Bereaved Family Member Perceptions of Quality of Care by Site of Death and Palliative Care Utilization in the Last Month of Life

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Overview

Using a retrospective cohort study of National Health & Aging Trends Study data from 2011-2020, we evaluated bereaved family member responses by site of death and pathway of palliative care utilization to assess quality of care over the last month of life.

Background

• Centers for Medicare and Medicaid Services have begun testing alternative payment models with palliative care to control healthcare costs and maintain or improve quality of care.

• Prior research reported higher perceived quality of care when only examining care received while on hospice or hospital based palliative care team, but not over a care episode.

• The last month of life reflects care transitions and increased symptom burden, making it an important period for studying bereaved respondent perceptions of quality of care.

Study Design

• The National Health Aging & Trends Study (NHATS) is a nationally representative prospective cohort study of Medicare enrollees 65 years and older. The Last Month of Life (LML) interview, a mortality follow-back survey of bereaved respondents, assesses quality of care delivered to decedent and their family.

• Of 3,580 decedents with completed LML interviews, 2,796 (Weighted N = 12.6 million) were close friends or family familiar with the decedent in the last month of life completed the survey.

• The exposure of interest was the receipt of palliative care stratified by site of death.

• Primary outcomes: overall ratings of quality of care, symptom management, being treated with respect, spiritual support, shared medical decision-making, and communication with the bereaved respondent.

• Multivariate models with appropriate survey weights to account for the sampling design of NHATS examined the marginal difference of care settings stratified by hospice or palliative medicine involvement. Analysis was adjusted for age, gender, race, diagnoses, functional status, and respondent relationship with the decedent.

Results

• Across all care settings, respondents of decedents who died in home with hospice services reported highest ratings of care as excellent (60.2%, 95% CI (55.5, 64.7) with adjusted marginal difference from home with hospice shown above for each care setting.

• Other family and friend perceptions of quality of care in symptom management, spiritual support, shared-decision-making, and care communication were significantly poorer compared to dying at home with hospice.

• Acute care settings such as the hospital and ICU had the most significant disparities in symptom management (ex. unmet pain or dyspnea) and had the greatest room for improvement in shared decision-making, care communication, and treating the decedent with respect.

Conclusion

• Consistently, dying at home with hospice is superior to other settings of care in improved ratings of quality of care, symptom management, shared decision-making, and care communication.

• The last month of life is a vital period over which transitions in the healthcare utilization pathway affects ratings of quality of care when examined as a care episode as opposed to individual silos of care.

• These findings support shifting to evaluation of quality of care over a care episode to assess if alternative payment models maintain quality of care in end-of-life care.