Residents’ view of dignity and dying in nursing homes

Dignity and the challenge of dying in nursing homes: the residents’ view

SABINE PLESCHBERGER

Department of Palliative Care and Organisational Ethics, Faculty for Interdisciplinary Research and Education (IFF), Vienna, University of Klagenfurt, Austria

Address correspondence to: S. Pleschberger. Tel: +43 1 522 4000-104 Fax: +43 1 522 4000-178. Email: sabine.pleschberger@univ-klu.ac.at

Abstract

Background: human dignity is discussed in almost all public debates on the care of the dying, as well as in international policies for health and social care of older people. Because nursing homes are gaining importance as places where residents live out their lives in modern western societies and since there is evidence that end-of-life care in nursing homes lacks quality, there is a growing discussion on introducing improved end-of-life care in these institutions. In order to accomplish this, the view of those who are most affected is of utmost importance.

Objective: to explore the meaning of dignity with regard to end-of-life issues from the perspective of older nursing home residents in western Germany.

Methods: this qualitative study is based on the Grounded Theory Approach, and the design included three steps of data generation; narrative interviews with residents of nursing homes constitute the main data pool (n = 20) of the results presented in this paper. Theoretical sampling was aimed at maximising the variety of organisational as well as residents’ characteristics. Analysis of the transcripts was supported by Atlas/ni program and followed several different coding procedures and aimed at generating a concept of dignity.

Results: dignity was differentiated into intrapersonal dignity and relational dignity, socially constructed by the act of recognition. Social relations and encounters are a prerequisite for relational dignity, which underlines the vulnerability of nursing home residents’ who increasingly lack social networks. A broad spectrum of attitudes and behaviour, which aimed at recognising dignity, was bundled under the category ‘not being a burden’. In this light, dignity was challenged most by the threat of illness and having care needs. This was fostered by the perception of insufficient care in the nursing homes. In the light of this concept, death with dignity meant ‘death at the right time’, though the residents in the sample did not want to comment on the time of death, other than aspects like (i) being active to the very last, (ii) respecting one’s will and being allowed to die, (iii) not being in pain, (iv) being amongst persons close to one (valediction and showing respect).

Conclusion: the study emphasizes the high vulnerability of nursing home residents with regard to dignity. They place their dignity under the constraints of the need for help and care into question. This appears alarming, if one does not manage to, with the help of different ethics, obtain a new perspective on these phases of life. It is evident that the understanding of dignity is not solely individualistic and personal, but rather has a close relationship to social ideas of value, which ultimately influence the basic requirements of institutions in which ‘frail old people’ live.

Keywords: dignity, older age, qualitative research, nursing home, palliative care, elderly

Background

The dignity of men and women must not be violated (Article 1 of the German Constitution). This basic principle, anchored in constitutional law, is referred to in almost all public debates on the care of the dying as well as on international policies for health and social care of older people [1]. However, exactly
S. Pleschberger

how ‘dying with dignity’ is defined—and who is to define it—is not discussed.

The amount of literature on dignity as a concept in health care, especially concerning older or dying people, is comparatively small, though it has been increasing in recent years. For example, Chochinov et al. derived a rather functional concept of dignity, in which illness-related concerns and a social dignity inventory can have a detrimental influence on dignity, though a buffer against these ill effects can be provided by a ‘dignity conserving repertoire’ [2]. Nordenfelt differentiated between four kinds of dignity: dignity as merit, dignity as moral stature, dignity of identity and the dignity of ‘Menschenwürde’ (‘human dignity’) [3], and this approach serves as a framework for empirical research [4, 5]. In the light of this, it seems to be important to perceive dignity not as an ‘either/or’ concept, but rather to think of it as several aspects that are more or less interrelated, since many articles show selective losses of dignity in the context of care [6–8].

Because nursing homes are gaining importance as places where people live out their lives in modern western societies [9, 10], and since there is evidence that end-of-life care in nursing homes lacks quality [11], there is a growing discussion on introducing palliative care principles in nursing homes in order to improve end-of-life care in these institutions [12–15]. In order to accomplish this, the views of those who are most affected is of utmost importance [16, 17], although they are difficult to be surveyed. This qualitative study explores the meaning of dignity with regard to end-of-life issues from the perspective of older nursing home residents in Western Germany.

