

Care at the Intersections: A Case Study

By Alyssa Camp, MA

Learning Objectives

1. Increase understanding of trans elder care.
2. Recognize the ethical considerations of caring for a trans elder with dementia.
3. Understand the value of LGBTQ+ training and programing in assisted living.

Background

As of 2021, roughly .05% of those aged 65 and over in the U.S. identify as transgender (Beehuspoteea & Badrakalimuthu, 2021) and that number is expected to grow (Baril, & Silverman, 2022). While there is some research addressing LGBTQ+ aging and many studies covering dementia, there are scarce resources at the intersection of dementia and LGBTQ+ aging. This case study seeks to close that gap and address some of the unique needs and circumstances of trans elders with dementia.

Baril and Silverman (2022) suggest a fluid trans-affirmative approach to allow for and support the changing nature of this complex, but growing, set of circumstances. This approach is indicated in the following case study.

Case Study

Jordan is a Personal Care Aide for an 84-year-old transgender female named Terry who was recently diagnosed with mild dementia. Jordan has worked with Terry for only a few months but the two have become very close. They both enjoy poetry, bird-watching, and documentaries.

Terry has been open about her past, including her transition right before her divorce 30 years ago. She rarely sees anyone other than Jordan and her son, Drew, who visits every weekend and assists with meal preparation and light cleaning.

Drew, a bank executive, has had power of attorney for more than one year and although Jordan doesn't think Drew would ever do anything to harm Terry, Jordan sometimes questions Drew's stoic approach. Noting several falls, some weight loss, and poor memory, Drew has investigated assisted living arrangements. Drew is willing to pay quite a bit to cover the expense of assisted living but there are few options in the area. Drew has mentioned an assisted living group that Jordan has heard is not accepting of trans elders. In fact, Jordan, after a few years in the field, is aware that very few assisted living facilities are welcoming or even safe for trans elders. Terry has confided in Jordan that assisted living would be terrifying and has requested help in convincing Drew not to pursue this path.

Terry has frequently forgotten to take medication, including gender-affirming hormone therapy to block testosterone production, and has recently started to re-identify with her sex assigned at birth. She has asked that her son refer to her as Dad, although he continues to refer to Terry as

Mom as he's done for 30 years. Jordan has allowed Terry to steer and will pick up on queues to determine how Terry might like to be addressed. This trans-affirmative approach demonstrates Jordan's technical competence. If Terry shifts to identify as man, Jordan accommodates this shift and uses he/him pronouns to refer to Terry. Drew has overheard this practice and asked Jordan to stop, indicating that their family has been through a tough transition and *isn't looking for another one*.

Jordan is concerned for Terry's future and steps back to evaluate the best course of action to uphold a person-centered approach. While there are several frameworks, she begins by leveraging the 7-Step Model of Ethical Decision Making and the caring response (Doherty & Purtilo, 2016 as modified by Inker). The 7-step model is a guide for critical thinking and provides a framework for best practices in ethical decision making. The caring response outlines a more personal, relationship-oriented approach to care and relies on an inner judgement to evaluate the ethics of a situation (Maio, 2018). Key features of an ethic of care include person-centeredness or responsive, situation-specific, a preference for emotional knowledge, and tolerance for ambiguity; the practice is rooted in relationships and emotional responsiveness (Doherty & Purtilo, 2016).

The 7 Step Model of Ethical Decision Making

Step One: Center Yourself

At the outset, Jordan feels anxious for Terry's wellbeing. She is frustrated with Drew, but tries to understand that this must be incredibly difficult for him, too. After all, Drew adjusted years ago to Terry's transition and has gone through the process of changing his language and adjusting the way he saw his parent, so asking him to do that again must be hard. Then again, Jordan recognizes that her duty is to Terry and her concern for Terry's wellbeing is valid. Discrimination is insidious and Jordan is aware of the research that outlines the negative health outcomes for those who experience it as well as the poor health outcomes specifically for transgender adults facing stigma (Drabish & Theeke, 2022). Despite these feelings, or perhaps because of them, it's important that Jordan trust this process and remain open to the solution.

Step Two: Gather Relevant Information

Jordan knows a handful of things for certain. She knows that Terry was recently diagnosed with mild dementia and that hormone pills remain in the pill minder at the end of the day. She is aware that Terry was assigned the sex of male at birth but began identifying as female 30 years ago. Despite their very different approaches, Jordan knows that Drew loves Terry. Drew has said Terry was happy once she transitioned and said she never wanted to go back to being someone she wasn't. Jordan also knows that Terry has a right to refuse medication, including hormone therapy, Jordan knows she doesn't have all the answers and, in fact, is aware she has neither the expertise nor the education to address or solve this unique and complex situation. After a fairly intense search, Jordan finds little research on evidence-based practices for trans elders living with dementia.

