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Death and Dying in Nursing Homes: A Burden for the Staff?

Brigitte Jenull

Eva Brunner

University of Klagenfurt, Austria

Changes in our society increasingly place the old and impaired in institutions, where they spend their last remaining days. The authors explore the burden of being confronted with death and dying on nursing home staff using mixed methodology. Findings from open-ended interviews with 17 representatives of different occupational groups inform the design of a questionnaire used to conduct a survey in 52 nursing homes of the Federal Province of Carinthia (Austria). In total, 894 questionnaires were returned, yielding a response rate of 49%. Results indicate that it is more difficult to talk about death with family members of terminally ill residents than with the dying themselves. The need for end-of-life training is not only essential for nursing staff but is also needed for nonnursing staff, who are found to be substantially strained by aspects of death and dying in their workplace.

Keywords: elderly; end-of-life care; mixed methodology

Hardly anything touches more than the confrontation with death. On one hand, we try to banish the subject matter of death and dying from our lives (Parker Oliver, Porock, & Oliver, 2006), which is not difficult for people who have no recent contact with death in their close family (N. Fischer, 2001). On the other hand, the media features death and dying on a daily basis. Rest (1998) speaks of “death pornography,” meaning the debate of media coverage over this taboo topic. We erect memorials for our dead, constructing magnificent, fancy, or even obscure gravesites (e.g., see, www.crazycoffins.co.uk). Along with air funerals or burials in outer space (e.g., see www.memorialspaceflights.com; www.seaservices.com), these public trends suggest clear changes in attitudes toward death and dying.

Life expectancy has continued to rise. At the beginning of the year 2007, nearly 2% of the Austrian population was more than 85 years old (Statistik Austria, 2007). Within this age group, the risk of impairments increases and

the need for care becomes more and more important. Up to 75% of high-aged people who are in need of care stay at home and are looked after by their relatives, predominately by their daughters and daughters-in-law (Wilkening & Kunz, 2003). It is well recognized that family support and home care for the elderly is not available for all, because of the changing role of women and the increase in one-parent families (Exley & Allen, 2007). This trend is supposed to accelerate within the next few years. These social changes have a substantial impact on the place of death (Cohen et al., 2006). The majority of old and frail people spend their last days in an institution (Teno, 2003; Zerzan, Stearns, & Hanson, 2000), and 70% of older people in Canada die in institutions (Wilson et al., 2001). This is likewise true in German-speaking countries, where 37% die in hospitals and 33% in nursing homes (S. Fischer, Bosshard, Zellweger, & Faisst, 2004). Our health care providers are faced with the increasingly important duty to care for old people until they die (Seale, 2000).

Improving quality of life for nursing home residents is particularly important at the end of life (Forbes-Thompson & Gessert, 2006). People who are dying have extensive needs, including pain and symptom management as well as emotional and spiritual support (Ersek, Grant, & Miller Kraybill, 2005). In a study by Lloyd-Williams, Kennedy, Sixsmith, and Sixsmith (2007), older people had precise views of their dying. They hoped for an easy and dignified death without pain and fear. Perceiving their increasing dependency, they did not want to be a burden for others, not even wanting to leave funeral arrangements to their family members. Although nurses have to deal with mortality in their everyday routine, many have no formal or adequate training in working with dying residents and their varying degrees of burden-related distress and needs (Badger, 2005; Winchester, 2003).

Dunn, Otten, and Stephens (2005) indicate that nurses' personal feelings have an influence on how they cope with dying persons. Those with a greater fear of death have more negative attitudes toward caring for dying patients than those with less fear of death. Many nurses feel uncomfortable with the gap between theoretical knowledge and their practical understanding of a dignified dying process (Hart, Yates, Clinton, & Windsor, 1998). Vachon (2001) uses the concept of "ethical stress" to describe nurses' ongoing difficulty with complex care and death situations compounded by various occupational problems such as lack of interdisciplinary cooperation, heavy workload, and rigid hierarchical structures (Kayser-Jones et al., 2003; Sander & Russel, 2001). Nursing staff believe that most deaths are "good deaths" (Hanson & Henderson, 2000), characterized by a lack of physical suffering and little fear and anxiety. Physical suffering as criteria of a "bad death" makes palliative care an important field within the branch of nursing home care

(Adriaansen & van Achterberg, 2004; Hirai, Miyashita, Morita, Sanjo, & Uchitomi, 2006).

