Title: Dignity in End of life Care at Hospice: An Action Research Study

Running title: Dignity in End of life Care at Hospice

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Author contribution:
The first author conducted the study and drafted the work. The second author was involved in establishing relationships with the research field and designing the study. All three authors coded data to ensure reliability in the themes. All authors revised and discussed the data.

Ethical approval:
The study follows the standards for good research practice of the Danish Cancer Society, version 12.12.2011 and meets the criteria for ethical guidelines for nursing research of the Nordic Nurses Federation (1). The study has been reported to the Danish Protection Agency, and their requirements for safe storage and destruction were followed (record number 2017-41-5246).

Keywords:
Dignity, end of life, palliative care, hospice, patients’ needs, action research, autonomy, existential needs
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Abstract

Background: Safeguarding the dignity of patients at the end of life is a key objective in palliative care practice in Denmark. The concept of dignity and how it influences a dying persons’ quality of life is thus influential in end-of-life care at hospices. However, what is meant by dignity, how dignity is understood and practiced by healthcare professionals in Danish hospices, and whether this relates to the patients’ understandings and needs concerning dignity remains unanswered.

Aim: The aim of this study was to explore and improve dignity in care through an action research study with patients and hospice staff at two different hospices in Denmark. This was done by exploring how patients and health care professionals expressed their understandings and needs concerning dignity and involving participants in the research process with the goal of improving dignity in care.

Methods: An action research method with reflection-of-praxis and action-in-praxis was applied. It was combined with methods of semi-structured individual interviews with twelve patients, five staff, and nine focus-group interviews with staff.

Results:

Three themes emerged from the analysis of data. The themes were: 1) Being understood, 2) contributing, and 3) holistic care. Deeper analysis indicated, that staff understandings of dignity mostly focused on preserving patients’ autonomy, whereas patients expressed needs for relational and spiritual aspects of dignity. Staff were mostly concerned about preserving patients’ autonomy when providing dignity in care, however, through the action-in-praxis they increased their awareness on their own praxis and patients’ needs and understanding concerning dignity. The
theoretical model on dignity presented in the study also worked as a map to guide staffs’ reflections on dignity in praxis and facilitated a broader focus on supporting and caring for patients’ dignity in care. We believe this study has improved dignity in care at the two hospices involved in the study.

*Keywords:* Dignity, end of life, palliative care, hospice, patient-centred care, action research, autonomy, existential needs
Introduction

Safeguarding the dignity of patients at the end of life is a key objective in palliative care practice (2-4). It is an important ambition to enhance feelings of dignity and worthiness for every patient within the specialty of palliative care in Scandinavia (5-7). Dignity is also an important concept in the Danish guidelines for ethics in nursing (1) as well as the other Scandinavian countries (8, 9). The concept of dignity and how it influences a dying persons’ quality of life is thus significant and influential in health care and particularly within end of life care at hospices in Scandinavia. The concept is also an important part of the overall hospice philosophy about providing care enhancing quality of life. However, critical voices have been raised, problematizing how quality of life in a dying person’s life is to be understood. A study by Tullis et al. (10) considers what happens when patients’ personal definitions of quality of life at the end of life resist the prevailing narrative of appropriate hospice care. Foci at hospices are most often on maximizing quality of life over quantity of life, however the study by Tullis et al. shows that some patients resist this idea. Tullis et al. introduce the concept of ‘narrative of resistance’, which is a theoretical framework for understanding the significance of interactions and situations where patients’ experiences and needs do not correlate with the existing dominant hospice narrative (10). In the present study, we are interested in the existing dominating understandings of the concept of dignity among health professionals in Danish hospices, and whether it relates to the patients’ understandings, needs, and experiences concerning dignity. Furthermore, the aim is to improve dignity within hospice care in cooperation with both patients and hospice staff.

