“He’s on His Dying Bed”: Next-of-Kin’s Experiences of the Dying Body


SUMMARY: Interviews were conducted with the next-of-kin of 78 Veterans who died in Veterans Affairs (VA) hospitals, to discuss their experiences transitioning from home care to hospital care. Next-of-kin expressed concerns over cleanliness and alterations in routine, and recommended speaking to patients.

KEY FINDINGS:
- Interview respondents were grateful when staff spoke to patients, regardless of the patients’ mental functioning.
- Moving patients and altering schedules upset next-of-kin, who reported feeling disoriented and unable to monitor care.
- Next-of-kin commonly reported being upset when their loved ones’ bodies were not kept clean.

IMPLICATIONS FOR PROGRAMS:
Programs could:
- Create systems that encourage open communication among families and healthcare providers
- Offer avenues for airing and addressing grievances related to care quality
- Provide virtual access to patients and hospital staff via mobile phone apps or video calling services

IMPLICATIONS FOR POLICIES:
Policies could:
- Recommend the elimination of restrictions on visitations from family members for seriously ill or dying Service members
- Encourage standards of care to include attention to family members’ concerns
- Promote open communication between staff and family members regarding patient care
METHODS

- Next-of-kin were recruited through electronic medical records of Veterans who died within one year of the study intervention.
- Letters were sent to 362 next-of-kin, of whom 126 responded, and 78 agreed to participate in the study.
- Two-hour interviews were conducted with the next-of-kin of 78 Veterans who died in six VA hospitals in the southeastern United States.
- Interviews were recorded, listened to, transcribed, and coded by members of the research team.

PARTICIPANTS

- Next-of-kin were primarily White (60%), and female (78%), with a mean age of 64 years.
- Participants consisted of surviving spouses (40%), adult children (31%), and siblings (17%) of the deceased.
- Veterans were predominantly male (98%), and principal causes of death included cancer (30%), heart disease (23%), lung disease (12%), neurological conditions (10%), kidney disease (6%), liver disease (5%).

LIMITATIONS

- All deaths occurred in a VA hospital. It is unclear how relevant these findings are for civilian hospitals or other non-hospital locations.
- Interviews were conducted between three and six months after Veteran deaths, thus transition experiences were told retrospectively and may not accurately reflect lived experiences.
- Only one Veteran was female; therefore, it is unclear how end of life care is experienced by families of female Veterans.

AVENUES FOR FUTURE RESEARCH

Future research could:

- Interview family of terminally ill or dying female Service members
- Evaluate the impact of various settings (e.g., VA hospitals, civilian hospitals, hospice, and home settings) on families’ experience of a loved one’s death
- Focus on the transition from home to hospital as experienced by the patients themselves

ASSESSING RESEARCH THAT WORKS

Design

Appropriate Research Plan and Sample

Methods

Appropriate Measurement and Analysis

Limitations

Few

For more information about the Assessing Research that Works rating scale visit:
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