Palliative care teams support the dying person and his or her family in the individual's physical, psychological, social, spiritual, and emotional needs (Exley & Allen, 2007). In Austria, they work in the community to enable people to die in their family surroundings. There are also efforts to implement palliative care in hospitals, but there is currently little financial support available for these endeavors (Pleschberger, 2006). The focus on palliation is also insufficiently addressed in the majority of nursing homes (Hanson, Reynolds, Henderson, & Pickard, 2005; Raudonis, Kyba, & Kinsey, 2002). Family members are not integrated sufficiently into the dying process, where they need preparation for existential situations and support for coping with grief (Steinhauser et al., 2000). To meet all these requirements, nursing home staff need education and training in palliative care. An important aspect in this context is the willingness to enter into the dying person's experience and one's own coping with mortality and death (Boston, Towers, & Barnard, 2001).

Cohen-Mansfield's (1995) model provides a framework of examining nursing home staff experiences with death and dying. The model discusses two crucial aspects: work-related demands and stressors as well as personal stressors and individual resources. Dealing with death and dying in the workplace is defined as a demand on the patient level, which describes the interaction between staff, patients, and their families (Cohen-Mansfield, 1995). Individuals who care for the oldest old are routinely confronted with periods of intense suffering, dying, and death (Forbes-Thompson & Gessert, 2006), and being confronted with these existential situations is often stressful (Badger, 2005; Dunn et al., 2005). Cohen-Mansfield's model suggests that individual resources such as social support or adaptive coping mechanisms serve as protective factors during these experiences.

We conducted a two-phase mixed-method design to investigate how nursing home staff perceived confrontation with death in routine care (Creswell & Plano Clark, 2007; Johnson & Onwuegbuzie, 2004). In Phase 1, we used a qualitative approach and asked 17 representatives of different occupational groups about their feelings and experiences with institutional death and dying. Qualitative methods are appropriate to deal with taboo and to convey humane sensitivity to respondents (Weitzman & Levkoff, 2000). Findings from these open-ended interviews informed the design of a questionnaire that was used in the second, quantitative phase. The qualitative phase primarily provided a basis for creating the quantitative instrument but was also important for the interpretation and clarification of the quantitative

results (Bryman, 2007). This underlines the recursive and interactional characteristic of mixed research (Johnson & Onwuegbuzie, 2004).

Method

Data Collection

Data were collected over a 20-month period in all 52 nursing homes of the Federal Province of Carinthia (Austria). The study not only focused on the nursing staff but also considered other occupational groups, such as cleaners, physicians, or unskilled employees. Representatives of these occupations confirmed that they frequently functioned as social interaction partners for nursing home residents.

Ethical Considerations

Participants were informed that participation was voluntary and that information provided would be treated confidentially. The first author gave full information about the aims, methods, and expected benefits of this study. This approach is consistent with the ethical principles and code of conduct of psychologists (American Psychological Association, 2002).

Qualitative Phase

Instrumentation and data collection. Three nursing homes, differing in size and institutional background, were approached and asked to participate in Study 1. We conducted interviews with 17 employees, who participated voluntarily. The interviews were conducted in the workplace so that the everyday situation provided the background for natural answers. The interview outlined three central questions based on the theoretical background presented earlier: (a) How do you feel about being confronted with death and dying in your job? (b) What positive and negative experiences have you had with the dying? (c) What aspects are helpful in the exposure to death?

These questions helped to explore the staff's feelings and perceptions regarding death and dying as well as their coping strategies. The interviews lasted from 37 to 90 min, with a mean duration of 1 hr. The interviews were taped and transcribed verbatim.

Participants. The interviews were conducted with three hospital service chiefs, five registered nurses, three nursing auxiliaries, one carer for the elderly, one care assistant, one civil servant, and three cleaners. We chose participants of different age, sex, and professional status, maintaining a high level of heterogeneity with regard to age (ranging from 21 to 56 years old) and professional experience (6 months to 16 years).

