End-of-life care considerations for LGBTQ older adults with Carey Candrian, PhD

AMA's Moving Medicine video series amplifies physician voices and highlights developments and achievements throughout medicine.

Featured topic and speakers

In today’s episode of Moving Medicine, AMA Chief Experience Officer Todd Unger discusses caring for LGBTQ seniors and addressing disparities during end-of-life care with Carey Candrian, PhD, an associate professor at the University of Colorado School of Medicine in Denver.

Speaker

- Carey Candrian, PhD, associate professor, University of Colorado School of Medicine

Transcript

Unger: Hello. This is the American Medical Association's Moving Medicine video and podcast. In recognition of Pride Month, today we're joined by Dr. Carey Candrian, an associate professor at the University of Colorado School of Medicine in Denver, who's going to discuss caring for LGBTQ seniors and addressing disparities during end-of-life care. I'm Todd Unger, AMA's chief experience officer in Chicago.

Thank you so much for joining us, Dr. Candrian. Several years ago, the National Institutes of Health announced that it was recognizing the LGBTQ community as a health disparity population. Now, there are a lot of letters in that particular acronym and, as we've learned from previous guests here on our update, there are different things that apply. In particular, we're going to be talking about one population, which are seniors, older adults, so let's start by talking about the health disparity population aspect of this and how we see this designation playing out, particularly for older adults.
Dr. Candrian: Great. Well, thanks so much for having me, Todd. In 2016, the NIH recognized the LGBT community as a health disparity population in an effort to really do something about the health-related issues that disproportionately affect this community. Mounting evidence suggests that LGBT communities have less access to health care and higher burdens of certain diseases. Unfortunately, the extent of these disparities have not been fully understood, and research on how to really close these gaps is lacking. By becoming a health disparity population, it really is a way to, I think, help make LGBT research more important, take it more seriously, be better coordinated and, hopefully, will ensure that LGBT people, particularly, older LGBT people are actually included in the research process and part of the evidence.

Unger: You say we get a lot to learn here in this particular realm. What do we know about what’s driving the disparities?

Dr. Candrian: I mean, when you think about serious illness and end of life, I mean, these are hard events for everyone but they’re even harder for LGBT older adults because they’re really entering this last phase of life from a disadvantage in really three main areas—financial security, social support and really the effects of this lifetime of stigma and discrimination.

First, financial security, one out of three older LGBT adults live at or below the poverty line and there are a number of factors that contribute to this. Just to name a few, gay marriage wasn’t legalized until 2015. If you did have a partner, you were often denied spousal benefits and pensions, which really matter as you age. A second driver for financial insecurity is really job discrimination for their entire lives. If they were open about who they were, they could be fired for that and many of them were.

Second, family support, LGBT older adults are two to three times less likely to be married, and they’re three to four times less likely to have kids. They’re often more likely to be estranged from family, which means they’re aging with a really thin network of support. A final factor that really is the undercurrent to all of this is the effects of this lifetime of stigma and discrimination that it takes a serious toll. Research shows that this leads directly to higher rates of anxiety, depression, substance abuse, certain cancers, cardiovascular issues and suicide, and the big one is that the stress of hiding this fundamental part of who you are actually takes up to 12 years off their lives and that was from Harvard Medical Magazine in—

Unger: That’s incredible.

Dr. Candrian: ... yeah, in 2020.

Unger: Obviously, I mean, the factors that you just laid out there are obviously having a huge effect not only on lifespan but on mental health. Are there any other ways that that is characterized?
Dr. Candrian: Yeah, it is. I think, when you think about this generation, those who grew up in the '40s, the '50s and the '60s, I mean, being gay or lesbian or trans was unthinkable. It was really dangerous, and it was illegal in most cases. According to the American Psychiatric Association, I mean, they listed homosexuality as a mental illness until 1973 and so this stigma I think that they grew up with really stays with them and has serious costs as they age. As a result, for these seniors who grew up in this culture, they've really developed what I call this habit of silence around this core part of themselves that really became a critical defense strategy that they've used for decades but this habit of silence takes a serious toll on their mental and physical health.

Unger: One thing you also point out is, as we move into end-of-life care, which is difficult under any circumstances, of course, that there are specific concerns. You coauthored an article that was published in The Gerontologist during the pandemic that looked specifically at disparities and end-of-life care for LGBT older adults. Why is this population at a particular risk for receiving inequitable end-of-life care as well?

Dr. Candrian: Yeah, it's a great question. I think, when you think about end of life, I think we often think about how important it is to be able to express what you want, what you don't want, who you need in the room to advocate on your behalf, who you need in the room to hold your hand, who you need to identify if you're no longer able to speak on your behalf. The thing is, if you can't say these things, it's very hard to have these things and so all that really contributes to inequitable care for end-of-life for older LGBT adults.

Let me give you an example and I'll keep it brief. Esther, I met about three years ago as part of my research and when I met her, she'd recently lost her wife, Cathy, to cancer. The thing was, was that when the hospital staff realized they were a couple, Cathy's care got worse and so they felt like they had to hide their relationship.

When I asked Esther what the hardest part of the whole thing was, I remember her saying, "She was dying and I couldn't even say we were married." Since they were hiding their relationship, Esther couldn't be in the room. She couldn't talk with the care team about next steps. She couldn't advocate for her wife on any level. She couldn't even hold Cathy's hand and when Cathy died, nothing. No one said a word to Esther. She was just the good friend, the emergency contact, not a grieving spouse who just lost the love of her life. No one acknowledged her loss and no one offered her grief support. Esther and Cathy had been together 33 years.

