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# Dignity in long-term care: The application of Nordenfelt's 'four notions of dignity'

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## Abstract

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The concept of dignity is recognised as a fundamental right in many countries. It is embedded into law, human rights legislation and is often visible in organisations' philosophy of care, particularly in aged care. Yet, many authors describe difficulties in defining dignity and how it can be preserved for people living in long-term care. In this article, Nordenfelt's 'four notions of dignity' are considered, drawing on the different perspectives of those who receive, observe or deliver care in the context of the long-term care environment. On examination of the literature we suggest that two of Nordenfelt's notions, 'dignity of identity' and 'dignity of Menschenwürde', are a common thread for residents, family members and staff when conceptualising dignity within long-term care environments.

## Keywords

Aged care, human dignity, long-term care, Nordenfelt, nursing homes, residential care

## Introduction

The human right to be treated with dignity and respect is deep-rooted in many jurisdictions across the globe. The Declaration of Human Rights<sup>1</sup> and the International Council of Nursing Code<sup>2</sup> underline the inherent nature of dignity as a fundamental human right. However, a review of the theoretical and empirical literature highlighted difficulties in defining dignity.<sup>3</sup> Of the literature reviewed on the subject, eight authors agree that it is easier to describe undignified care.<sup>3-10</sup> There have also been suggestions that dignity is a vague and nebulous concept detached from the reality of care delivery.<sup>3,9-13</sup> Wainwright and Gallagher<sup>14</sup> argue that paying more attention to being respectful and to doing no harm could provide a better guide to action than an appeal to dignity.

Several reports and campaigns in the last decade highlight dignity in care in response to reports of undignified care in aged/long-term care facilities.<sup>12-17</sup> The Picker Institute published a 2008 report for Help

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the Aged (United Kingdom) on measuring dignity in care for older people.<sup>16</sup> In 2012, recommendations for practice were produced in the United Kingdom in response to reports on failure of care in the National Health Service (NHS).<sup>15</sup> Since these publications, there has been little follow-up evaluation on the implementation of the recommendations discussed in both documents.

In order to understand the concept fully within long-term care facilities, it is necessary to explore dignity from the perspectives of the range of key stakeholders. In this article, we discuss dignity from the perspectives of residents, family and significant others and staff, drawing on empirical research, and relate the perspectives identified in the research to Nordenfelt's 'four notions of dignity'.

## Literature review

A search of Cumulative Index to Nursing and Allied Health Literature (CINAHL) and PubMed databases was conducted using the terms 'nursing homes', 'residential care' or 'long-term care' with no date restrictions in April 2014. The terms were combined and the term 'human dignity' was added. Addition of the terms 'aged' and 'frail elderly' did not alter the search results and therefore were omitted. A filter of over 65 years of age was included to narrow the search. A further hand search revealed five additional relevant articles.

All articles that involved consideration of dignity for older people in long-term care were included. Articles discussing person-centred care and personhood were excluded unless they specifically referred to dignity. Although closely related to dignity, these articles addressed broader topics such as independence and quality of life. A total of 29 articles met the inclusion criteria from the United Kingdom (14), United States (2), Australia (1), Sweden (3), Hong Kong (2), Norway (3), Nordic (1), Taiwan (1), Netherlands (1) and West Germany (1). Of these, nine were empirical and the remainder were theoretical, concept analyses, discussion papers, opinions, features and news articles.

## Nordenfelt's four notions of dignity

Nordenfelt published a paper in 2005 that presented a theoretical model of dignity that was created within the Dignity and Older Europeans Project.<sup>18</sup> Dignity has been defined in many different ways and the model presented by Nordenfelt is often referred to as providing a comprehensive definition of the concept.<sup>3,6,8,18-22</sup> Nordenfelt's four notions are as follows:

- *Dignity of merit*: related to a person's formal or informal status in society;
- *Dignity as moral stature*: dignity that is tied to self-respect and dependent on the conduct of the individual;
- *Dignity of identity*: dignity that is attached to the person's identity as a human being which can be altered by others or external events;
- *Dignity of Menschenwürde*: a German word meaning innate or inner dignity that is afforded all humans.

The degree of dignity described in the first three of Nordenfelt's four notions can fluctuate and is often dependent on the conduct, autonomy and integrity of individuals and the people with whom they have contact. In contrast, Nordenfelt's dignity of *Menschenwürde* is described as dignity everyone possesses to the same degree. It cannot be lost as long as we (the person) exist. Overall, Nordenfelt's four notions align with numerous authors who draw the conclusion that dignity is dependent on one's inner self (including outlook and interpretation of events) and the impact of interactions with others,<sup>4,6,8,9,11,19,20,22-24</sup> described by some as 'absolute dignity' and 'relational dignity'.<sup>23,24</sup> The notion that dignity is intrinsic to being human (dignity of *Menschenwürde*) is accepted in both Eastern and Western cultures.