Study design

The work presented here is derived from a larger study [18], which was based on the Grounded Theory Approach and involved three steps. First, qualitative interviews with heads of nursing homes were conducted (n = 17), in which a total of 23 persons from 15 different organisations were involved (see Table 1). Subsequently, narrative interviews with residents of nursing homes were undertaken, which constitute the main data pool (n = 20) on which the results described in this article are based. Finally, for reasons of validation and further interpretation, three focus group discussions were held with interdisciplinary teams involving 30 participants. The data-collecting process ran from November 2001 to February 2003.

Sampling and data collection

The study followed the principles of theoretical sampling and aimed at including a wide range of relevant aspects, e.g. age, gender, level of care needs as well as organisational characteristics (see Table 1). Interviews with residents took place in six different nursing homes. Data collection and analysis followed an iterative procedure [19]. An interview guide was used to structure the introduction and include central topics if they were not mentioned in the open narratives of the interviewed persons. The tapes were transcribed verbatim.

Analysis

The open coding process supported by Atlas/ti generated more than 80 different codes. They were structured by themes and analysed in detail. Further steps contained a search for codes representing dimensions of superordinated categories. Afterwards the ‘axial-coding procedure’ was done following the coding-paradigms by Strauss [20]. Finally, a network of codes arranged around one key-category emerged (selective coding). A systematic search for conflicting cases or sequences was undertaken until the emerging concept seemed to be saturated. The entire analytic process was accompanied by feedback processes between the author and at least one member (though typically several) of the project team.

Limitations of this study arise from concerns about access to the interviewed residents, since the participants were recommended by the nursing home managers. We can only speculate about the residents who were not chosen or who refused to participate. The methodology is limited to those who can speak and tell stories—the many residents with dementia were not included.

Ethical considerations

Informed consent for an interview was obtained via verbal agreements. The consideration of ethical aspects was observed especially strongly while carrying out the interviews. If the interview led to stress or aroused emotions, which often was the case, we broke off the dialogue. The statement was interrupted and then resumed after a rest period, if and when the interviewee was ready. A small gift (flowers) was given at

Table 1. Sampling criteria

<table>
<thead>
<tr>
<th>Organisations (nursing homes)</th>
<th>Size</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of residents:</td>
<td>64–380 (mean: 160)</td>
</tr>
<tr>
<td>Placement</td>
<td>9 in the area of Munich</td>
</tr>
<tr>
<td></td>
<td>6 in the area of Dortmund</td>
</tr>
<tr>
<td></td>
<td>9 urban</td>
</tr>
<tr>
<td></td>
<td>6 rural area</td>
</tr>
<tr>
<td>Type of head organisation</td>
<td>1 for profit</td>
</tr>
<tr>
<td></td>
<td>5 non-profit, non-confessional</td>
</tr>
<tr>
<td></td>
<td>9 non-profit, confessional</td>
</tr>
<tr>
<td></td>
<td>[5 Catholic, 4 Protestant]</td>
</tr>
<tr>
<td>Residents</td>
<td>Level of needed care*</td>
</tr>
<tr>
<td></td>
<td>12 in level 0</td>
</tr>
<tr>
<td></td>
<td>6 in level 1</td>
</tr>
<tr>
<td></td>
<td>2 in level 2</td>
</tr>
<tr>
<td></td>
<td>0 in level 3</td>
</tr>
<tr>
<td>Age</td>
<td>63–93 (mean: 82)</td>
</tr>
<tr>
<td>Gender</td>
<td>15 female, 5 male</td>
</tr>
<tr>
<td>Nearby family existent</td>
<td>13 ‘yes’, 7 ‘no’</td>
</tr>
<tr>
<td>In the home since . . .</td>
<td>0.5–18 years (mean: 5.6 years)</td>
</tr>
</tbody>
</table>

*According to the German Care-Allowances-Scheme; 3 = highest level of needs.
Residents' view of dignity and dying in nursing homes

the end of the interview, which was intended to demonstrate at least a rudimentary reciprocity between the researcher and the interviewee.

Results

Dignity was not stated explicitly by the residents, but had to be traced from their narratives. The results of this study suggest that one needs to differentiate between dignity as an interpersonal concept and relational dignity (see Figure 1). Dignity as an interpersonal concept contains those elements that are grounded in personal beliefs and aspects of the body. Dignity seems to be a personal refuge; one cannot be deprived of the core of dignity even under the worst circumstances. This core is surrounded by dignity as a relational concept—dignity is socially constructed by the act of recognition, and therefore requires recognition. Preconditions and influencing factors on relational dignity in the context of nursing homes are further elaborated below. This understanding of dignity influenced the participants’ perspectives on a dignified death, as well as other aspects closely linked to the time of death, which was rather surprising and are discussed in more detail below.