Theoretical and empirical understandings of dignity

Several both Scandinavian and international studies have focused on clarifying what is meant by dignity (11-14) as well as how dignity is perceived by patients, their families, and healthcare
professionals (15-18). Rodríguez-Prat et al. (19) conclude on the basis of their systematic review and interpretative synthesis of twenty-one studies summarising experiences of 400 participants that even though dignity can be considered to be an intrinsic feature of human life, it is also a complex, multifaceted, and dynamic concept closely linked to the notion of personal identity. There are, broadly speaking, two ways in which the concept of dignity is conceptualised in empirical studies: The first one is to consider dignity as something intrinsic and ontological. In this understanding dignity is an irrevocable feature of personhood in the sense that the dignity of every person is inviolable and inherent, and does not depend on external conditions; this is called basic dignity (20-22). We understand basic dignity as central to care at hospice but being an intrinsic and abstract concept, it might also be difficult for staff to have a shared understanding of how to apply basic dignity in everyday hospice praxis. The second way to understand dignity is called dynamic dignity, which is a personal quality relating to the patient’s perception of him or herself as well as external circumstances (20-22). It is dynamic because it depends on patients’ own perceptions, feelings, and understandings of dignity (23-25). The concept of dynamic dignity has focus on the patient’s individual feelings and perceptions, however most Scandinavian studies with this conceptualisation have primarily focused on patients’ experiences of loss of autonomy and how such loss relates to change in personal identity (7, 26-29). When dignity is related to concepts of autonomy and self-management, it is often associated with values about the patients being able to cope, being independent of others, and being respected as the master of his or her own life (30-32). In this understanding, preservation of the patient’s dignity is met through respecting and preserving the patient’s autonomy in every situation and interaction (3, 30, 33). This understanding also support values about the independent and active patient, which in a Scandinavian context have grown from a reaction to traditional ideas of care where the patient is a passive recipient (32, 34).
However, critique about the self-managing patient and independent values of current times’ health care professionals have also been raised (30, 35). Delmar et al. (35) emphasize a relational view of the human being. They emphasize it as a basic condition that people always enter into relations of dependence, and therefore there is no contradiction between being independent and dependent of other people. This relational perspective on dignity calls for a broader understanding of dynamic dignity than a focus on patients’ autonomy and independence. Other studies have also found that for some patients, a positive sense of dignity was maintained in spite of loss of autonomy and control; these patients highlighted an inner dignity linked to personal or spiritual values that enabled them to feel that life still had value and meaning despite their current circumstances and dependencies of others (36-38).

The Danish nurse and researcher Rita Nielsen (39-41) differentiates between three conceptions of dignity: 1) Perceived dignity is related to the notion of dynamic dignity and patients’ self-management and autonomy. 2) Spiritual dignity is closely related to the concept of inner dignity. 3) Relational dignity is about dependency and receiving help from others. The dignity of the patient is preserved through how care is given in his or her dependence. Relational dignity encompasses the relational perspective of dependence introduced previously by Delmar et al. (35) and opens for an understanding of how patients’ dignity is broader than the mere preservation of autonomy.

Grounded in the different understandings and critiques of the concept of dignity, we present a model for dignity for this study. This model holds the irrevocable basic dignity of every person at its core, and relational dignity, dynamic/perceived dignity, and inner/spiritual dignity interact and rise from this core.
The aim of this study was to explore and improve dignity in care through an action research study with patients and hospice staff at two different hospices in Denmark. This was done by exploring how patients and health professionals expressed their understandings and needs concerning dignity and involving them in the research process with the goal of improving dignity in care.

Method

The applied method for this study was action research where the objective is to join research and praxis through involvement of patients and staff at hospices in the research process (42, 43). The aim of action research is to improve practice through open, experimenting, collaborative research processes that facilitates new insights and knowledge (44). The methodology was based on philosophical hermeneutics (45, 46) and existential phenomenology (47, 48) which has been positively applied together with an action research in other studies concerning death and dying (49). An action research method was considered an apt choice for a study aiming at a close collaboration...
with patients and health professions at hospices in improving dignity in care at the two hospices involved in the study.

**Study Site**

The Study took place at two hospices in Denmark. The first, Arresødal Hospice, is located in the Northern-Western part of Sealand, whereas the other, Hospice Sydfyn is located in the Southern part of the island of Funen. Both hospices accommodate 12 patients and have approximately 45 hospice staff. Both hospices had volunteered to participate in an action research project in corporation with the researchers at the University.