## Dignity and residents' experiences in long-term care

The most significant of Nordenfelt's notions of dignity, in relation to the experiences of residents in long-term care, and based on empirical research, is that of 'dignity of identity'. Older people living in long-term care are particularly vulnerable due to increasing dependence on others to deliver intimate care interventions. This dependency affects their dignity as it can lead to a loss of choice and control,<sup>4,6,8,11,21,23-26</sup> which is closely linked to the notion of dignity of identity.

In 2007, the US National Survey of Nursing Homes<sup>17</sup> reported the findings of questionnaires completed by Directors of Nursing from 1435 nursing homes. The survey focused on changes in practice to incorporate more resident-directed care. The striking statistic from the survey was that only '1 in 3 nursing homes currently let residents determine their own daily schedules'<sup>17</sup> (p. 4). The power imbalance described above can be detrimental to a person's dignity, especially for those unable to advocate for themselves.<sup>24</sup> If the power imbalance is not recognised, there is a risk of de-personalising the care.<sup>6,20</sup> Depersonalised care, with a lack of choice and control, relates to dignity of identity and concepts such as integrity and inclusion. This kind of dignity can be taken away from people when, for example, they are humiliated, insulted or treated as objects. There is evidence that, for some residents living in long-term care, dignity of identity can also be affected by changes in physical appearance and altered self-image and that these changes could lead to objectified care and isolation from others.<sup>6,24,26</sup>

Some qualitative studies have identified how the actions of staff can have a harmful effect on a resident's dignity.<sup>6,24,27</sup> Residents interviewed expressed their desire for autonomy which can be in conflict with the organisations' wish to limit risks. In these situations it was shown that there was a tension between residents maintaining control and choice and the staff seeking to maintain a safe and risk-free environment.<sup>27</sup> Staff felt that residents should 'obey' care home rules to ensure their safety, particularly in relation to their health.<sup>27</sup> In other instances, the intent may not necessarily be for the resident's benefit. For example, limiting someone's choice and control in order to reduce workload is a significant departure from reducing choice and control to protect someone from harm.<sup>27</sup>

'Dignity of *Menschenwürde*' may prevail throughout the experiences of loss of dignity within the notion of dignity of identity. Views of residents from an empirical study in the Netherlands<sup>24</sup> highlighted autonomy as an important factor in maintaining dignity, but recognised that individual coping strategies and outlook on life influenced their ability to accept loss of control of everyday decision-making. The residents from the Netherlands study<sup>24</sup> also recognised preserved cognition and the ability to communicate their needs as important factors for a dignified life. A Swedish study involving 12 residents from two nursing homes reported that some residents found bodily losses related to ageing a 'violation of a person's dignity';<sup>6</sup> however, as in the study from the Netherlands,<sup>24</sup> residents also recognised that their experience could be affected by both their inner strength and interaction with others,<sup>6</sup> in keeping with dignity of *Menschenwürde*. Both of these empirical qualitative studies acknowledged that they relied on obtaining the experience of residents who were cognitively and physically able to participate. Ethnographic research using observational data could potentially provide more insight into the experiences of dignity for cognitively impaired residents.

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Being able to maintain dignity of *Menschenwürde* in the context of relational interactions has been found to be precarious for residents in long-term care. A sense of belonging and being involved in society is important for residents in maintaining their inner dignity.<sup>6,21,24</sup> Residents have highlighted barriers to social encounters in long-term care, namely, few opportunities for contact outside of the home and declining health of other residents in the home,<sup>21</sup> and participation in a social network is viewed as a way to preserve dignity and enhance a sense of personal fulfilment.<sup>6,24</sup>

There remains significant ageism and stereotyping of older people, particularly within Western society.<sup>12,13,15,24</sup> This has a direct impact on an older person's dignity of identity. The importance of

intergenerational contact for older people, to preserve inner strength and a sense of cohesion, has also been demonstrated.<sup>6,12</sup> Residents in two nursing homes in Sweden described staff as being physically but not emotionally present and their self-image and sense of belonging was gained from connections with their families.<sup>6</sup>

It is in this manner that Wah<sup>9</sup> links the maintenance of dignity to connection with the family network, that is, dignity of merit, that is, formal recognition of the position of the older person in the family. The position of the older person as one afforded dignity of rank, status or rights on the basis of holding certain roles or office is predominantly cultural and can be observed in some cultures, for example, Hong Kong.<sup>7</sup> However, in stark contrast to Wah's<sup>9</sup> description of the older person being a source of pride for a family in Hong Kong, data from the Netherland<sup>24</sup> study showed that some residents were fearful of being a burden to both their family and staff.