Impact of social relations

A basic requirement for building dignity—in the sense of the construction of relational dignity—derives from one’s existing (dignifying) social relationships and encounters. Nursing home residents emerge as especially vulnerable in this regard, firstly because there are few opportunities for socially dignifying relationships within the nursing home. Members of the staff were not considered appropriate for such relationships on the grounds that nursing homes were often short-staffed, and this was evident to the residents. Relations with other residents were limited because of old age, decline in health and dementia.

In the light of this, familial relationships should be given considerable attention, but one must also consider that many nursing home residents have few living family members, as illustrated in the following remark:

“They are all gone; all are already gone. Kith and kin, all of them. And I am the only one of them still running around. So it is. ( . . . )” (24; 430–442)

The very old, above all, experience the death of both family members and other figures to whom they are attached. Relevant family relationships for nursing home residents are, when still available, limited to the later generations. Although there were conflicts in these relationships, the conduct of many of the participants was strongly geared towards preventing these relationships from being jeopardized, e.g. using various strategies in an attempt to ‘not being a burden’ to the younger generation (see below).

Recognising dignity ‘in spite of’ old age

The fact that old age, per se, does not (any longer) suffice as a basis for dignity was evident from the statements of the nursing home residents. For them, the formula, dignity ‘because’ I have become old, appears to be increasingly replaced by their attempt to gain dignity ‘despite’ old age. An important category is depicted by ‘not being a burden,’ under which a broad spectrum of attitudes is bundled. It encompasses (i) adaptation to the organisational rules of the nursing home, (ii) the application of existing resources, e.g. for self care, (iii) consideration of the economic implications of the death of loved ones, and (iv) acceptance of the facts of life.

Figure 1. Nursing home resident’s concept of dignity.
of one’s life in the nursing home on one’s successors, as well as (iv) decision making (e.g. on end-of-life care issues). The following statement is a typical example regarding the attitude of the interviewed nursing home residents:

“I have already arranged the burial, . . . so that they won’t have so much work with me. . . . Everything is already written down, mass, . . . flowers. . . . a cremation and then it’s all done. One does not need to make a single additional call.” (23; 328–329)

In order that the social network of one’s lifetime is cared for and supported, the expectations on later generations are kept as few as possible.

Dignity at risk
The increasing need for help and care that nursing home residents are confronted with daily represents a major threat. The interpersonal aspects of dignity are threatened because illness and the need for care directly affect the human body and, consequently, one’s identity. Furthermore, the need for help and care appears to notably jeopardize relational dignity. Why? Active maintenance of dignity, in the sense of the above (not being a burden), becomes more difficult, and in some cases, even impossible. This is shown most clearly by the threat that dementia represents for older people. One person expressed it thus:

“If you lose your mind you will soon lose in value.” (19; 385)

It is also important to note that the perception of insufficient care in the nursing home was a characteristic of nearly all the interviews:

“I am highly pleased anyway, as long as you can help yourself it is wonderful in this place. But when you cannot help yourself and get ill then it is not that jolly any longer.” (5; 44)

However, the provision of comprehensive and dignified care can afford a notion of a dignified life ‘despite’ the need for help and care, as shown in the following answer of a resident to the question: can one have a dignified old age, despite dementia?

“I think that, when you become bed-ridden, you should above all be kept clean, and that they should nevertheless try to talk with you, and that you shouldn’t be left alone so much if you become bed-ridden, that’s basically what I understand under that.” (24; 599)

Criteria for a dignified death
“Yes, my father had a good death, out at the potato field. . . .” Many stories began like this, when the interviewees were asked in the interviews to provide examples for either a dignified or an undignified dying process. These narratives mostly referred to the interviewees’ loved ones. In these sequences, the following aspects of a dignified death were identified: (i) being active to the very last, (ii) respecting one’s will and being allowed to die, (iii) not being in pain, (iv) being amongst persons close to one (saying farewell and showing respect).

It should be kept in mind that there is a difference between talking about the death of another person and thinking of one’s own wishes at the end of life. Saying goodbye, in particular, seems to be of utmost importance for the bereaved. The interviews with residents clearly showed that being alone or not was not of much importance, but also should be there was a central issue.