**Data Generation**

The data generation consisted of two elements of action research: Reflection-of-praxis and actions-in-praxis (50, 51). These were combined with other qualitative research methods such as individual interviews and focus-group interviews (52-54). Reflection-of-praxis is a ‘mirror’ method where the researchers reflect their observations and understandings of praxis (42). They explicate these reflections in collaboration with the participants. In this study, reflection-of-praxis were organised as individual interviews and focus-group interviews with patients and staff at hospice. Actions-in-praxis is an experiment or intervention where praxis-oriented knowledge and change are facilitated (50). For this study the actions-in-praxis were facilitated as focus-group interviews with different groups of staff where the aim was to improve dignity in care.

The project began with the first author being a participating observer at hospice: For two months (April and May 2017) with 20 hours per week she participated in the everyday life at hospice, being in dialogue with the research field: patients, relatives, staff, and different situations with patients.
She made different observations and wrote fieldnotes on her reflections about dignity in praxis. She conducted interviews as a reflection-of-praxis with patients and staff based on these observations and notes. She reflected her observations on dignity in these reflection-of-praxis, and together with patients and staff the aim of the study was explored. Data from observations as well as the interviews of the reflection-of-praxis were presented to the hospice staff as an action-in-praxis: The action was structured as a focus-group interview where the staff was presented with data on patients’ expressions of their understanding and needs concerning dignity in care together with data on hospice staff’s meanings and values about dignity. As a part of the action-in-praxis, staff were invited into the process of analysing and interpreting data. Therefore, the results presented have emerged from the collaboration between researchers and field of praxis.

The length of each interview ranged from nineteen minutes to one hour and forty-five minutes. The longest interviews were the focus-group interviews, and the shortest interviews were with patients.

In this process of reflection-of-praxis and action-in-praxis, deeper understanding and knowledge about dignity were gained in collaboration between patients, staff and researcher. Data was generated between May 2017 and February 2018.

Participants

The first author spoke with almost all the staff and approximately thirty patients and interviewed twelve patients over a period of ten months. Hospice staff was strategically selected based on desire to obtain variation within age, gender, and interdisciplinarity. Based on ethical concerns, patients should fulfil inclusion and exclusion criteria. The inclusion criteria were: Patients at hospice. They should volunteer freely to participate after receiving throughout information about the study. The exclusion criteria were: Persons suffering from a distorted perception of reality, severe cognitive or
memory problems, or people who recently (i.e. within the past 0-4 weeks) had been suicidal. Semi-structured individual interviews with twelve patients and five staff-members as well as three focus-group interviews with staff were conducted as reflection-of-praxis. Six focus-group interviews with staff were conducted as action-in-praxis. There were between 6 and 10 persons in the focus-group interviews.

Validity

The criteria for validity in qualitative research concern the question: Do we study what we intend to study? And whether the methods or approaches applied achieve what they intend? (55). The editors of *The Handbook of Action Research* (56), Peter Reason and Hillary Bradbury, describe six underlying principles for action research that can become questions of validity to ask each study (57). Is the study 1) grounded in lived experience? This was sought throughout the study by keeping the lived experience of the participants central, 2) developed in partnership? The understandings and knowledge were gained from close collaboration between research and praxis, 3) addressing significant problems? The problem addressed in the study concerned optimizing care for dying patients, 4) working with, rather than simply studying, people? This was kept by close collaboration with the participants as well as involving them in all facets of the study, 5) developing new ways of seeing/theorizing the world? Knowledge gained from the study was applied in praxis by the staff, and 6) leaving infrastructure in its wake? The present study aimed at implementing some lasting capacities amongst those involved as well as influencing future policies for end of life care.

Researcher Reflexivity

The first author conducted the study and drafted the work. The second author was involved in establishing relationships with the research field and designing the study. All authors coded data to
ensure reliability in the themes, and all authors revised and discussed the data. In an action research study with multiple stakeholders it is important to keep awareness of the different motivations, interests, and goals of researchers and praxis field for conducting the study, as well as personal beliefs, values, and preconceptions. These were written in notes during the different aspects of the research process and discussed between the authors. Authors were aware of being as transparent as possible about own preconceptions concerning dignity in healthcare and about being embedded in a specific caring paradigm; ourselves being positioned in theology, psychology, and midwifery. Preconceptions were for example: Dignity being religiously or spiritually motivated and dignity being primarily at concept within healthcare and not among patients. These and other preconceptions were discussed among the three authors who represent different fields within healthcare.