Jordan has read much of the research on assisted living communities not being welcoming to trans elders, and she has heard a great deal about the assisted living community in question, but she does not have data to support this suspicion. She doesn't know that Terry would be unhappy there.

She needs to discuss other options with Drew, particularly if he insists on long term care. It's important that Jordan fully investigate the facility Drew is considering. It's also important that Jordan consult an LGBTQ+ therapist or organization to determine what those with experience would recommend as the best course of action. And she needs to talk to Terry about the reasons for terror when Drew brings up assisted living.

Terry's relationship with Drew is tremendously important in this case. Through an ethic of care lens, Drew also needs support and education. Terry and Drew both wish to be decision makers. Jordan will need to be careful in brokering this conversation.

Step Three: Identify the Type of Ethical Problem

Doing this in an impartial way will be tremendously difficult. The ethical problem is that Drew has power of attorney, but his decision on long term care (and specifically the facility Jordan has concerns about) may have a detrimental, irrevocable effect on her client. While this is a legal issue, the question is, if the decision isn't in Terry's best interest, *should* Drew have the power to make this call? Terry needs qualified guidance from someone who understands this particularly unique journey.

Jordan considers whether this is a case of moral distress type A, in which case she would understand but be prevented from pursuing the correct course of action or moral distress type B, in which case a path to resolution would be unclear as there is complexity and uncertainty (Doherty & Purtilo, 2016). After much reflection, Jordan determines this is a case of moral distress type B as she does not know the best course of action, the situation is complex, and she does not know of anyone who has faced this problem, particularly as it relates to Terry re-identifying with her sex assigned at birth.

Step Four: Run the Problem through Different Ethical Lenses

A caring response would be to keep Terry in her home as requested and accommodate Terry with pronoun usage as Terry indicates. If and when Terry requires a professional facility, it should be one that meets the specific needs of trans elders. The most important ethical principle in this context is beneficence as it relates to Terry's unique needs.

Step Five: Explore Alternative Courses of Action

Alternative courses of action could be inviting a family counselor (one familiar with the LGBTQ+ community) to speak with Drew and Terry to determine the best next steps. This suggestion would remove Jordan from the equation. Another option may be tour Drew's recommended facility to look for trans friendly indicators such as support groups, training, and

LGBTQ+ meet-ups. It may be helpful to bring in additional 24/7 support if Drew feels this level of care may be warranted.

Leveraging a caring response, Jordan displays technical competence through her acknowledgement that she is there to facilitate a conversation, not to solve the problem. Bringing in a disinterested third party to help Terry and Drew come to an agreement may be the best course of action as this person could provide support for Terry and education for Drew. Based on their assessment, Drew and Terry could proceed as recommended and not blame one another. While 24/7 support may be a caring response, it is often cost prohibitive and may not be the best course of action.

Step Six: Complete the Action

Jordan decides to reach out for help through a variety of services, including the Gay and Lesbian Medical Association and the National Resource Center on LGBT Aging. Her most successful interaction, however, is with Services & Advocacy for GLBT Elders (SAGE), an advocacy group for LGBTQ+ elders. After speaking with a volunteer there, Jordan is put in touch with a company which specializes in matching LGBTQ+ older adults with assisted living placements that meet their specific needs. The volunteer at this free service, offered through A Place For Everybody, commits to researching facilities in Terry's area and getting back to Jordan within a week. The volunteer emails Jordan three days later with two facilities in a 50-mile radius that meet Terry's needs. Drew's original selection is, unsurprisingly, not on the list. Once Jordan receives the email, she asks Drew if he might be open to reviewing the alternative options and discussing with Terry.

Step Seven: Evaluate the Process

Jordan documents her lessons learned and even puts together an information packet with the resources she has found regarding placement services for trans elders. After discussing options and visiting the facilities, Drew and Terry decide on a small assisted living community a little under an hour away with inclusive programming, LGBTQ+ training for staff, and social groups for trans elders.

Study Questions

1. What barriers exist for LGBTQ+ elders in healthcare? What can be done to remove those barriers?
2. What implications are there for LGBTQ+ elders with dementia?
3. What might a fluid trans-affirmative approach look like?

About the Author

Alyssa Camp is a current graduate student in the Gerontology program and previously earned her MA in English as well as a graduate certificate in Homeland Security and Emergency Management. She is a learning program manager at Capital One, focused on accessibility and

inclusive engagement. Her research interests include disability policy and late-life suicide. She's a member of the Southern Gerontological Society.

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Recommended Reading/Viewing

- Baril, A., & Silverman, M. (2022). Forgotten lives: Trans older adults living with dementia at the intersection of cisgenderism, ableism/cogniticism and ageism. *Sexualities*, 25(1-2), 117-131.
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