Nurses study the needs of transgender senior citizens

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Of the 1.5 million Americans who identify as transgender, roughly

217,000—about 14—are older than age 65. According to a 2011 report by the National Gay and Lesbian Task Force, 97 percent transitioned (claimed their preferred gender identity that differed from their sex at birth) at age 55 or older.

Sometimes called "Generation Silent," many transgender senior citizens—like LGBTQ seniors more generally—are particularly vulnerable at the end of their lives, and sometimes conceal their status with care providers out of fear of being mistreated, according to University of Virginia nursing professor and scholar Cathy Campbell. Without a concerted effort to prevent such discrimination, these groups may experience gaps in care, unchecked pain associated with their illness or even outright abandonment by clinicians.

Clinician education is key to countering this discrimination. UVA Health, like many U.S. hospitals, participates in the Human Rights Campaign Foundation's annual Healthcare Equality Index program, and each year offers dozens of learning opportunities and on-demand courses through the National LGBTQ Health and Education Center and the Human Rights Campaign's Center for Affiliated Learning to ensure clinicians' understanding of, and commitment to, compassionate, holistic care of LGBTQ patients.

As frontline caregivers, nurses are particularly well-positioned advocates for these individuals. Campbell, with nurse and Ph.D. student Lauren Catlett, recently wrote a case study examining the unique social and spiritual needs of a transgender woman named Carmelita who, at age 60, was dying of esophageal cancer. The study, which offers an intensely personal glimpse into the life of a transgender senior, was just published in the Journal of Hospice & Palliative Care Nursing.

UVA Today spoke with them both.

Q. Explain "Generation Silent."

Campbell: Many trans-identified people I've worked with have lived a dual life; they've been shape-shifters. They may be in the closet with some people, but out to other people. But when you are older, maybe close to the end of your life, you're vulnerable. You're receiving services because you need help. People are coming to your home; people are doing your personal care. Some trans-identified people may have transitioned fully with surgery and hormones, socially (presenting as their gender identity) – or some combination of those things, or not at all—and all those intensely personal things intersect when you care for someone. It's a literal and figurative nakedness.

They don't want care workers to judge them. Some caregivers proselytize, try to convert people, and might even withhold care because of their own biases.

"I'm sick. I'm dying. I need you," these patients say. What they really want to know is: "Can I be safe with you?"

For every Caitlyn Jenner who transitions in a reality TV show, there are many, many other people who are transitioning in a quieter way, who are not as visible. We need to be there for them. The vast majority transition after age 55; they're just beginning their lives, even though most of them are well into middle age. And when they die, their needs are distinct.

Q. How did you meet Carmelita, whose case study you wrote about?

Catlett: I was friends with her when we both volunteered at JABA (the Jefferson Area Board for Aging), and we crossed paths again later when she was being cared for in hospice, where I volunteered. At the end of

her life, Carmelita wanted to create a book about her experiences; I had published books before, and understood the process.

The book we created, "Little Star," was Carmelita's final wish; she wanted this story to be told and heard and help influence people who are suffering or who have suffered as she had. For me to be one of those people to help keep her voice alive is very rewarding.

For me, the process was transformative. It would have been enough for her to talk about her life experience as a transgender woman, but that she came out of it all with a sense of forgiveness and gratitude was just miraculous to me. I saw this book as an important work not only because it highlights the story of somebody who was marginalized in society, but also because it was a larger human story, and really spoke to themes we all can relate to: acceptance, forgiveness, transformation, hope.

Campbell: For the last two years, I've used the stories in this book in class with my students to illustrate a spiritual care intervention—showing and telling what Lauren did with Carmelita, and what it meant.

Q. What unique social and spiritual needs do transgender seniors have?

Catlett: When you think about it, gender identity is how you see yourself at your core, and thus it's tied into your sense of spirituality. Trans-identified elders need a sense of acceptance and belonging and understanding of gender identity as part of their spiritual selves.

One form of spiritual expression for older adults is volunteerism, or giving back. And this applies to trans-identified elders, too. Carmelita wanted to volunteer because she cared about serving her community, but she had a really hard time getting positions as a volunteer because of her

gender identity. That's just another dimension of LGBTQ aging; if they have something to give, will they be accepted?

Q. What should caregivers know when caring for transgender patients who are dying?

Campbell: Acknowledging the configuration of family is extremely important. In the hospital, they ask all these questions: Do straight people get asked for birth certificates, marriage licenses, all this nonsense? No. Whoever you designate as your people, your care circle, we welcome them. And we work with them.

What words we use with transgender and LGBTQ patients are important, too. In my class, I remind my students to use the pronouns and names their patients prefer. "I want you to call me by this name. My pronoun is ..." It's who they are.

Catlett: We can also help bring out the light that dying patients have. It's important to recognize that even if a person is at the end of their life, they're still living. They can still contribute, and might have unmet needs that need to be addressed. In Carmelita's case, she had family difficulties that needed to be worked out, and she wanted to share her life lessons with her community. Whatever we can do to shore those things up to help with a peaceful transition is important.

Another takeaway from this is to be creative. It doesn't necessarily mean you have to do art with your patients (as I did with Carmelita) as much as you should be creative in how you connect with people. I had a patient one time who couldn't communicate verbally … so we had an iPad, he had a board with letters he could point to, a notepad he could write on. It's really about seeing a need and responding in a way that's not in a textbook, but gets to the point where you can truly connect with and help

that person.

Q. What's it like to work as hospice nurses, so close to people who are in the last days, weeks or months of their life?

Catlett: A midwife is kind of the way I see my role as a hospice nurse: almost like helping someone transition out of life as they transitioned into life. It's a sacred time. It's an honor to be there. Truthfully, that's almost the most important thing: just being there at a time that can be difficult. It's not easy to see people who are suffering and in pain, but hospice nurses have a valuable role in being present and restoring peace of body, mind and spirit for these patients.

Campbell: You bring your gifts, whatever they are, and provide care for someone's spirit. In nursing, we have to honor spiritual care, because it's part of what we do. With your hands, with your presence, you are honoring their spirit.

It's why we're here. Those spaces between, those gaps—that's where you find a nurse.

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