Ethical Considerations

Before giving their consent to participate in the study, patients and staff were informed about the purpose of the study both orally and in writing. They were informed that participation was voluntary, and they could withdraw from the study at any time, just as all personal data would be made anonymous. Only the name and location of the two hospices have not been anonymous. The ethical implications of the different aspects of the research process were regularly discussed between the authors, particularly the distinctive ethical implications for patients at a hospice. The study follows the standards for good research practice of the Danish Cancer Society, version 12.12.2011 (58) and meets the criteria for ethical guidelines for nursing research of the Nordic Nurses Federation (59).

Data Analysis
In analysing the data the methods of action research were combined with philosophical hermeneutics (45, 46) and existential phenomenology (47, 48), and a thematic analysis was applied (60). This analytic approach has been positively applied together with an action research in other studies concerning death and dying (49). The approach applied for analysing the data is described in table 1:

<table>
<thead>
<tr>
<th>Stages</th>
<th>Researchers’ role</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Different statements and understandings of dignity emerged in the reflection-of-praxis (interviews with patients and staff at hospice). These were presented as different themes to the hospice staff as an action-in-praxis (audio recorded as focus-group interviews) where the focus was to improve praxis on dignity in care. In the action-in-praxis these themes were validated, elaborated, analyzed, and interpreted in collaboration with the hospice staff. Then the researchers read and reread the observational notes, transcripts from reflections-of-praxis, and transcripts from action-in-praxis with staff at both hospices in order to become familiar with the dataset. The researchers wrote comments attempting to summarize or paraphrase, make associations or connections, and make preliminary interpretations. Each researcher did this individually.</td>
</tr>
<tr>
<td>2.</td>
<td>The researchers returned to the beginning of the different data. They began to systemize the data into different themes based on specific statements or descriptions of experiences of dignity. Each researcher transformed initial notes for each manuscript of the first stage into overall themes across all the transcripts.</td>
</tr>
<tr>
<td>3.</td>
<td>The emergent themes of stage two were listed and connections and clusters between them were explored by the researchers in collaboration to check for interreliability of the themes, and to obtain an analytical or theoretical ordering of the connections between the themes.</td>
</tr>
<tr>
<td>4.</td>
<td>The clusters of themes which emerged in stage three were given names and a structure of the participants’ lived meanings and experiences about dignity became emergent. Themes without rich evidence within the data or themes that did not fit well in the emergent structure were omitted. The researchers prioritized and reduced the themes in order to decide which themes to focus upon. The three themes identified reflected the authors’ interpretation and were repeatedly checked against data to ensure their grounding in the empirical material.</td>
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(Table 1: Stages of Analysis)

Findings
When analysing the data material through these four stages three themes emerged. The themes were: 1) Being understood, 2) contributing, and 3) holistic care. Below an analysis of the themes is presented. Subsequently the analysis is discussed in relation to the aim of the study and the presented model on dignity.

Theme 1: Being understood

This theme concerns how staff and patients experienced dignity in care at hospice when patients were met with understanding by the staff. Several patients emphasized how being met with attempts of understanding from the staff felt valuable to them. For example, a male patient said:

“I try not to think too much about my situation because it doesn’t change anything anyway [...] off course there are people here (at the hospice) who have knowledge about what I am going through but still, they will never understand... people here are compassionate and they sometimes suffer with me... but to really understand from within, that will never happen. If they try to understand; that is fine [...] I am standing out here on the edge of the cliff; they are not”

The patient was aware of his situation being different from that of the staff and how they could only try to understand, but he still experienced their attempts to understand as compassionate and dignifying. A female patient also described how a nurse cared for her in a way where her dignity was upheld:

“...and that day when I had diarrhoea. Firstly, I felt it was very embarrassing for me, and secondly, I felt sorry for them [hospice staff]. Don’t think about that, she [the nurse] said, cause we are here
for you. But for me it was very humiliating, and they understood that, but I shouldn’t think about it as being humiliating. It [helping un-humiliate the situation] was their job!”