Data analysis. The transcribed interviews were analyzed using qualitative content analysis (Mayring, 2005; Patton, 2002). Qualitative content analysis is characterized by rigor, pursuing the aim of transparent and comprehensible procedures. Categories were formulated inductively by working through the material line by line. During the process, peer debriefing (Lincoln & Guba, 1985) was used to ensure intersubjective comprehensibility (Steinke, 2004).

Results. We found 41 categories, which were subsumed under four main categories to achieve a higher level of abstraction. Reliability was assessed by randomly selecting six interviews and having another researcher independently code them. Fleiss and Cohen (1973) defined a kappa between .60 and .75 as an indicator of sufficient interrater agreement. A kappa of .81 was found in the present study, indicating a satisfactory category system and acceptable reliability. Table 1 presents the main categories and statements associated with them.

Being confronted with dying residents in the daily working routine was perceived as a burden by staff members. Participants underlined stressful events such as the sudden and unexpected death of residents and the emotional involvement in long and painful dying processes. They also described their work with the family members as problematic. Relatives who could not accept the residents' death were perceived as nonsupportive and difficult to handle. Participants emphasized difficulties in facing the relatives' grief in situations involving death. It seemed to be essential to participants to separate their work from their private lives. Sometimes, however, they could not forget their stressful work-related experiences with death. In their everyday routine, staff members wished to have more help from "outside" to care for residents and their family members. They emphasized the role of collaboration with physicians, religious groups, and mobile palliative care teams in dealing with experiences of death and dying.

Four main categories represent crucial stressful aspects in the staff's work with dying residents and their family members. These results served as a basis for the development of the questionnaire items used in Phase 2.

Table 1. Statements and Main Categories Related to the Staff's Experience of Death and Dying

<i>Statements^a</i>	<i>Main Categories</i>
"It is really horrible when you find one of the residents, already dead, and you didn't count on that! You didn't even have the possibility to say goodbye . . . that's really hard." (48 years old, female)	Contact with dying residents (12 subcategories)
"Well, it is awful when the residents cannot die. For example, Mr. W. suffered from fear and pain for days and days. I gave him sedatives, but they didn't have any effect. Mr. W. didn't want to die, he was struggling with death. It was terrible to observe that." (48 years old, female)	
"It is so hard to face the relatives; I hardly can pull myself together. I feel like crying when I tell them about the fact that the resident is dead." (27 years old, female)	Contact with family members (9 subcategories)
"The problem was the daughter . . . she couldn't take that her mother has reached the end of life. The mother struggled with death for months because of that." (25 years old, female)	
"It is not good to talk about dying residents with your family. My partner, for example, works in a completely different area, that's asking a bit much to talk with him about that." (25 years old, female)	Separating private life from work (8 subcategories)
"I cannot get away from my work at all, when I come home, I reflect on my working day again and again, I can hardly escape." (48 years old, female)	
"Sometimes the dying process takes so long time and is so painful for the residents . . . that is terrible. It would be possible to ease the pain, but therefore the physicians have to collaborate with us. But they do not come to the nursing home." (34 years old, female)	Need of help from "outside" (12 subcategories)
"We need support in the work with the dying residents and their relatives. Mobile palliative care teams would be a great help, but there is little money for that and no appropriate offers." (28 years old, male)	

a. Statements are translated into English and made more readable without changing the meanings.

Quantitative Phase

Instrumentation and data collection. Using a survey, we investigated confrontation with death as well as stress and coping. The questionnaire items included the following:

1. The contact with dying residents is difficult.
2. The contact with family members of dying residents is difficult.
3. As far as death and dying are concerned, I separate private life from work.
4. I would like to have help with terminally ill persons (e.g., hospice care).
5. The confrontation with death and dying is often stressful for me.

All questions used a 5-point response scale ranging from *exactly* to *not at all*. Questions 1 to 4 were formulated based on the four main categories identified in Phase 1. Question 5 was added to get an overall assessment of death as a stressful event. It was adopted from a questionnaire that explores psychological loads in inpatient health care (Büssing, Glaser, & Höge, 2002).

