

In my eight-month experience working and shadowing hospice care, I met one patient who was in a same-sex marriage. During the intake, the patient and his husband discussed their love story, discussing how they had to marry outside of the state due to laws prohibiting same-sex marriage. The patient was dying of a terminal illness, and we were assisting the couple with end-of-life care, ensuring that they were cared for and supported as the patient moved out of the home to a facility. I vividly remember my supervisor wisely ensuring that all people on the care team would treat the couple with dignity and respect. Being in TN, I realize that the beliefs surrounding sexual orientation are not inclusive, and this began my search for how to create a space where all are given dignity in death. I wanted to know the gaps in care for LGBTQ+ individuals.

### **Disparities within the Healthcare System**

LGBTQ individuals have historically encountered discrimination, marginalization, and other disparities within the healthcare system. (Kemery, S. A. (2021). Some of those disparities include healthcare barriers, mental health disparities, and economic barriers (Javier, N. M. 2021). One study identified the barriers that LGBTQ+ individuals may encounter. These include isolation, advanced planning, stress relating to stigmas perpetuated by individuals, and support systems (Kemery, S. A. (2021). Heterosexual adults were also found to be more likely to have health insurance (Wondafrash, 2021). In one study, family members of people who were in hospice care took the Quality of Dying and Death Version 3.2a Family Member/Friend After-Death Self-Administered Questionnaire in order to identify the quality of life from the perspective of patients who identified as LGBTQ and families of individuals who did not. It was found that non-LGBTQ+ individuals reported higher quality of death and dying than LGBTQ+ individuals, even those with lower income. It was also found that non-LGBTQ+ reported a

higher quality of end-of-life than non-LGBTQ+ individuals (Kemery, S. A. (2021). Due to state laws, some same-sex marriages are not recognized by law, which could affect preferred care if a directive or legal documents are not completed (Wondafrash, 2021).

### **What Can Be Done**

Hospice can be an integral part of the dying process. They offer many ways of support, but it is crucial to support in ways that align with the values of the individual who is being served (Dhawan, et al., 2021). In an editorial by the Palliative Care & Social Practice, hospice providers must realize the importance of sexual identity to their personhood, and allow patients to express themselves in ways that are comforting and align with their identity and values (Dhawan, et al., 2021). In the intake process, it is imperative to know what patients' preferences and values are, so that the entire care team can abide by and respect those values (Dhawan, et al., 2021). Another way to be intentional about creating a safe space for LGBTQ+ individuals is to know who is within their community—friends, or partners— knowing who the patient would like to be a part of the conversations relating to their health and well-being (Dhawan, et al., 2021).

Dr. Kimberly Acqualviva, a social worker and professor at the UVA School of Nursing, conducted research surrounding LGBTQ+ care within hospice and palliative care (School of Nursing). As a guest on the podcast *The Heart of Hospice Podcast*, she shared the importance of having a non-discrimination statement within hospice organizations that specifically mentions protection from discriminating against sexual orientation or gender identity. She asks listeners to ask the question of what policies are in place that are welcoming to all people. She continues by urging hospice organizations to do training for all members that teach inclusivity. She mentioned that “Good intent is not equal to good impact” meaning that intentional work must be done to

truly be inclusive for all individuals. It is important not to make assumptions, indicating the importance of not allowing tokenism to guide actions or beliefs. There are systematic and policy changes that should occur, but she also urges listeners to identify their religious beliefs and how it may shape the way in which they perceive people. She also notes that the language that clinicians use must align with values, specifically mentioning that for some, mention of God in certain contexts can cause discomfort due to past experiences.

### **Resources**

Dr. Kimberly Acqualviva suggests the program Sage to train hospice providers. It is a training program for skilled nurses, organizations, hospice & palliative care, and other providers. The training is intended to educate providers about how to create an inclusive and welcoming environment/organization (Sagecare). Fenway Institute also offers training programs to build cultural awareness among employees and providers (Wondafrash, 2021). The National Hospice and Palliative Care Organization also contains resources that are intended to train professionals about LGBTQ+ individuals in hospice and palliative care.

## References

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