The situation was humiliating for the patient but because she felt the nurse understood her situation, she experienced being cared for with dignity. The experience of dignity when staff attempted to understand was recurrent across patient interviews. The hospice staff also expressed how they were concerned about understanding each patient. They expressed how understanding each patient was necessary for providing care with dignity. For example, one staff responded in an action-of-praxis to the above statement by exemplifying, as oppose to this, patients who refuse help:

“We have also witnessed these patients who didn’t want us. They wanted to be here [at hospice] but they didn’t want us. They didn’t want our help, and we should go away. Then if we just left them alone in their room... even though they were feeling terrible poorly, we should just leave them at that. Then at last, they would invite us in... that is dignity.”

She emphasized, that only when staff also understood to leave patients like these alone, they were able to treat them with dignity. The group continued the discussion and there was consensus about waiting for patients’ initiatives. However, even though the staff believed waiting was to care dignifying for them, one staff commented: “Sometimes patients die before letting us in.”

It seemed the staff’s understanding of dignity was closely connected to preserving autonomy, and the patient being respected as the master of his or her own life. The same focus on autonomy was, however, not seen in the interviews with patients who primarily expressed experiences of dignity in relation to how the staff would provide care and try to understand them. The staff seemed to be
highly concerned about issues of autonomy in their attempts to understand patients, whereas patients were more occupied with relational aspects of dignity.

2. Contributing

The focus of this theme is patients at hospice being allowed to contribute in different ways in life, relationships, and/or activities up till the time of dying. It was considered dignity in care, when staff helped patients to contribute. For example, a female patient explained the importance of maintaining her identity and sense of self by contributing as a mother in her family and through her hobbies:

“I am so sick of being the weak and I have been that for so long. It happens when you are often hospitalized. Then you become nothing but a patient; anonymous. Education, personal interests, everything just vanishes...[...]...I get up every day, take a bath, and put on clothes... I need to do that to maintain myself...[...]... my children, my family are important to me, and I am also very involved in my hobby. I still do all these things while I am here”

The importance of maintaining a sense of self through contributing in life and relationships while being at hospice was recurrent across patient-interviews. However, when looking deeper into the patient-interviews, it became apparent that patients believed the way staff best helped them to contribute till the end of life was by talking with them. For example, one female patient explained:

“I think the staff are really good at knowing you and talking with you about everything...[...]...I talk with them about everything. It has mainly been about those things that have been difficult in my family, where it has been hard...they always take time to talk with me, and they give good advice
and so on... they help with the medication and all the physical stuff while they also help relieve my mind...”

Patients experienced contributing as dignity. Furthermore, they believed staff helped them to contribute by talking with them. When presenting this for hospice staff in reflection-of-praxis, staff would emphasize the importance of talking with patients at ‘eye-level’. For example, a nurse explained:

“If you boiled down dignity, it comes down to giving the patient a feeling of being involved. We must be at eye level with the patients and showing respect and interest...(...)... always respecting and being aware of the patient’s boundaries.”

The importance of ‘eye-level’ and involving patients were expressed widely by the staff when describing dignity and letting patients contribute, however as presented in this example, they tended to emphasize patients’ boundaries and autonomy. Even though both patients and staff emphasized staff talking with patients was important for them being able to contribute, it seemed their view on dignity had different foci. Patients talked about contributing from a relational perspective where they would both receive and contribute in dependent relationships. Staff had a tendency to view talking with patients’ and patients’ needs to contribute with a focus on respecting and preserving the patient’s autonomy.

3. Holistic care

This last theme centres on the participants emphasizing dignity being about patients being cared for holistically. Across the interviews, participants explained this was when care was comprised by
physical, social, psychological, and spiritual aspects, and patients’ not just being cared for as ‘sick physical bodies’. For example, a female patient described dignity as staff also being concerned about her spiritual values:

”They made it clear to me that here (at the hospice) is room for my values... for me it is my Christian values that carries me through it all...[...]... they also talk with me about my faith and ask about it. They are open for the way I understand the world and my Christian values. They never question or doubt it... It is not just those of the staff who also are Christians; Those that don’t have any faith themselves also ask about my faith”

The hospice staff was highly aware of caring for patients holistically and not just their physical bodies. An example of this is from a reflection-of-praxis where a staff explained:

“... but we almost forgot her (a patient) medical condition, because it was not the most important thing... The important things were who she was, and the issues she had. That was what we cared for... It was not the illness. That was not the main thing we talked with her about....”

