Palliative care involved a specific concept of care focusing on life and optimising patient quality of life


From the experiences of patients, their relatives, and their professional caregivers, what are the processes occurring within a residential palliative care unit?

DESIGN
Grounded theory approach within a symbolic interactionism framework.

SETTING
2 residential palliative care units in Belgium.

PARTICIPANTS
8 patients who were admitted to the palliative care unit with terminal illness and an estimated lifespan of 3 months; 9 relatives of patients (not relatives of the patients interviewed); and 24 team members of the palliative care unit (3 doctors, 1 physiotherapist, 1 pastor, 1 social worker, 11 nurses, 1 nurses’ aide, 2 psychologists, and 4 volunteers).

METHODS
Data were collected by semi-structured indepth interviews lasting 30 minutes to 1.5 hours. Interviews were loosely structured, using an interview guide. Data were also collected from observations of care, team meetings, and analyses of patient records. Data collection and analysis used an iterative process, and questions were added as needed to the interview guide to explore emergent themes. Interviews and team meetings were tape recorded and transcribed verbatim. Interview and team meeting transcripts, field notes, patient records, and observations were coded and analysed. Themes and concepts that reflected the palliative care experiences of patients, relatives, and caregivers were identified. Findings were presented to palliative care team members external to the study to check the interpretation of the data.

MAIN FINDINGS
Findings showed a high correspondence between the experiences of patients, relatives, and caregivers. The specific concept of palliative care shown in this study was a focus on life, with the objective of optimising quality of life. The caregiving process focused on creating opportunities for patients to live and enjoy life as much as possible. Maximising quality of life was ensured by a combination of strategies and conditions.

The caregivers sought to use strategies to create space for living for the patients. These strategies included controlling the symptoms (eg, use of effective pain management), creating a safe environment, alleviating anxiety (eg, helping patients to express feelings of anxiety), accompanying patients in truth (eg, keeping patients and relatives informed about the illness so that decisions about death could be made and lives could be lived as fully as possible), and giving physical care in a respectful manner. Caregivers also searched for ways to help patients fill the space in their lives as meaningfully as possible, using strategies such as regarding the patient as the “norm” (eg, accepting patient needs and wishes), providing creative and active care, providing comprehensive care, and giving physical care. All participants identified several conditions that were essential to good palliative care: sufficient time to get to know patients, caring attitude of caregivers, competence in providing creative and active care, interdisciplinary team work, and characteristics of the setting (small units, homelike infrastructure, and non-hospital environment). These strategies were used to ensure that patients enjoyed life as much as possible even in the face of death. The conditions permitted patients and relatives to experience effective and high quality palliative care.

CONCLUSIONS
Palliative care involved a specific concept of care with the central focus on life and the goal of optimising quality of life. The processes of palliative care involved 2 strategies: creating space to live by taking the focus off the illness and filling the space as meaningfully as possible so that patients could fully enjoy life. Certain conditions determined the effectiveness of the strategies and the quality of the palliative care experience.