State University, Ross and Carol Nese College of Nursing, Scranton Campus, Megan Lucey is a senior honors nursing student, Natalie Faybisovich is a junior nursing student, and Michael M. Evans is the Assistant Dean of undergraduate nursing education at the Commonwealth Campuses and a Teaching Professor of Nursing. At Pennsylvania State University, Ross and Carol Nese College of Nursing, University Park Campus, Kaléi Kowalchik is a BSN to PhD Student, and Marisa Milton is a senior nursing student. At Pennsylvania State University, Ross and Carol Nese College of Nursing, World Campus, Lucy Adams is a BSN to DNP student, Logan DeSanto is a BSN to DNP student, and Charles C. Robinson is a BSN to DNP student.

The authors and planners have disclosed no potential conflicts of interest, financial or otherwise.

DOI-10.1097/01.NME.0000923360.04300.b3

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