Both staff and patients emphasized that dignity was when staff cared holistically for patients. However, in a reflection-of-praxis it became apparent that focus on patients’ boundaries and autonomy was highly recurrent in staffs’ values concerning holistic care. For example, when staff reflected upon the above patient quote, they began talking about other patients who were less explicit about spirituality or religious faith. During an action-in-praxis, staff reached consensus on not addressing patients’ spiritual concerns, unless patients explicitly opted this:
“I think it is important that we delimit what of this [the patient’s spiritual concerns] we shall address, and what we shall keep our fingers from (…) Another staff: There is no need to confront her, because it shall be her choice. It is her life, and we shall support her where she is right now. Only that is our job… we cannot solve these issues for her…”

This quote serves to illustrate how staff were aware of treating patients holistically but at the same time they were highly concerned about not violating patients’ boundaries. Therefore, staff would wait for patients’ initiative. They tended to have a wait-and-see attitude towards initiating conversation and care they believed could violate patients’ autonomy. When interviewing patients, they expressed being cared for holistically, however beneath their evident gratitude, staff’s extensive focus on patients’ autonomy and initiative could be found in patients’ statements. For example, a female patient said:

“They [the staff] are incredible. They are so caring and they take so good care of you. They talk with me about everything; they know my family and the names of my grandchildren (…) they often come and just sit with me and talk (…) Question: …so they are also good at talking with you about how you feel about being sick, and what you think about dying... and those things? Patient: …narj, it is not that deep. It’s more talk about family and cosy stuff… I actually thought this place would be more devout... you know, a more Christian place. I haven’t felt that”

This patient did not feel hospice was a religious place or that staff addressed ‘deep stuff’, even though staff was respectful about patients’ spiritual values. This difference in care between the two patients may be explained by this patient not initiating conversation about spiritual concerns, whereas the religious patient did. The staff would fear violating the patient’s boundaries and
autonomy and therefore wait for her initiative before caring for her ‘deeper’ and more spiritual needs; an initiative this patient did not take.

The staff was presented with this interpretation of data in an action-in-praxis, and it led to an extensive discussion. Several staff emphasized the importance of preserving patients’ autonomy “under all circumstances”, however some staff also discussed how patients’ autonomy could be preserved without primarily waiting for patients’ initiative in spiritual matters: “Perhaps, we also wait because we feel those issues (spiritual issues) are private...” and one staff said: “Maybe, we should just ask them... they can always say no. We respect a no.”

I general, staff were highly concerned about preserving patients’ autonomy when providing dignity in care, however, through action-in-praxis they began reflecting upon, how this also influenced their praxis in ways where the holistic care for patients was diminished.

Discussion:

Three aspects of dignity in care are presented as three themes found in data throughout the action research process. Offhand, it would therefore seem that both patients and health professionals at the hospices would share the same understandings about dignity. However, when analysing the themes, we found that patients and staff emphasized the three aspects of dignity differently. We will apply the previously presented theoretical model to shed further light on these differences.

The concept of basic dignity is understood as the core of both patients’ and staff’s values and understandings about dignity. The three themes arose from participants believing dignity to be an irrevocable feature of personhood (19, 20). However, when analysing the lived meanings about
dignity in everyday praxis at hospice differences emerged between how patients and hospice staff experience and express understandings about dignity.