### Family's observations of dignity in long-term care

As for residents, the notion of 'dignity of identity' was a significant factor for families and significant others from their observations in long-term care facilities. Alongside physical appearance, choice and control were identified by family members as key factors in maintaining a sense of dignity.<sup>8,27,28</sup> Independence, autonomy, choice and control were listed as the most important aspects in providing dignified care by family members in a UK study.<sup>27</sup> The next most important aspect was privacy.<sup>27</sup> The authors of this UK study identify a possible bias in their findings due to low response rates and convenience rather than purposeful sampling. The examples summarised by the authors included knocking on residents' doors before entering and ensuring privacy when giving personal care. Näden et al.<sup>8</sup> cite one family member who could tell which member of staff had cared for her husband on any particular day from his physical appearance.

Some family members described disturbing physical humiliation, such as pulling a duvet off a resident and starting to wash them without any communication, or talking on a mobile phone while feeding a resident.<sup>8</sup> Rees<sup>29</sup> described the shock she felt when she discovered how much power 'strangers' had over every part of her mother's physical and emotional well-being, exemplifying the impact of disempowerment and de-personalised care, not only on the resident's dignity of identity but also on how the family members perceived undermining of dignity of identity.

Family members have reported that residents can be deprived of a sense of belonging.<sup>8</sup> This is echoed by the views of residents from the empirical studies described above.<sup>6,21,24</sup> An example given by a family member participant in Näden et al.'s<sup>8</sup> study describes a situation where a resident was prevented from attending a musical event because a staff member felt 'it was not any good for people with dementia to listen to music: they might become upset by it' (p. 756). A study carried out in Norway, Denmark and Sweden with 28 relatives of nursing home residents aimed to establish their view of the meaning of dignity in nursing home care.<sup>28</sup> The authors concluded that dignity can be maintained by delivering person-centred care which they described as 'at-home-ness' and 'the little extra'. As in the UK study,<sup>27</sup> they also refer to 'being seen as a human being'.

### Staff views of dignity in long-term care

Dignity of identity also dominates the literature on staff experiences of working in long-term care. Studies relating to the views of staff tend to focus on the powerlessness that they feel in relation to organisational structure and culture.<sup>8,19,23,24,27</sup> Factors such as time, fiscal restraints, heavy workloads and burnout have been cited as barriers to dignified care.<sup>19,23,27</sup> A Swedish study of 21 staff members in four different nursing homes showed that staff had a good understanding of dignity enhancing care, but the researchers also identified threats to dignity.<sup>19</sup> Threats were related to lack of resources such as having insufficient time to

deliver good care, difficulties in recruitment of competent and motivated staff and teamwork issues. Staff expressed frustration at lack of support from managers and organisations which led to them feeling ignored and worthless.<sup>19</sup> The lack of interest shown by some staff, which went unaddressed by management, led to moral distress for other staff who felt unable to uphold their genuine desire to provide dignity of identity and maintain respect for the dignity of *Menschenwürde* for older people in long-term care.

In their responses to one open-ended question, 23 members of staff from a nursing home in Norway described an awareness and enthusiasm to uphold the dignity of residents, but described ethical dilemmas when caring for people with dementia.<sup>23</sup> Often the situation was exacerbated by the wishes of relatives whose concern for the safety of the resident did not match the resident's wishes. While narrative research is useful for ethical discussion, it is dependent on the interpretation of findings. In this study, the authors utilised a phenomenological-hermeneutic method in an effort to limit any bias.

Other ethical dilemmas faced by staff were related to experiencing internal conflict and powerlessness<sup>23</sup> when offering choice and control to residents, while at the same time being challenged by other organisational constraints such as time, established routines and workloads.<sup>19,27</sup> Nordenfelt notes that dignity of identity is most important in the context of illness and ageing and can be maintained or removed by the actions of other people. This is upheld in the research where residents have described a sense of belonging and being involved in society as important aspects to maintain their dignity of identity.<sup>6,21,24</sup> In contrast, staff focused on their obligation to meet physical needs and the ethical dilemmas they have to face when providing care to residents in long-term care.<sup>19,23</sup> They struggled with moral conflict between what they were able to deliver and what they would like to provide in the care of older people,<sup>19</sup> the implication being that while staff endeavour to maintain residents' dignity of identity, it is often difficult to do so due to the work environment and culture.

