Feature Article

End of life care in nursing homes: Translating focus group findings into action

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A B S T R A C T

Therapeutic options for nursing home residents focus on functional improvement, while inadequate hospital admissions in the dying phase are frequent. The aim of this study was to explore views, attitudes, and concerns among staff and to embark on a process that facilitates end-of-life care on an institutional level. Three focus group interviews were conducted with nursing home staff (nurses, care managers, physicians). The discussants (22) expressed the following issues: workload; ethical conflicts; additional resources; "living palliative care"; deleterious effect of restorative aims; lack of training; fear; knowledge and skills; rituals; lack of attachment, frustration, and abuse; team; discouragement; resilience enhanced by good care; style of communication; avoidance; the "palliative status"; legal concerns and hospital admissions. Nursing home staff expressed willingness to care for the dying. Providing good end of life care may promote professional resilience and personal integrity. Therefore, team issues, fears, and avoidance should be addressed.

Introduction

Palliative care encompasses a wide range of multi-dimensional symptom control measures, regardless of the stage of disease, while end-of-life (EoL) care is a specific component of palliative care referring to the dying phase which usually is defined as the last days and hours of life. A growing number of elderly people live and die in nursing homes. However, death and dying is rarely acknowledged in long term care facilities. Adequate EoL care may be unavailable, leading to unrelieved suffering and undignified deaths. Mortality in residents is associated with a diagnosis of cancer or heart failure, the presence of dyspnea, or being bedridden.[1] It has been shown that symptoms are frequent – for example in patients with cancer[2] or dementia[3–5] – but may be poorly managed,[6] particularly in cognitively impaired persons.[7] Furthermore, nursing staff have knowledge gaps and low confidence regarding end-of-life care and they may underestimate its complexity.[8]

Relatives play an important role in decision making. If they are aware of the resident's poor prognosis, aggressive interventions are performed less often during the last three months of life.[4] Residents themselves are expecting staff and their relatives to make important decisions on their behalf, while this expectation may be experienced as burdensome by the relatives.[9] However, formal discussion of prognosis and advance care planning (ACP) are not provided on a standard basis,[10] and specific interventions may be needed to address this issue.[11]

Thus, many residents are not dying peacefully[12] or are admitted to hospital during the final weeks of their lives.[13] A large U.S. survey recently found that increased hospice use was associated with less aggressive care (i.e. hospital transfers, tube feeding, and intensive care) at the EoL[14] while the financial implications are controversial.[15]

While support by (external) hospice and palliative care services is appreciated by the staff, residents are referred usually late as these services are considered appropriate for dying persons only.[16] Moreover, perception of EoL care may differ considerably interprofessionally: nurse assistants and volunteers seem to be more critical than upper-level professionals and managers.[17] On an institutional level, barriers to accessing palliative care services are identified,[18] among them conflicting paradigms of restorative and

palliative approaches.[19] Various groups have presented implementation models for palliative care[20,21] and symptom management[6] in nursing homes. Core elements include ACP, measurement of staff turnover, staff education in palliative core competencies, awareness of management, and political incentives to set the default type of care to palliative.[19]

Therefore, this study was initiated to obtain a baseline status before implementing hospice and palliative care in a nursing home. The aims were to explore attitudes and views of nursing home staff on EoL care, and to identify barriers and facilitators. Results of a focus group interview (FGI) study are discussed in this paper.

Methods

Design

The objective was to explore the attitudes, needs, and concerns of health care staff regarding EoL care in a large municipal nursing home. To obtain a diversity of themes as broad as possible, three FGIs were conducted. The work presented here is embedded in a larger framework of action research that is still ongoing. Action research requires a flexible protocol continuously being adjusted and updated by the collaborating parties, leading to a spiral of action, measurement, and reflection.[22] Each step will be defined by research subjects and the research team.

Setting and participants

The researchers were asked by the executive director of a community-owned nursing home (300 beds) to assist with the implementation of hospice and palliative care services within that institution, a key trigger being a high rate of hospital transfers in dying residents. A full-time nursing expert in palliative care was available. There was mutual agreement to perform a formal needs assessment before suggesting specific interventions. Anonymity of all discussants was guaranteed as no personal identifiers were collected. All staff members that routinely had any kind of personal contact with residents were eligible. Purposive sampling was performed to include the whole range of professions and hierarchical levels. All subjects were asked for participation by the palliative nurse expert and were provided oral and written information on the study; in addition, participants agreed to the discussions being tape recorded. After giving informed consent, they were assigned to a specific FGI according to their profession and/or rank.

The staff council ("Betriebsrat"), which is a very strong proponent of employees' rights in Germany – thus equivalent to an ethics committee protecting study subjects' rights – formally approved of the protocol.

Data collection

Based on available literature, the researchers (BB, PP) set up an interview manual (Table 1) to make sure all relevant topics were covered. Nevertheless, participants were encouraged to address any topic that they felt being relevant.

Three separate FGIs for the following professions/ranks were scheduled to ensure open discussion and to avoid fear of discrimination: (A) nurses/nurse assistants, (B) experts/managers, (C) primary physicians. All meetings were held on the premises of the institution; interview duration was approximately 2 h each. A brief introduction was given to assure confidentiality and to explain the purpose of the study. The discussions were moderated by one of the researchers (JB), audiotaped, and transcribed verbatim. Feedback

meetings were scheduled with the participants to ensure an ongoing action research cycle.

Data analysis

The full-length transcripts were prepared by inserting line numbers and then analyzed by one of the researchers (PP) who applied thematic content analysis for data extraction.[23] After careful reading, meaning units emerging from the content of the transcripts were identified (=extraction) and paraphrased into codes (=coding). These codes were written down on file cards of one color for each FGI. A panel consisting of the authors (JB, PP, PN) and the palliative care nursing expert then grouped the codes deductively into thematically coherent categories by arranging and reorganizing the file cards until mutual consensus was accomplished (=categorization). Categories were named using original wording from the transcripts. At all stages of extraction, coding, and categorization, the original transcripts were re-assessed repeatedly. The panel used display boards to visualize and summarize the findings.

Access to the raw data (transcripts) may be obtained from the corresponding author.

Results

Participants and characteristics of FGIs

Twenty-two staff members whose characteristics are shown in Table 2 attended the FGIs.

Compared to the other groups, in the nurse/nurse assistant group there was a stronger female predominance and a shorter working experience (both in terms of the whole curriculum vitae and of the time of employment in this institution). Of note, some participants in this group were employed only a couple of weeks before the focus group study.

In general, the atmosphere in each of the groups was respectful. However, there were group-specific characteristics: while group A initially expressed concerns about confidentiality, group B acted under time pressure, and participants in group C

Table 1
Focus group interview manual.

Topics	Interview questions	Specific items (examples)
1. EoL care in the institution	In terms of resources, knowledge, and skills: • What is available? • What is missing?	• How do you notice someone is dying? • Which guidelines do you use? • In your view, how is EoL care organized?
2. Team experience of death and dying	• What is usually happening when a resident is dying? • What, in your opinion, is going well, what is rather dissatisfying? • What do you feel comfortable with, what not?	• What is communication with physicians, relatives, peers … like? • Do you perform rituals at the EoL? • Is spirituality/religion of the residents of importance?
3. Personal needs and preferences	• When do you need support? • What kind of support would you like to get?	• How do you cope with the death of someone you have been caring for? • Is symptom control difficult, do you need more training? • Does ethical dilemma arise?