Advance Directives and the LGBTQ+ Population: Preparing Nurses for Practice

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Article

Abstract

The LGBTQ+ population encounters barriers related to advance directive completion in healthcare settings. Nursing curricula lack advance directive education specifically related to the challenges faced by the LGBTQ+ population. Nurses' lack of understanding of these issues can impact informed end-of-life care choices. Nursing programs must improve advance directive education to prepare students for practice. Active learning and application strategies will provide students with opportunities to understand advance directives and the unique needs of the LGBTQ+ population. Practicing nurses must be able to advocate for LGBTQ+ persons when making informed end-of-life decisions and help them navigate barriers that may arise at the end of life. This article discusses the unique needs of the LGBTQ+ population and presents case examples to illustrate the barriers faced by LGBTQ+ people related to advance directives.

Key Words: Advance directives, advanced care planning, nursing students, curriculum, LGBTQ+ populations, end-of-life care, advance directives and nursing education, LGBTQ+ and advance directives, nurses

Advance directives allow individuals to document end-of-life care choices if they cannot make care decisions for themselves. Individuals can choose to complete a living will, which guides medical treatment preferences, or a durable power of attorney for healthcare, allowing an individual to appoint someone to make healthcare choices. Executing an advance directive reduces aggressive care at the end of life, promoting hospice care and a higher quality end-of-life experience (Tyacke et al. 2019). However, completion rates for advance directives are low, with rates ranging from 18% to 33% (Auriemma et al., 2020; Cohen & Nirenberg, 2011; Rao et al., 2014; Wenger et al., 2012).

Factors related to low completion rates of advance directives have been examined. Cartwright et al. (2012) report a general lack of knowledge about advance directives and the belief that if an individual is healthy, there is no need for an advance directive. Other barriers include difficulty completing advance directive forms, lack of knowledge about the process of completing an advance directive and state law requirements, indecisiveness regarding the type and level of healthcare at end-of-life due to unpredictable and complex situations that may arise, and fear that if an advance directive is executed, treatment may be withheld (House & Lach, 2014; Nehra & Gupta, 2019; Rao et al., 2014; Schickedanz et al., 2009). LGBTQ+-specific barriers are state laws or protections that do not recognize same-sex marriages and family interference with end-of-life choices because partners or friends are not recognized as decision-makers (Cartwright et al., 2012; Marsack & Stephenson, 2018).

Advance Directives and Nursing Education

The American Nurses Association ([ANA], 2015) *Code of Ethics with Interpretive Statements*, Provision 1.4, "The Right to Self-Determination," promotes an expectation of nurses to advocate and educate patients regarding end-of-life care based on nurses' knowledge and experience. However, a significant gap exists in the literature on advance directives, particularly regarding how nursing students learn about advance directives. Brohard, Moreland, Shammas, and Tonsul (2021) found

students that participated in a simulation focused on caring for a terminally ill patient had gained knowledge and confidence on how to assist terminally ill patients with advance care planning. George et al., (2018) reported that nursing students' knowledge of advance directives increased as they progressed from the first junior to the second senior semesters.

Nursing students reported the fear of individuals perceiving student behaviors as inappropriate and fear of discussing death and dying as barriers to advance care planning (Nash et al., 2016). Students also reported the challenge of discussing and assisting with completing advance directives. The importance of moral courage in students when preparing to meet with individuals, during the meeting, and when assisting with completing advance directives is highlighted in this study (Nash et al., 2016).

Active learning strategies of role-playing an advance care planning discussion, reviewing and discussing a landmark legal case, and discussing advance care planning barriers and facilitators increased readiness to advocate for Advance Care Planning (ACP) for clients (Tilton & Paul, 2020). Hall and Grant (2014) reported similar results when using active learning strategies requiring students to complete their advance directive and discuss choices with the person appointed to be their power of attorney for healthcare. The learning activity positively affected students, making them more likely to recommend and assist family members with advance directive completion. The research on advance care planning and nursing education provides a promising direction for strategies to increase advance care planning. There is a need for further research regarding how nursing education can increase advance care planning rates.

