The Financial Impact of Terminal Illness on Patients’ and Families’ Quality of Life: Perceptions of Hospice Social Workers

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**Purpose:** The purpose of this research is to advance our understanding of the impact of terminal illness on patients’ and families’ quality of life. This research is aimed at uncovering the following question: What are hospice social workers’ perceptions of financial status related to quality of life in hospice patients and their families? The researchers would like to improve the current understanding of the financial burden/impact that terminal illness has on a family.

**Methodology:** Purposive sampling was utilized for this qualitative study, and ten hospice social workers at various hospice agencies in Wisconsin were interviewed for approximately 30-45 minutes. Open-ended questions posed to the participants allowed them to describe their experiences and perceptions in their own words. Interview responses were transcribed and patterns and themes within the data were identified and analyzed.

**Interview Questions:**
1) How many years have you been a social worker? If less than one year, how many months?
2) How many years have you been a hospice social worker? If less than one year, how many months?
3) Do you serve an urban, suburban, and/or rural population?
4) Do you work full time or part time? If you work part time, how many hours do you work per week?
5) On average, how many patients are on your caseload?
6) How is financial security related to quality of life in hospice patients and their families?
7) In your opinion, what is important to hospice patients and families at the end of life?
8) How do financial issues impact terminally ill patients and families?
9) How often do hospice patients and families face financial issues?
10) Do you complete a financial assessment on hospice patients? If yes, how? If no, do you believe that a financial assessment should be completed on hospice patients?
11) What, if any, changes would you like to see regarding financial issues related to the terminally ill?
12) Is there anything you would like to add concerning this topic?

**Themes:**
1: At the end of life, hospice patients most value pain control, dignity, support, comfort, that they are honored, and that they are at peace with their family.
2: Younger adult hospice patients are less likely to have funeral arrangements and life insurance and are thus more likely to face financial hardship.
3: Comprehensive financial assessments are rarely used by hospice social workers. Part of this stems from hospice patients and families’ hesitation to disclose financial need.
4: Hospice social workers would like to see Medicare coverage extend to cover custodial care, funeral costs, and costs involving comfort at the end of life.
5: Hospice patients are frequently concerned about finances near the end of life. Financial hardship often leads to hospice patients ignoring their physical, emotional, spiritual, and psychosocial comfort. Stress is exacerbated by financial worry.

"It's not all about the money, but it's always about the money."

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**Bibliography:**