Participants. We recruited participants in a two-step preparatory stage. First, all nursing homes received mailed information. Then, we presented the aims and procedure of our study during a meeting, asked the staff to participate, and distributed the questionnaire to all persons employed at the nursing homes. All occupational groups active in nursing homes were asked to participate (see Figure 1). The completed questionnaires were collected in a letterbox in each nursing home and retrieved by the authors. Of the 52 nursing homes, 49 took part in the quantitative survey study. The return rates varied between 14% and 100% in each nursing home. Data from 894 home employees were available, yielding a mean response rate of 49%.

As illustrated in Figure 1, primarily nursing staff took part in the study. The response rate of the nursing staff (registered nurses, carer for the elderly, nursing auxiliaries, assistant nurse, trainees, and care assistants) was higher (59%) than in the group of the nonnursing staff (38%, all other occupational groups; cf. Figure 1). The total sample consisted of 802 women (89.7%) and 88 men (9.8%); 4 persons gave no indication whether they were male or female. The predominant majority (64%) were employed full-time, 40.6% worked during the day, and 41.2% worked shifts.

Data analysis. The quantitative analysis of questionnaire items included nonparametric procedures because only ordinal data were available. The Mann-Whitney test was used to test group differences between nursing and nonnursing staff, the Wilcoxon test was used for dependent samples, and Spearman correlations were calculated to assess associations between variables.

Results. The following analyses focused on the comparison between nursing ($n = 670$) and nonnursing staff ($n = 224$). Most of the employees in the two groups had no particular difficulties in having contact with residents who were close to the end of life (see Table 2).

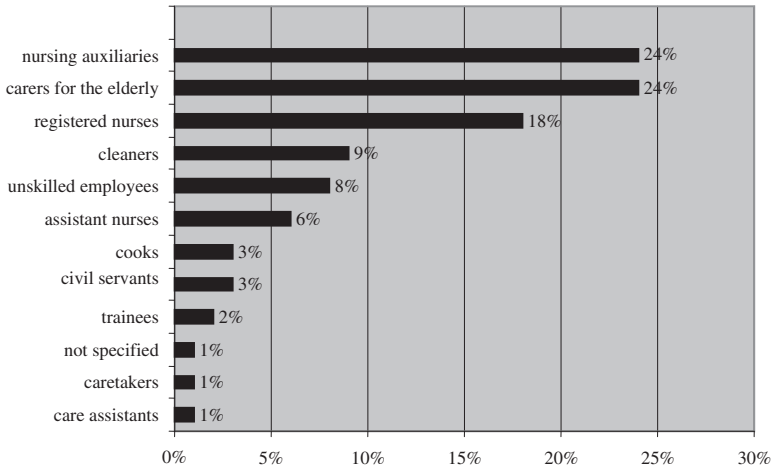


Figure 1. Distribution of Occupational Groups in the Sample

Nonnursing staff reported more difficulties in being confronted with terminally ill residents ($z = -2.426, p = .015$). In general, it seemed to be more problematic for both groups to discuss mortality with the family members (see Table 2, Item 2) than with the dying residents themselves. The following interview statements show attitudes toward the relatives: “The family members notice by themselves, when the end is near” (nursing auxiliary, female, 56 years old). “Only family members are a burden, never the dying” (carer for the elderly, male, 28 years old). Although the majority of the nursing and nonnursing staff could separate private life from work, it was much harder for the nonnursing staff to do this (Table 2, Item 3, $z = -3.205, p = .001$). One staff member told us, “When I leave work at the end of office hours, I try to shake off all the misery I have seen. I tell myself that I worked well and I cannot do more” (nursing auxiliary, male, 41 years old). The two groups did not differ on perceived importance of help from outside (Table 2, Item 4). One participant noted that “perhaps it would be good for the dying if someone had a little time for them . . . some would like to talk” (registered nurse, female, 34 years old). Another stated, “It needs more than we can do” (registered nurse, female, 53 years old). The confrontation with death was seen as a stressful duty by the majority of the respondents (see

Table 2. Answers to the Questionnaire Items (Study 2)