The American Association of Colleges of Nursing ([AACN], 2008) *Essentials of Baccalaureate Education for Professional Nursing Practice* recommends improving end-of-life curriculum content. Curriculum changes must provide nursing students with the knowledge needed to improve end-of-life care, decrease futile care, and address shortcomings or inconsistencies in nursing curricula. Connell and Mallory (2007) stress the importance of nursing programs improving advance directive education to prepare students with the information needed to discuss this critical topic with patients and families. They posit further that expecting healthcare organizations to provide advance directive education to practicing entry-level nurses is ineffective (Connell & Mallory, 2007). Nursing curricula must introduce advance directives early on in programs and build on the knowledge learned each semester as students progress (Connell & Mallory, 2007; Jezewski et al., 2003).

LGBTQ+ and Advance Directives

LGBTQ+ people execute advance directives to prevent family members from attempting to overturn end-of-life choices, fear that family may interfere or ignore a partner's role in their lives, and to communicate in writing their end-of-life care choices to those involved in their life, including their partner, family members, and friends (Buckey & Browning, 2013; Hash & Netting, 2007; Thomeer et al., 2017). Individuals with partners are more likely than singles to have an advance care planning document. Couples who do not have children or family support often feel they only have each other to rely on if something were to happen, which motivates them to address their end-of-life choices and execute an advance directive (Buckey & Browning, 2013; Hash & Netting, 2007; Thomeer et al., 2017).

Nurses and Advance Directives with LGBTQ+ People

Nurses and other health care professionals lack knowledge about advance directives and end-of-life care decisions in the LGBTQ+ population. Carabez & Scott (2016) conducted a study using the Healthcare Equality Index to examine nurses' knowledge of advance care planning in the LGBT client population. About half (49.4%) of nurses reported no experience with advance care documents or statutes regarding advance directives. Some respondents did not believe it was their responsibility to help clients complete advance directives. Others identified social workers or pastoral care as the ones who should assist clients with advance care planning documents. In addition, nurses reported using heterosexist language because they lacked knowledge about inclusive language when addressing LGBTQ+ clients and advance directives and end-of-life care (Carabez & Scott, 2016). Nurses reported that it would be easier to honor advance directives if couples proved marriage status. In contrast, others reported it would not matter because they had witnessed advance directives being overridden by healthcare providers, leaving family members to make decisions for incapacitated clients (Carabez & Scott, 2016).

Healthcare providers should be aware of complex family dynamics and how to address situations that may arise...

Cultural competence is another factor related to nurses caring for LGBTQ+ clients. One-fourth of nurses reported limited awareness and knowledge about caring for LGBTQ+ clients (Carabez & Scott, 2016). Rawlings (2012) recommends health care providers be aware of their feelings toward caring for this population. Providing culturally sensitive care is vital to addressing clients' risk factors, stigmatization, and health needs. Healthcare providers should be aware of complex family dynamics and how to address situations that may arise, especially when family members choose to override a client's end-of-life decisions. This

may leave the client feeling abandoned and grieving (Candrian & Lum, 2015). Harding et al., (2012) recommend that healthcare professionals be aware of staff discrimination toward clients and address it immediately. They also recommend a welcoming, nonjudgmental environment that addresses the specific needs of this population.

There is a paucity of research addressing nursing students and advance directive education in the LGBTQ+ population. Few studies addressed nurses' and other healthcare professionals' lack of knowledge when having discussions with LGBTQ+ clients and assisting them with advance directive completion. For example, Lim & Bernstein (2012) recommend the integration of LGBTQ+ aging into the curriculum. Using a standardized client in simulation scenarios, incorporating LGBTQ+ health issues during clinical orientation, and educating faculty about LGBTQ+ health will assist in integration into the curriculum. However, they did not address advance directive education specific to this population. Other articles related to LGBTQ+ and nursing education included perceptions, health education, knowledge, attitudes, and cultural competence. Advance directive education and nursing student preparation specific to the LGBTQ+ population are absent in the literature.

Model Case Scenarios

Patrick Bailey

Patrick Bailey is a 63-year-old caucasian who identifies as a transgender female-to-male person. Patrick's legal name at birth was Patricia Bailey. Patrick was brought to the emergency room by his partner Jim because he was not feeling well. Patrick has complained of weakness, abdominal discomfort, diarrhea, and intermittent rectal bleeding. Patrick received two units of packed red blood cells (PRBCs) in the emergency room, where his abdomen was scanned.

