End-of-Life Care Homes

Executive Summary

Hospice care is an interdisciplinary end-of-life healthcare approach that focuses on quality of life when a patient is terminally ill and a cure is no longer possible. Hospice care can be delivered at a variety of locations, including the home or in home-like hospice residences, nursing homes, assisted living facilities, veterans' facilities, and hospitals. While hospice care is often fully covered by Medicare, Medicaid, and private insurance companies, the care is often provided by family members. Families may face additional out-of-pocket costs when hiring an in-home nurse or placing the family member in a nursing home to receive adequate care. Proposed 2021 legislation (HB 632) seeks to add End-of-Life Care Homes, a relatively new strategy in hospice care, into RSMo 198.190 to operate as registered care facilities.

Highlights

- Hospice patients can be any age with any terminal illness, however, most patients who enter hospice care are seniors (greater than 65 years old).
    - In Missouri, 17.3% of the population are seniors.
    - At the time of death, 1 out of 2 Medicare beneficiaries were in hospice care programs.
- End-of-Life Care Homes provide a home-like dwelling for terminally ill individuals and supplemental care by non-medical volunteers at no cost when familial caregivers cannot be fully available.
- Almost 9% of seniors live below 100% of the poverty level and may not be able to afford out-of-pocket costs associated with hospice care.
- In recent years, hospice use has slowly increased for a variety of reasons including accessibility and eligibility.
    - Hospice reduces other expensive health care costs including hospital visits.

Limitations

- End-of-Life Care Homes are relatively new hospice care strategies; research investigating their effectiveness, including quality of care, has yet to be completed.
- Hospice care research investigations about how to best provide end-of-life care in terms of both quality of life and cost effectiveness are ongoing.

Research Background

Hospice Care Approaches and Costs

Hospice care focuses on quality of life when a cure is no longer possible, or the burden of treatment outweighs the benefit; medical treatment geared towards disease progression stops and the focus of care is about comfort and pain alleviation.[1] It is an interdisciplinary approach

that includes medical care, pain management, and emotional support personalized to a terminally ill patient and their family's needs.[2] In these instances, patients are confirmed by two medical physicians to have less than 6 months to live. Patients can be any age with any terminal illness, but most patients who enter hospice care are seniors (greater than 65 years old) with cancer or dementia.[3] In Missouri, 17.3% of the population are seniors.[4] In 2018, there were 1.2 million Missouri Medicare beneficiaries. At the time of death, 1 out of 2 Medicare beneficiaries were on hospice care programs.[5,6]

Currently, there are approximately 135 hospice centers in Missouri.[7] Hospice care can be delivered at home or in home-like hospice residences, nursing homes, assisted living facilities, veterans' facilities, and hospitals. Hospice care costs (e.g., physician and nursing services, medical appliances and supplies) are often fully covered by Medicare, Medicaid and private insurance. However, family members provide the majority of hospice care. Additional out-of-pocket costs to the individual or family may include hiring an in-home nurse or placing the family member in a nursing home to receive adequate care. It is estimated that approximately 35% of Missouri seniors live below 200% of the poverty level, and associated costs may be a barrier to access this level of additional care.[8]

End-of-Life Care Homes

There are three nonprofit organizations in the state that operate as End-of-Life Care Homes: Solace House of the Ozarks in Joplin, Caring Hearts and Hands in Columbia, and Jacob's Ladder in Springfield. These homes are not medical centers or facility-based long-term care services (e.g., residential care facilities, assisted living facilities, nursing homes); they are home-like dwelling places for terminally ill residents in a hospice program, with medical guidelines of admission to hospice care outlined by the Center of Medicare and Medicaid Services, overseen by their hospice care team. As alternatives to an at-home nurse or nursing home facility, these homes assist dying individuals and their families in receiving the comfort care needed at the end of life through non-medical volunteer and staff coordination at no cost when familial caregivers are unavailable.

<u>End-of-Life Care Homes Legislation</u>

Proposed in the Missouri 2021 legislative session, HB 632 adds and defines "End-of-Life Care Homes" in RSMo 198.190 as a residence operated by a nonprofit organization that provides a home-like dwelling place for terminally ill residents with a life expectancy of six months or less who are enrolled in a hospice program. The bill requires the Department of Health and Senior Services to establish reasonable standards and regulations, in addition to registration for these homes. Staff and volunteers of the homes must be trained to recognize abuse, neglect, and exploitation, similarly to medical and residential care employees. This legislation would allow end-of-life homes to operate as registered facilities and assist more than two persons. Homes caring for no more than two persons, or only persons related to the provider are exempt from registration requirements.

Similar institutions can be found throughout the United States, including Iowa, Kansas, and Oklahoma. However, statutory regulations and registration requirements may vary within each state. In California, these facilities may be licensed through the Department of Social Services.

Changes in Hospice Facilities

The Medicare Hospice Benefit, passed by Congress in 1982, enabled older adults to receive hospice care and can create a savings of approximately $18,000 per hospice user in hospital visits and associated costs.[5] However, eligibility is restricted to individuals with a life expectancy of 6 months and individuals had to be willing to forgo all treatment directed at their underlying disease.[9] These enrollment requirements created barriers and underuse of hospice and instead contribute to excess use of intensive care and hospital costs at the end of life.[9] In recent years, hospice use has slowly increased for a variety of reasons including accessibility and eligibility.[10]

There has been a large increase in the number of hospice care facilities over the last 30 years, specifically for-profit hospices.[11] In Missouri, 99% of hospice centers are for-profit.[7] While higher costs are associated with for-profit hospices when compared to non-profits, differences regarding quality of care received by patients are continuously under investigation.[11] The National Hospice and Palliative Care Organization has policies in place to ensure standardized care across hospice organizations, regardless of funding status, and outlines various levels of care to assist patients that need differing needs during the course of their disease progression.[12]

Lastly, private insurance companies have extended eligibility criteria from 6 months to 12 months and allowed patients to continue to receive treatments that alleviate symptoms.[8] For example, in a study of 774 hospice patients conducted by Aetna, those in the extended hospice program had lower incidences of hospital admissions for emergency (9.8%), acute (16.8%), and critical care units (9.6%) compared to the non-extended hospice program (15.2%, 40.3%, 23.0%, respectively).[13] This indicates that changes to hospice by expanding eligibility criteria and access to additional treatments for symptoms can provide effective symptom management in the home setting, and reduce associated hospital visits and costs for the patient.[9,13]

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