Questionnaire Items	Percentages		U	
	Nurses	Nonnurses	z	p
The contact with dying residents is difficult.				
1 = <i>exactly</i>	5.5	7.0	-2.426*	.015
2 = <i>indeed</i>	13.0	19.1		
3 = <i>partly</i>	20.9	23.6		
4 = <i>rather not</i>	35.1	30.6		
5 = <i>not at all</i>	25.4	9.7		
The contact with family members of dying residents is difficult.				
1 = <i>exactly</i>	9.3	10.5	-0.438	.662
2 = <i>indeed</i>	19.7	20.9		
3 = <i>partly</i>	36.0	34.6		
4 = <i>rather not</i>	23.4	22.2		
5 = <i>not at all</i>	11.6	11.8		
As far as death and dying are concerned, I separate private life from work.				
1 = <i>exactly</i>	26.1	17.7	-3.205**	.001
2 = <i>indeed</i>	41.7	38.0		
3 = <i>partly</i>	23.5	30.4		
4 = <i>rather not</i>	7.0	7.6		
5 = <i>not at all</i>	1.6	6.3		
I would like to have help with terminally ill persons.				
1 = <i>exactly</i>	27.2	18.3	-1.497	.134
2 = <i>indeed</i>	28.3	34.2		
3 = <i>partly</i>	17.5	18.3		
4 = <i>rather not</i>	20.1	17.5		
5 = <i>not at all</i>	6.9	11.7		
The confrontation with death and dying is often stressful for me.				
1 = <i>exactly</i>	27.2	20.7	-2.008*	.045
2 = <i>indeed</i>	33.7	35.6		
3 = <i>partly</i>	27.5	26.4		
4 = <i>rather not</i>	7.8	12.1		
5 = <i>not at all</i>	3.8	5.2		

* $p < .05$. ** $p < .01$.

Table 2, Item 5, $z = -2.008$, $p = .045$), especially for the nonnursing staff. A participant said, "Being in touch with dying people every day will be my break up sooner or later" (civil servant, male, 22 years old).

No differences could be determined between male and female employees. There were small but significant negative correlations between age and Item 1 ($r = -.096$, $p = .006$) and Item 2 ($r = -.079$, $p = .026$). For the total sample, it was more difficult to talk with family members about death and dying than to talk with terminally ill persons ($z = -10.988$, $p < .001$).

Discussion

Nursing homes have increasingly become places where old and impaired people spend their remaining days. Nurses play a very important role in giving end-of-life care (Whittaker, Kernohan, Hasson, Howard, & McLaughlin, 2006). We found that working with terminally ill persons is perceived as an occupational stressor for nursing home staff. The support of dying people can never be reduced to vocational routine. Apart from the physical care of dying residents, psychological support for the residents seemed to be an important concern for staff members (Byrock, 1998). As the findings of our qualitative study showed, nurses had problems dealing with long and painful dying processes, or to use Hirai et al.'s (2006) term, *bad deaths*, and unexpected deaths. Although residents and nurses expressed the desire for a "good death" experience, it did not seem to be representative of nursing home reality. Nurses could cope neither with the residents' fear of dying nor with residents' physical pain. Pain management needs the collaboration with physicians. In Austria, they are normally not part of the staff of the nursing homes. Residents choose their general practitioner, and only if necessary do those physicians come to the nursing homes to look after their patients (Pleschberger, 2006). That leads to the problem of physicians visiting too late or not having enough time to accompany the dying process, and physicians are quite often not very well qualified or sensitized for terminal care (Katz & Peace, 2003).

The results of our study underlined the importance of coordinated collaborations with physicians and palliative care teams, which was expressed by interview participants' need for help from "outside." The implementation of palliative care in nursing homes is limited by the fact that the dying process of patients with a diagnosis of cancer is more predictable regarding the time frame than the dying process of residents suffering from dementia (Pleschberger, 2006). Interventions on an organizational level are the precedent for the lasting change of handling death and dying in nursing homes. Bereavement care should become a standard in nursing home care, and the interaction between staff, dying residents, and relatives should become a

main issue. The latter is confirmed in our participants' descriptions of their relationship with the residents' family members as problematic. Badger (2005) assumes that direct contact with family members is the most difficult task for the nurses. Families are in need of timely and clear information and communication about death and dying (Rabow, Hauser, & Adams, 2004; Steinhäuser et al., 2000). For the future, nursing homes should reflect the role of family members and recognize them as an important source in caring for the dying. But who is going to take care of the family members and integrate them into the daily routine? The implementation of a palliative care team could also be a very useful investment in future nursing home structures.