Following an esophagogastroduodenoscopy (EGD) and colonoscopy with biopsies, Patrick was diagnosed with colorectal cancer with metastasis to the liver and lungs. Palliative care has been consulted while Patrick and Jim discuss their next steps with this devastating news. The couple has inquired about getting their "affairs" in order.

When helping Patrick and Jim complete the ACP, the nurses must understand the barriers to completing these documents, how to complete and execute ACP documents and use non-gender language when asking about sexual orientation and gender identity. Providing privacy is essential since many LGBTQ+ people feel uncomfortable "coming out' or making their sexual identity or gender orientation public. It may be helpful to speak with the patient alone (per patient preference) to provide this level of privacy. Nurses should understand transitional care therapies and procedures, such as hormone replacement therapy and sex reassignment surgeries, as well as the health disparities that transgender people face.

Brandon Price

Brandon Price is a 74-year-old male who has been HIV-positive since 1996 and has been living with his partner, James, for the last 27 years. He has been estranged from his family of origin since his early twenties when he publicly announced his sexual orientation while attending college. He has a daughter, Bri, who is an important part of his life but is unaware of his HIV-positive diagnosis. He has been under treatment for HIV and has not seen a provider in several years. He was taken to his physician's office for severe abdominal pain and ongoing muscle fatigue. His physician admitted him to the hospital after assessing his swollen lymph nodes. An abdominal scan and subsequent biopsies reveal stage IV non-Hodgkin's Lymphoma that has metastasized to multiple organs. Hospice, palliative care, Brandon's daughter, and a spiritual advisor were all contacted to help.

Brandon's wish is not to inform Bri about his HIV status, which means that the healthcare professionals will have to provide privacy regarding his medical information. Signing and executing ACP documents would give James the power to make medical decisions in case Brandon could not make these decisions. This would also ensure that Brandon's family of origin will not be able to make decisions for him if he cannot make these decisions for himself. Instead, James would be the designated medical power of attorney if Brandon is unable to make decisions due to his deteriorating condition.

Implications for Nursing Education

Nursing education must improve end-of-life care so nursing students can converse and assist clients with advance directive completion upon graduation. There must also be education specific to the LGBTQ+ population. The nursing curriculum needs to educate nurses about sexual orientation and gender identities, how to use respectful non-gender language, gender transition therapies and procedures, and the disparities that LGBTQ+ people face, especially when facing end-of-life care. Education must include communication, safe environment creation, advance directive needs, family dynamics, biases, and discrimination. Simulations about teaching LGBTQ+ clients about advance directives and addressing the barriers are recommended. Simulation scenarios using examples like the model cases presented is a strategy that could be used to improve end-of-life care for LGBTQ+ people. Civic engagement activities designed to increase interaction between nursing students and LGBTQ+ people are another strategy to educate nursing students about the needs of ACP for LGBTQ+ people.

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More broadly, AACN and other accrediting bodies could provide specific information about what advance directives should be covered in nursing curricula and include specific population needs, such as the LGBTQ+ population. Developing standards would provide consistency among nursing programs about what information students receive. In addition, these standards could help emphasize the importance of ACP for LGBTQ+ people to improve their quality of life.

Individuals identifying as LGBTQ+ have unique healthcare needs, making advance care planning important so their wishes are honored at the end of life. Nurses must be prepared to meet clients' needs and assist them with completing advance directives. They must also have the knowledge and skills to assist LGBTQ+ clients with advance care planning. Ensuring this content is available to nursing students will improve the healthcare outcomes of this population.

Conclusion

Nursing curricula needs to include specific information about advance care planning and how end of life care can be improved for LGBTQ+ populations. Various approaches including increasing the civic engagement between nursing students and LGBTQ+ groups and the use of simulation to address the use of advanced directives for groups with non-traditional gender identities and differing sexual orientations are some potential strategies to address this gap in nursing curricula. Other methods and tactics should also be explored so nursing education can teach how to improve the quality of life of LGBTQ+ populations when instructing patients in advanced care planning.

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