It was also clear, with regard to themselves, that a dignified death also meant death ‘at the right time’, where ‘at the right time’ meant before something that is considered undignified happened. There are various reasons for this, and in many cases it hinged upon not needing (or not needing more) care or help, as given in the following excerpt:

“( . . . ) And that is a horror for me, that I might possibly have to lie in bed from morning to evening and from evening to morning and that I am dependent on another person to make every handhold that is important for my care and support. That I cannot any longer do everything alone, that is a terror for me. And I say, quite honestly, . . . when I pray, I pray that I may also be spared that.” (7; 400–408)

The stance on whether an intervention affecting the time of death can or should be allowed was independent of how strongly dying at the right time was voiced as a desire. Thus, one should not interpret these results as a vote for physician-assisted suicide or euthanasia. The nursing home residents frequently referred to religious attitudes and beliefs that precluded influencing the time of death.

Discussion
If one compares these results with the discussion in the literature, parallels as well as differences may be identified. The concept of the nursing home residents points at parallels to the approach of Nordenfelt [3], that dignity is differentiated. The ‘dignity of merit’, e.g. played a predominant role for the nursing home residents. This did not generally refer to socially accredited merit, but more often concerned individual achievements. Even the category of ‘not being a burden’ can be regarded as merit. Relational dignity, however, overlapped the dignity of merit in so far as relationships and the active creation of dignity in social relationships were given a strong emphasis. Evidence for another type, the ‘dignity of personal identity’, which emphasizes peoples’ autonomy and integrity, is also found in the data, although admittedly less explicitly.

Along with relational dignity, an understanding of a generally valid dignity (interpersonal dignity) was evident among the interviewees; however, these were grounded in religious beliefs, and therefore mostly seen as being
Resident's view of dignity and dying in nursing homes

bestowed by God, and thus they established no basis for a secular human dignity. Human rights and the like were not a reference model for these participants. This is notable in that the nursing home residents did not emphasize their rights when talking about their situation. It is assumed that this will be different for future generations. Cultural differences must also be assumed, which admittedly could not be explored in this study. Nevertheless, the extreme vulnerability of old people in institutions like nursing homes is illustrated through their views on dignity.

Concerning the issue of a dignified death, there are parallels with other studies examining the quality of end-of-life care [2, 5, 21, 22]. Referring to the residents in this sample, an emphasis is placed on avoiding inappropriate prolongation of dying and being recognized in the sense of relational dignity. One has to be aware of the fact that old residents of long-term care facilities often do not have a loved one who is still alive.

Research work suggests that the basic requirements of the institutions influence the limits of the preservation of dignity [5, 23, 24]. The results of this study fall into line with these accounts and bring into play the public debates currently found in the media. Therein, the nursing home residents hear on an almost daily basis that their care represents an economic burden for society. The general threat that the need for help and care represents for dignity is illustrated by the residents' wishes to be able to die before such care is needed, and this should be discussed in the context of the public debate on euthanasia or physician-assisted suicide.

Conclusion

The results of this work emphasize the enormous potential of a dignity-oriented approach to the care of older people. From the participants' understanding of dignity, it is clear that they represent a particularly vulnerable group in the established social ideas of worth. They placed their dignity under the constraints of the need for help and care. Approaches to long-term or end-of-life care for older people, which emphasize that people matter as individuals, for who they are and not what they can do' seem promising here, such as those developed in the context of dementia [25, 26].

It is clear from this research that the understanding of dignity is not simply individual and personal, but is closely related to social ideas of value, which ultimately influence the basic requirements of institutions in which ‘real old people’ must live. Precisely for that reason, it appears that interdisciplinary research that takes aspects of dignity and care, including dying, under consideration in the contexts of dementia care, long-term care and palliative care is urgently needed.

Key points

- Dignity was differentiated as intrapersonal dignity and relational dignity, socially constructed by the act of recognition.
- Dignity is challenged most by the threat of illness and having care needs. This is fostered by the perception of insufficient care in the nursing homes.
- In the light of this concept, a dignified death means 'death at the right time' though the residents in the sample did not wish to influence the time of death.

Acknowledgements

I would like to thank all my colleagues at the department of Palliative Care and Organisational Ethics at the IFF, Vienna, for critical comments and other support during the process of the study. Special acknowledgements are due to Andreas Heller and Katharina Heimerl, who served as scientific advisors at the department, as well as Harald Weikl and Sabine Wadenpohl, who collected data and contributed to the analysis.

Funding

The study was funded by the German Hospice Fund. After finishing the study, further analysis was done, as a part of the author's dissertation thesis, without additional funding. There are no conflicts of interests in this study.

References