The current situation leads to occupational stress for the nurses and has a negative impact on job satisfaction and on the daily work routine with residents and family members. This is associated with higher absence from work, lower quality of care, and the desire to leave the job (Cohen-Mansfield, 1995). Another consequence seems to be the difficulty of separating private life from work. Our interviewees reported that they did not want to burden their partners, although they were thinking about their working experiences over and over again. Because of workload and emotional stress, nurses tended to avoid a deeper involvement in the process of dying. They seemed to protect themselves from burden through their own personal delimitation (Badger, 2005; Vachon, 2001). Rest (1998) reported shorter time periods spent in rooms with dying patients. To prevent such maladaptive coping strategies, it needs intensive training in the field of terminal care. Studies show that educational programs should include quality management in end-of-life care, pain and symptom management, handling of grief and bereavement, and communication with all persons concerned (Ersek et al., 2005; Paice et al., 2006a). Evidence for the effectiveness of such trainings already exists (Hanson et al., 2005; Paice et al., 2006b; Sandgathe Husebø, Husebø, & Hysing Dahl, 2004).

Education in palliative care is necessary for all staff members to recognize handling death and dying as a significant duty in nursing homes (Teno, 2003; Toscani, Di Giulio, Brunelli, Miccinesi, & La Quintana, 2005). The comparison of the occupational groups made in our quantitative study also pointed toward the importance of those staff members (cleaning and helping personnel) who were not educated in care, as they had often been selected by residents as communication and interaction partners. So another question arises for the future: Don't these groups deserve closer attention and basic training in key aspects of death and dying?

Therefore, it is necessary to establish an institutional basis that allows spending time for this duty, and we need to rethink the way we deliver care in institutions. Ethical care for the elderly, which ensures dignity and individuality until the moment of death, requires financial and personnel resources and concrete organizational implementation (Jeong & Keatinge, 2004). Maintaining a professional demeanor during the interactions with all persons concerned is too limited; we rather all have to face up emotionally to death and dying. Instead of trying to banish it from our direct perception, we should learn to deal with death and dying of our older generation as an important life task.

Limitations

Because of our close contact with the nursing homes, we met a high acceptance of the study. Forty-nine of the 52 nursing homes took part in the quantitative survey study. Nevertheless, the response rate was only 49%. We hypothesize that our sample is biased. Those who find dealing with death and dying more difficult, who are confident in future changes and motivated to enhance the conditions of institutionalized dying might have been more likely to answer the questions. Although our study aimed to reach all occupational groups, nursing staff were overrepresented. Maybe nonnursing staff are not as accustomed to participating in such studies. Therefore, future projects should especially encourage nonnursing staff to take part. Furthermore, we do not have any information about nonrespondents because of our guarantee of anonymity. Because of the level of measurement, we could not use multivariate analysis in our quantitative study. Comparisons between the different occupational groups could only be investigated by grouping our sample in "nursing staff" and "nonnursing staff" because of the low number of respondents in the second group. The two phases of our study were conducted in rural areas and small towns, so the results cannot be generalized to urban areas. Further research is needed to consolidate the results and replicate the study in other areas. Combining qualitative and quantitative methods helped to get a deepened insight into the area of research interest. Although it is difficult to find a proper way to integrate both approaches (Bryman, 2007), the advantages are obvious. Our qualitative study yielded sensitive information, which provided the basis for the development of the questionnaire. By using a quantitative measurement in Phase 2, we had the opportunity to reach a lot of staff members in the nursing homes. Our qualitative results also served for the interpretation and clarification of the quantitative findings, which reflected successful integration of both studies.

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Brigitte Jenull is an assistant professor at the University of Klagenfurt, in Austria. The main focus of her research is self-determination and autonomy of elderly people in nursing homes. She is also interested in stress, coping, and health behavior of nursing home staff.

Eva Brunner is an assistant professor at the University of Klagenfurt, in Austria. Her interests include health behavior in adolescents and elderly people, with a specific focus on mixed-methods research.