Spirituality among the Terminally Ill in a Rural Hospice Program

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Abstract

Rural populations are unique compared to their urban and suburban counterparts in relation to both healthcare mindsets and spiritual needs. Rural populations tend to be more religious, more accepting of death, and less likely to pursue aggressive care at the end-of-life. This research project looked at the utilization of chaplaincy services among a rural, southwestern hospice population. It also examined outcomes related to patient and family satisfaction surrounding spiritual themes. Results were compared to 1700 other hospice programs. Areas where there were significant statistical differences from benchmarks were highlighted. It appears that overall hospice satisfaction and assistance with feelings of sadness and anxiety could be related to increased spiritual utilization.

Keywords: End-of-life, rural, spiritual, terminally ill

Rural America

There are several ways to define rural America, and yet no definition is entirely precise. The U. S. Census Bureau, the U. S. Office of Management and Budget, and the Federal Office of Rural Health Policy all have varying definitions. Those definitions range from 15% of the population to up to slightly over 19% of the population.[1] The Census Bureau defines rural America at 19.3%. It does so by not defining rural, but instead by defining urban as any area over 50,000 people.[1] By default anything which is not urban becomes rural. The line between urban and rural becomes vague and challenging to define.[2]

The number of people in rural America continues to decline as we experience more urban sprawl. In 1910 more than half of the country's population lived in a rural setting.[2] Today, that number has declined, based on how one defines rural, to fewer than 20%. However, that 20% equates to over 50 million people in the population.[3]

When it comes to healthcare, rural areas face unique challenges. In rural areas, where the population may be less, but the geography is much greater, only 1/10 of all physicians practice. In addition, 99% of physician residency programs are in urban or suburban areas. This creates two dilemmas in relation to rural providers. First, physicians who train in urban and suburban areas are likely to be hired in those areas where they trained. Second, physician training in urban areas does not prepare them for the unique needs of providing care in a rural health setting.[4]

Rural areas are historically medically underserved not just in providers, but in relation to access to all types of healthcare. There are issues with the quality of care in rural setting as opposed to the quality of care in an urbanized area. Outcomes are just generally poorer. More of the population struggles with chronic diseases and isolationism, impacting both physical and mental health.[3]

Spirituality

Religion and spirituality have varying definitions. Seeing religion as an outward manifestation of one's inner spirituality seems to be an acceptable interpretation.[5] In this article religion and spirituality will be used interchangeably. Research

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has long supported that religion and/or spirituality can help patients cope with illness, face life's challenges, and provide peace of mind.[6] It can also reduce feelings of isolation and have positive outcomes in the lives of older adults in particular.[5] It can serve as an anchor in troubling times.[7]

Religion seems to especially be prevalent in rural settings. In contrast to urban settings, rural populations see religion as more central to their lives.[7] Moreover, rural populations have higher levels of spirituality than their urban counterparts.[8] Rural patients also tend to have a greater willingness to be accepting of their death and more likely to resist unnecessary aggressive measures at end-of-life.[9]

Spirituality among the Terminally Ill

Dame Cicely Saunders, the founder of the modern hospice movement, saw spirituality and spiritual distress as one of the four fields of total pain.[10] Spiritual pain may be exacerbated by physical pain, and spiritual pain may impact physical outcomes. Decreased spiritual pain can lead to a decrease in physical pain.[11] Terminally ill patients by the very nature of their disease trajectory have unique spiritual needs such as finding meaning in life, finding forgiveness, and the reframing of hope. Patients at the end-of-life have a greater sense of spirituality than healthy adults and other sick nonterminally ill patients.[12]

Rural Spirituality

The hospice identified for this research covers five rural counties in southern Arkansas near the Louisiana border. The area is approximately 2 h from Little Rock, Arkansas and approximately 2 h from Shreveport, Louisiana. According to a Gallup poll, Louisiana and Arkansas were identified as the most religious states in the southwestern part of the United States.[13] The southwestern and southeastern parts of the United States are considered very religious and are the most religious regions in the United States at 45% and 43%, respectively. This is contrasted with New England, the least religious part of the United States, at 26%. An area is measured as very religious when individuals answer that religion is important to them and that they attend church services weekly or almost weekly.[13]

According to research by Barna, the top ten Bible-minded cities were rated. Shreveport, Louisiana came in at fifth while the Little Rock-Pine Bluff, Arkansas region came in at eighth.[14] The region the hospice serves is situated directly in between these two population areas. It also borders two of the most religious states in America.