The reason I share Esther's story is that communication really affected the outcomes of two people. Cathy's care got worse because she couldn't have the person she needed to advocate for her care in the room with her and Esther didn't get the support she needed as Cathy's spouse and really the caregiver.

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This is not right, but, unfortunately, this actually happens to a lot of older LGBT adults when they face end of life, either their own or their partners and really for them, at any point in health care, they face a choice. I mean, do I come out and risk being treated worse or do I stay silent and hide a fundamental part of who I am? It's a heck of a choice and it is with them throughout their health care experience and just really magnifies at the end of life.

**Unger:** That's a really heartbreaking story. Do you think that the end of life care is different from other areas of health care where we don't see such huge gaps?

**Dr. Candrian:** I think the gaps are still there. I think just though they do just become so much more magnified and the stakes are just that much higher when you are facing end of life or you're navigating the complexities of a serious illness.

**Unger:** Is there a data or other kind of system-level problem here that accounts for the gap?

**Dr. Candrian:** Yeah. I mean, I think we know the drivers about the discrimination. We know it's happening all throughout the health care ecosystem in hospices and hospitals, assisted living. The American Heart Association reported last year that 56% of LGBT adults report experiencing some form of discrimination from a health care provider. For those who are trans or gender nonconforming, it goes up to 70%. We know this discrimination is happening.

In a 2020 survey of over 850 hospice professionals led by Drs. Gary Stein and Cathy Berkman, 43% of the staff reported directly observing some form of discrimination towards LGBT patients and caregivers. We have data that we know these disparities are happening. The huge problem though is, really, we just don't have great data on the LGBT community in large part because we don't ask. We don't routinely collect sexual orientation and gender identity data.

**Unger:** Talk a little bit more about that. How can that change?

**Dr. Candrian:** Yeah. Since 2011, the joint commission has asked for these data to be collected. The CDC, the NIH have all encouraged the routine collection of sexual orientation and gender identity or SOGI data as it's called for short. Well, there are several factors to this. We don't routinely collect this information. I think, on the one hand, I think people can be uncomfortable asking these questions or they don't see the need to know this information when caring for someone or they don't know when to ask or how to ask.

Another thing is is that for LGBT patients and their caregivers is that this is still very scary to disclose this information. They can still be denied care. They still are being denied care sometimes if they disclose this. If these questions are not asked in a way that doesn't perpetuate discrimination, we still won't get this data. I think we've seen places that are adding these questions onto the forms, which is an excellent start, I think though without the proper training on really why these data matter, how to
ask in a way that patients feel safe and trusted and a way that they can understand that these questions are not just about knowing if someone is gay or trans but it's actually really critical information to someone's care, so I think it—

**Unger:** Yeah. When you talk about how to have that conversation, I mean, it sounds like there are a lot of obstacles in the communication part of this. One of the terms you've used is, quote, breaking the script. Talk to us about what that means and how you'd advise people in this situation to gather that data, be compassionate and have that open and honest communication that it takes to have the kind of end-of-life care that we need.

**Dr. Candrian:** Breaking the script for me is really about re-imagining the language we use in health care. I think one way to address the devastating disparities that older LGBT communities face is legislation, which is giving protections to people that are long overdue but we can't legislate the way people think and feel, but we can change the way we communicate, the way we talk and listen to each other. For communities that have been historically marginalized like the LGBT community and, particularly, older LGBT adults, change in the way we communicate can really make an immeasurable difference in the care they receive and in their outcomes.

The scripts are really the tools we use in medicine to get to know a patient—our forms, our intake questions, our admission conversations, DNRs, living wills. They're critical tools in medicine but they're scripted and they're loaded with assumptions that aren't always spoken but they're heard, and so, for LGBT people who have grown up in these cultures and carry this stigma with them, it can shut people down really quickly. The point of breaking these scripts is really to give people space, to allow them to answer in a way that actually fits them and in a way that they can actually share information that they need to and want to. Scripts like—

**Unger:** So—

**Dr. Candrian:** Sorry.

**Unger:** Yeah. That's all right. I was going to say do you ... Shining a light on this problem to begin with is a huge first step. Second is making people aware of this kind of approach and the resources to be able to teach people. Is there anything else that you'd like to see in terms of the evolution of end-of-life care for this population and how do we actually get there?

**Dr. Candrian:** Yeah, I think part of this is just to start doing it. I mean, instead of asking are you married, I mean, who's the biggest support in your life? Who do you need to have in the room? Or instead of we'd like to have a family meeting, who do you consider family? These subtle changes actually goes such a long way for the LGBT community.
I think, for me, the end of life is really a time of reunion and reconciliation and, to not be able to be who you are, to not be able to have who you love in the room with you or at home with you, I just don’t think there is really anything more detrimental than that and so I’ve really committed my career to hopefully making it not so difficult to be able to be who you are when you need it the most.

This avoidable suffering ... The extra suffering, I mean, is actually avoidable like Esther’s and Cathy’s case because, of all the seniors I’ve really met in my research, they’re not asking for a lot. They just want to be able to talk openly and be heard without prejudice. All we have to do is really break these scripts in a way that people feel safe and show them we’re safe and listen. I think the bonus then will be is that we’ll actually get the information we need to care for these patients and also get data on this community that has been so hidden and so ignored and so invisible for so long.

Unger: Dr. Candrian, thank you so much. It’s been a really moving conversation.

Dr. Candrian: Thank you so much, Todd.

Unger: I really appreciate your insight, your perspective and advice. That’s it for today’s Moving Medicine episode. We’ll be back with another one soon. In the meantime, you can see all of our videos and podcasts at ama-assn.org/podcasts. Thanks for joining us, and please take.

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