



KEY POINT SUMMARY

OBJECTIVES

This qualitative study aims to investigate the perceptions and experiences of family members of individuals nearing the end of life (EoL) regarding the role of the acute-care environment on their well-being.

Family members' experiences of the end-of-life care environments in acute care settings – a photo-elicitation study

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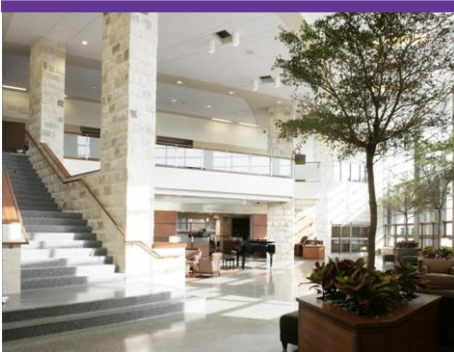
Key Concepts/Context

Research demonstrates that environmental features in varied healthcare settings can impact patient and staff outcomes. Room occupancy, acoustic environment, visual contact with nature, sound and lighting, ergonomics, and the work environment design are among the features with documented impacts on staff and patient health. The results of this research (conducted in acute-care end-of-life (EoL) settings suggest that family members of palliative patients can also benefit from healing impacts of environmental features (i.e., colors, art, lighting, minimal noise, spaces for privacy, and social connection, as well as spaces for connecting with staff).

Methods

The researchers conducted a qualitative, inductive study using participant-produced photographs and follow-up interviews to document experiences of family members of patients going through the palliative phase of a life-threatening disease. The method used was “photo-elicitation or photovoice,” where participants documented their experiences. The study took place at two acute-care units in southern-mid- Sweden, one in a major city and the other in a smaller city. Purposive sampling was used to recruit family members of palliative patients receiving inpatient care and with no cognitive impairments.

Data collection involved participants taking three photographs of what they identified as meaningful or important in the acute-care environment. They were provided with digital cameras and informed about obtaining consent if other people were included in the photographs. Follow-up individual interviews were conducted, during which the photographs were reviewed, and participants were asked about the content and its meaning to them. The interviews were audio-recorded and transcribed verbatim.



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The study involved a total of nine participants, including both genders and a range of ages. The participants had varying educational backgrounds and spent different amounts of time with the patients in the acute-care unit. The patients had late-stage lung or kidney disease and had been in contact with the hospital unit for varying durations.

The concurrent data collection and analysis followed “interpretive description” (Thorne, 2016). Each interview and its accompanying photographs were treated as an “analytic unit” and were only viewed in conjunction with each other. Inductive coding was used to identify themes. The authors collaborated, discussed codes, and developed variations and relationships. Three themes emerged: aesthetic impressions, space for privacy and social relationships, and the need for guidance in crucial times.

Findings

Three main themes of the research are summarized here:

1. Aesthetic and unaesthetic impressions: Participants’ photographs and descriptions highlighted the influence of various aesthetic factors related to sensory experiences, including colors, art, lighting, orderliness, cleanliness, and sound, on their overall experiences. Warm and joyful colors were found to relieve distress, while glaring and cold colors enhanced anxiety. Lighting and art were seen as important contributors to the aesthetic environment. Conversely, poor lighting, dirty and disordered surroundings, and unpleasant sounds (e.g., beeping machines and alarm buttons) from medical equipment created discomfort and distress for family members.
2. Space for privacy and social relationships: Family members emphasized the need for individual rooms, which provided a sense of security, control, and the ability to maintain social connections. Single rooms allowed for flexible visiting hours, uninterrupted conversations, and the opportunity to engage in everyday activities together. In contrast, shared rooms were seen as hindering privacy and social contact, leading to concerns about confidentiality and limited interaction. The findings also emphasized the significance of communication and shared experiences, such as meals, in maintaining family relationships. The linkage between environmental conditions and outcomes is evident in the impact of room arrangements on social interactions, emotional well-being, and the overall experience of patients and their families.
3. Need for guidance in crucial times: Family members expressed the lack of practical information and guidance, such as signage and navigating the environment, and knowing when to leave the unit with the patient for rest and break. The participants emphasized the importance of respectful



communication with staff, including being greeted and body language. Family members also faced challenges due to the lack of communication among staff members. Supportive gestures from staff, such as offering food or drinks, were appreciated. The linkage between environmental conditions and outcomes is evident in how guidance, communication, and staff attitudes can influence the experience and well-being of family members in the acute-care setting.

Limitations

- **Small sample size:** The study was based on a limited sample of nine participants from two hospitals in the same country (limited geographic and cultural scope). This small sample size may limit the generalizability of the findings to a broader situation with varied cultural, organizational, and healthcare systems.
- **Lack of long-term contact:** The short inpatient stays and limited contact with participants during ongoing care at the end of life may have limited the researchers' ability to capture a comprehensive understanding of the participants' experiences. This may affect the validity of the study.
- **Gatekeeping by staff:** The role of staff in deciding whether family members could participate in the study may have introduced bias.

Design Implications

This research demonstrated three pathways in which acute-care palliative settings can support family members' well-being: 1) The aesthetic and multi-sensory aspects (warm and joyful colors, proper lighting, art, orderliness, cleanliness, and minimum noise) along with 2) the provision of private spaces that foster social connections, as well as 3) spatial features that facilitate effective communication and interaction between staff and family members.

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