We found that staff would emphasize *dynamic/perceived dignity* with a focus on the autonomous and self-managing patient (19, 28). Their meanings and values about dignity arose from a notion of *basic dignity* but in their praxis they would mainly focus on preserving autonomy and the patient being respected as the master of his or her own life (30, 31). Patients, on the contrary did not express dignity being related to the maintenance of self-management and autonomy. They primary expressed the importance of *relational dignity* (30, 35), emphasizing the importance of how care was given by the staff. This could be a result of staff already being exceedingly good at preserving patients’ autonomy, leaving patients with no needs to comment that in the interviews. However, in the interviews, patients did express staff being good at care related to *relational dignity*. Indicating, that relational dignity correlated more with patients’ needs. In can also be suggested, that patients were highly aware of their dependence, both relational and in care, and therefore to them being understood and allowed to contribute in dependent relationships were significant for their experience of dignity (28). Finally it may also be, that some patients had a sense of *inner/spiritual dignity* linked to personal or spiritual values which enabled them to feel that life still had value and meaning despite their current circumstances and dependencies of others (36-38). However, this aspect of dignity was only cared for if patients themselves initiated conversation about spiritual issues. Staff would be concerned about respecting patients’ boundaries and wait for patients’ initiative before caring for spiritual concerns.

*Dynamic/perceived dignity* is related to the patient’s individual feelings and perception of self (20, 21) and it was apparent in the data that patients’ understanding of dignity concerned maintaining a
sense of self. However, for the patients, *dynamic/perceived dignity* seemed to be mostly related to relational aspects and less related to values about the independent and active patient (34). The patients’ experiences and emphasis on *relational dignity* did not seem to correlate with the existing dominating hospice understandings about dignity being primarily about respecting and preserving the patient’s autonomy (30, 33). Most studies on *dynamic/perceived dignity* have focused on patients’ experiences of loss of autonomy and how these relate to change in personal identity. However, this study suggests that *dynamic/perceived dignity* should also involve relational aspects of patients’ individual feelings and perception of self.

The dominating focus on autonomy and self-management in health care research on patients’ dignity may also have influenced the praxis of the staff involved in the study, explaining why staff were highly concerned about issues of autonomy and boundaries in their attempts to understand, be at ‘eye-level’, and involving patients. We found staff being afraid to violate patient’s boundaries and autonomy and therefore wait for patients’ initiative before caring for patients’ spiritual needs. Through action-in-praxis staff became aware of how their values concerning dignity could cause patients not to receive certain aspects of spiritual care.

We believe this study has improved dignity in care at the two hospices involved in the study through increased awareness on their own praxis and patients’ needs and understanding concerning dignity. The presented theoretical model also works as a map to guide staffs’ reflections on dignity in praxis and facilitate focus on supporting and caring for patients with all presented aspects of dignity in care.

*Limitations*
This study was carried out as an action research study aiming at improving practice through collaborative research processes. Action research seeks to empower research subjects to influence decision making for their own aspirations (57) but as all patients in the study will have died by the time of publications of data, the ideal of action research does not favour them individually. However, their voices were considered very important for improving hospice practice for future patients. The twelve patients interviewed for the study were selected based on their energy and interest in the study and therefore they may not be representative for patients at hospice in general. The themes identified in the data reflected the authors’ interpretation, and aspects of the participants’ experience could have been omitted. However, the findings of this study have been presented for the staff and they have verified their quotes. Unfortunately, this was not possible for patients’ quotes; which clearly is a limitation of the study.

**Conclusion**

In this study we were interested in exploring the existing dominating understandings about dignity in Danish hospices and improve dignity in care at hospices by involving patients and health professionals in the research process. Through the action research methods, reflection-of-praxis and action-in-praxis, patients and staff were involved in analysing and interpreting data; they would comment, elaborate, clarify, discuss, and explore themes and statements presented to them. We anticipated the action research approach and elements would facilitate positive changes in the dignifying care for patients.

Three themes emerged from the analysis of data that represented three aspects of dignity in care. The themes were: 1) Being understood, 2) contributing, and 3) holistic care. Deeper analysis of data indicated, staff understandings of dignity mostly focused on preserving patients’ self-management
and autonomy, whereas patients expressed needs for more relational and spiritual aspects of dignity, and patients did not express dignity being related to maintenance of their self-management and autonomy. Even though, staff were mostly concerned about preserving patients’ autonomy when providing dignity in care, through the action-in-praxis they increased their awareness of the discrepancy between their own praxis and patients’ needs and understanding concerning dignity. The theoretical model on dignity presented in the study also worked as a map to guide staffs’ reflections on dignity in praxis and facilitated a broader focus on supporting and caring for patients’ dignity in care. We believe this study has improved dignity in care at the two hospices involved in the study.