Table 1: Data from hospice electronic medical record

	2017	2018	2019
Admissions	423	385	349
Black	19.4	22.5	21.9
White	76.6	73.9	75.5
Percentage of admissions seen by a chaplain (%)	91.7	91.9	89.3

Research Questions and Methods

This research is designed to look at the prevalence of chaplain visits among the terminally ill population in a rural, religious setting. It is also designed to look at the satisfaction among the decedent's family members as to the level of spiritual care rendered. The hospice program did not have an Institutional Review Board. The research proposal was presented to the hospice program's Ethics Committee instead. The Ethics Committee approved the research project. Data were extrapolated from the electronic medical record related to admissions and the percentage of patients who received chaplain visits over the course of 3 years, 2017–2019. Finally, data were pulled from family satisfaction scores (Hospice Consumer Assessment of Healthcare Providers and Systems) which were benchmarked by Healthcare First. Healthcare first benchmarks 1700 different hospice providers nationally (www.healthcarefirst.com, personal communication, March 5, 2020). The CAHPS scores were pulled from a 3 years span from 2017 to 2019. For 2019, only data for the first three quarters were available at time of publication. While several questions are asked, the focus was on responses which were considered spiritual in nature and were also deemed to be positively statistically significant compared to national averages.

Results

There was also a question asked about religious and spiritual support for the caregiver. While the hospice averaged 96.8% over the 3 years span (minus the fourth quarter of 2019), the national average was 94.2% and not statistically significant. Another spiritually related question was the emotional support given to the caregiver. Both questions were based on the "right amount." The average over 3 years was 97.9% while the benchmark was 94.6%, again not statistically significant. The questions in the table relate to the spirituality of the patient (as assessed by the caregiver). The questions above are geared toward the caregiver alone.

Table 2: Data from hospice CAHPS scores

	2017 (%)	2018 (%)	2019 (first three quarters) (%)	Benchmark (included only data deemed statistically significant) (%)
Rating of hospice Care 9/10 or 10/10	94.7	95	94.3	85.1
Patient received help for anxiety or sadness (always)	84.4	76	80.6	64
Hospice team really cared for patient (always)	93.8	94.1	91.5	87.2

Discussion

The Medicare Hospice Regulations require a comprehensive spiritual assessment within 5 days of admission to the program.[15] Patients, of course, have a right to refuse a chaplain assessment and such would be documented. The patient also can pass away within hours or days of admission to the hospice program, hindering the chaplain from completing the spiritual assessment. While the percentage of patients seeing a chaplain appears to be high, it is unknown which factors contributed to the number not being higher.

The real-time data seems to indicate a high percentage of patients accepting of a chaplain visit [Table 1]. While this may seem normal in an area where people are inclined to be more religious, this data have to be also be examined in light of patients likely already having a strong spiritual support system. In spite of that or perhaps because of that, patients were still acceptable to additional spiritual support. There are no benchmarks known to the author related to the percentage of hospice patients seen by a hospice chaplain.

Overall there is a statistically higher satisfaction rate with this hospice compared to others [Table 2]. Could this be because rural populations are more accepting of death? Could is also indicate an increased desire to die naturally without aggressive treatment options? Could it also be indicative of having sufficient spiritual support in the dying process? Certainly, all the above options could be collectively true.

While the question surrounding anxiety and sadness could have psychological and medical implications, it surely has a spiritual implication as well. There is a large difference in the satisfaction rate related to this question compared to national benchmarks. With around 90% of patients receiving spiritual support, these patients felt that their anxiety and sadness were always addressed a significant amount of the time.

The implications for a rural, southern hospice program may involve ensuring sufficient staffing for spiritual support services. With around 90% of patients open to chaplaincy visits, this may be indicate staffing pattern norms may be need to be adjusted in this setting. Hospice provides interdisciplinary care, with such a significant satisfaction in helping patients cope with sadness and anxiety, it may be important for hospices to reevaluate the contributions of the hospice chaplain to providing interventions in this area. Certainly, a strong team approach to care can help patients with this question. This research may also indicate that while terminally ill patients have strong spiritual support from their local faith community, they still desire spiritual support from specialists in end-of-life care. Finally, this small research project centered on the singular hospice program and may not be representative of other hospice programs. Additional research is warranted to see national trends related to the percentage of hospice patients seen by chaplaincy services and the patient and family outcomes associated with.

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Conflicts of interest

There are no conflicts of interest.

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