## Implications for practice

The preservation of dignity implies that dignity is a quality inherent in us all. This links directly to the exploration and conclusions drawn from the literature review. Conversely, promoting dignity implies that dignity is something that can be influenced by others and external factors. Hence, implications for practice can be discussed under these two headings.

### *Preserving dignity*

In a policy and practice up-date published in 2013, Ibrahim and Davis<sup>20</sup> identify some potential solutions to what they describe as 'dignity of risk', that is, allowing residents to take risks that may increase their quality of life and hence maintain their sense of dignity. Ibrahim and Davis<sup>20</sup> advocate that education for staff working in long-term care should include clarity on the decision-making rights of those with cognitive impairment alongside leadership to support and guide application to practice.

Meaningful activity and social interactions have been highlighted as important factors in maintaining dignity. A sense of purpose and fulfilment contribute towards meaningful relationships, being part of a community with opportunities to feel valued and recognised as a unique person. The provision of meaningful activity and interaction remains a challenging area in long-term care and it requires resources and support from the organisation to implement.

Two studies state the importance of intergenerational contact to preserve inner strength and a sense of cohesion.<sup>6,12</sup> As described above, Franklin et al.<sup>6</sup> interviewed residents in two nursing homes in Sweden who described staff as being physically but not emotionally present. The resident's self-image and sense of belonging were gained from connections with their families. The provision of an environment which is

welcoming and inviting encourages family involvement. Continued family contacts helps to preserve the older person's place in society.

There are more opportunities now than in the past for older people to be involved in planning their future healthcare needs. With the onset of advance care planning and advance directives, preferences can be established long before residents enter long-term care, thereby promoting choice and control. However, on a day-to-day basis, preferred routines and individual idiosyncrasies are harder to capture and implement in practice, particularly when numerous staff are involved in care delivery.<sup>27</sup> Nevertheless, with appropriate resources, leadership and support, individual residents' needs can and should be met to preserve the dignity of older people in long-term care.

### **Promoting dignity**

The promotion of dignity in practice requires ongoing education and leadership within the clinical setting. As a family member, Rees<sup>29</sup> appeals to staff to anticipate the needs of residents with sensitivity. Rees<sup>29</sup> recognises that dignified care delivery is a result of education and support for staff within a culture of caring. The most powerful influence on changing culture is a combination of experiential learning and supportive leadership.<sup>25</sup>

Experiential learning provides an opportunity for staff to understand what it is like to be dependent on others.<sup>6</sup> Harrison<sup>25</sup> describes participants' feedback following participation in an experiential learning programme. Following 1 day and two nights receiving care from others, healthcare assistants expressed feelings of vulnerability and anxiety and were able to identify the importance of communication, education, meaningful activity and knowing the resident's history and preferences.

Unfortunately, there is still significant ageism and stereotyping of older people, particularly within Western society.<sup>12,15,24</sup> Tadd and Bayer<sup>13</sup> suggest that ageism should be challenged through education and intergenerational activities which would provide an opportunity for older people to be involved as valued members of the community. It would also provide an avenue for ageist and stereotypical language to be challenged as older people would be able to educate others on how it feels to be subject to such attitudes.

The Commission on Dignity in Care<sup>15</sup> in the United Kingdom outline steps that should be taken to ensure that all staff are well placed to deliver dignified care. They identify 'always' events as 'the foundations of dignified care' (p. 12). These include the following:

- Always treat those in your care as they wish to be treated - with respect, dignity and courtesy.
- Always remember nutrition and hydration needs.
- Always encourage formal and informal feedback from older people and their relatives, carers and advocates, to improve practice.
- Always challenge poor practice at the time - and learn as a team from the error.
- Always report poor practice where appropriate - the people in your care have rights and you have professional responsibilities.

Making a particular point of nutrition and hydration needs seems incongruent with the other generic points. However, the Commission does state that the list is not exhaustive and that organisations should develop their own templates. The Commission also goes on to promote active leadership, inter-professional and active learning strategies as well as working in partnership with residents and relevant others to safeguard human rights.

## Conclusion

The four notions of dignity outlined by Nordenfelt provide a comprehensive description of the concept of dignity which can be linked to the experiences of people living in long-term care today. The notions provide a useful means of contextualising the experiences of older people, their families and significant others and also of staff in long-term care facilities. Of particular interest are the similarities of perspectives of dignity between these groups. The notion of ‘dignity of morale stature’ did not feature strongly in the literature reviewed. This may be because morality is a difficult concept to measure and is dependent upon individuals’ values and beliefs. While the notions of dignity of moral stature and dignity of merit are important, dignity of identity and dignity of *Menschenwürde* were identified as the most significant of Nordenfelt’s four notions of dignity for all three groups.

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