

"He's on His Dying Bed": Next-of-Kin's Experiences of the Dying Body

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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

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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 orother nonhospital 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



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