

# Four aspects of spiritual care: a phenomenological action research study on practicing and improving spiritual care at two Danish hospices

Palliative Care & Social Practice

2021, Vol. 15: 1–14

DOI: 10.1177/  
26323524211050646

© The Author(s), 2021.  
Article reuse guidelines:  
sagepub.com/journals-  
permissions

Dorte Toudal Viftrup , Ricko Nissen, Jens Søndergaard and Niels Christian Hvidt

## Abstract

**Background:** In Denmark and internationally, there has been an increased focus on strengthening palliative care by enhancing spiritual care. Dying patients, however, do not experience their spiritual needs being adequately met.

**Methods:** Through an action research study design with four consecutive stages, namely, observation in practice, reflection-on-praxis, action-in-praxis, and evaluation of the action research process involving patients and hospice staff from two hospices in Denmark, two research questions were explored: (1) How do patients and staff perceive, feel, live, practice, and understand spiritual care at hospice? and (2) How can spiritual care be improved in hospice practice? The data material presented comprised 12 individual interviews with patients and nine focus group interviews with the staff.

**Results:** We found four aspects of spiritual care through which patients and staff seemed to perceive, feel, live, practice, and understand spiritual care at hospice, and from where spiritual care may be improved in hospice practice. These aspects constituted four themes: (1) relational, (2) individualistic, (3) embodied, and (4) verbal aspects of spiritual care.

**Conclusion:** Staff realized immanent limitations of individual aspects of spiritual care but learned to trust that their relational abilities could improve spiritual care. Embodied aspects seemed to open for verbal aspects of spiritual care, but staff were reluctant to initiative verbal dialogue. They would bodily sense values about preserving patients' boundaries in ways that seemed to hinder verbal aspects of spiritual care. During action-in-praxis, however, staff realized that they might have to initiate spiritual conversation in order to care for patients' spiritual needs.

**Keywords:** action research, hospice, palliative care, phenomenology, spiritual care

Received: 30 June 2021; revised manuscript accepted: 16 September 2021.

## Introduction

We present an action research study on how spiritual care is perceived, felt, lived, practiced, and understood by patients at the end of life and health care staff who provide spiritual care, as well as exploring in close collaboration with patients and staff how spiritual care may be improved. The study took place at two Danish hospices in Denmark.

In recent decades, both in Denmark and internationally, there has been focus on strengthening

palliative care by enhancing spiritual care.<sup>1,2</sup> In 2002, the Danish Ethical Council<sup>3</sup> stated that spiritual care for dying patients must be included in any health care education on both basic and continuing level, and that spiritual care includes both specific religious care and consideration of spiritual and existential struggles and concerns that may arise in any human being facing imminent death. Despite such widespread awareness of spiritual care in the health care system and education in Denmark and internationally, dying patients and their relatives do not experience their

Correspondence to:  
**Dorte Toudal Viftrup**  
Research Unit of General Practice, Department of Public Health, University of Southern Denmark, 5000 Odense C, Denmark.  
[dviftrup@health.sdu.dk](mailto:dviftrup@health.sdu.dk)  
**Ricko Nissen**  
**Jens Søndergaard**  
**Niels Christian Hvidt**  
Research Unit of General Practice, Department of Public Health, University of Southern Denmark, Odense C, Denmark



spiritual needs adequately met.<sup>4-7</sup> This is primarily caused by the health professionals' lack of knowledge and education in the field of spiritual care, experiences of lack of time, and personal barriers toward spirituality and religious faith.<sup>8-10</sup> Furthermore, knowledge in this field is primarily theoretically based, and how spiritual care is understood, experienced, and practiced in palliative care has been scarcely empirically studied.<sup>11</sup> The purpose of this study was therefore to fill this knowledge gap.

World Health Organization (WHO) defines spiritual pain as one of the four awareness areas in the definition of total pain in palliative care alongside physical, mental, and social pain.<sup>12</sup> International research has clarified that support of this fourth aspect of pain experienced by patients in palliative care is the most underdeveloped.<sup>13-15</sup> Danish research indicates this being even more the case in Denmark, which is often referred to as 'the world's least religious country'<sup>16</sup> where even religious Danes exhibit a high degree of private and individualized spirituality.<sup>17-19</sup> International research has found that life-threatening illness leads to an increase of spiritual and religious needs and thoughts. These increase with the severity of the disease and the prospect of imminent death.<sup>20,21</sup> The same tendency is found in Denmark, where correlations between the severity of illness and the tendency for spiritual and religious beliefs have been found.<sup>22</sup> Another Danish study has shown that women with breast cancer are more spiritual than Danes in general,<sup>23</sup> and a Danish study at hospice found an increase in patients' spiritual and religious thoughts as well as turning to a transcendent reality for support at the end of life.<sup>11</sup> Several studies also indicate that spiritual care can increase the quality of life and reduce cost of care for patients at the end of life.<sup>2,9,24,25</sup> In nation-wide guidelines, the notion of spirituality is multidimensional and includes (1) existential challenges, (2) value-based considerations and attitudes, and (3) religious considerations and foundations.<sup>26,27</sup>

For this study, we embraced a concept of spiritual care that includes general psychosocial (secular), spiritual, religious, and existential aspects of patient support and care.<sup>28-32</sup> Furthermore, spiritual care, particularly in the Scandinavian countries, is understood broader than merely caring for the spiritual or religious needs of patients.<sup>33-35</sup> It is based on sensory phenomenology where health professionals are concerned about sensing and

interpreting the patient's bodily expressions in order to spiritually care for and help patients unfold themselves in life. Patients may not be able to express their spiritual needs verbally, but the health professionals sense the patients' spiritual longing for dignity, recognition, being met as a person, and so on. The health professionals care for patients in ways where their humanity and what is meant to be human are protected and supported.<sup>33-35</sup> Through a sensory phenomenological approach, spiritual care also includes caring for embodied dimensions of patients' spiritual needs.

The aim of the study was to explore how spiritual care at Danish hospices was perceived, felt, lived, practiced, and understood by patients at the end of life and by the healthcare staff who cared for them. Through an action research study design involving patients and hospice staff from two different hospices in Denmark, two research questions were explored: (1) How do patients and staff perceive, feel, live, practice, and understand spiritual care at hospice? and (2) How can spiritual care be improved in hospice practice?

## Methods

The applied method for this study is action research where the objective is to join research and the field of practice through involvement of patients and staff at hospices in the research process.<sup>36,37</sup> The aim of action research is to improve practice through open, experimenting, collaborative research processes that facilitate new insights and knowledge, and the research ideal of action research is to have an equal and reciprocal relation between researchers and field of research.<sup>38,39</sup> In order to explore how patients and staff perceive, feel, live, practice, and understand spiritual care at hospice, we combined the action research design with the phenomenology of perception.<sup>40,41</sup> An action research design combined with phenomenology has elsewhere been successfully applied for studying a field where death and dying are impending, where the researchers are just as inexperienced and meek, if not more, than patients and hospice staff, when facing the big questions of life.<sup>39</sup> The study required a methodology where participants were highly involved in the research process and included embodied dimensions of patients' spiritual needs. In Denmark where religious and spiritual thoughts, needs, and feelings are considered private and usually not freely discussed in public, we believe a method focusing on the structures of subjective

experience as an embodied way of being in the world and with others<sup>42,43</sup> was required for studying spiritual care in practice.

We present theoretical concepts of German psychiatrist and philosopher Thomas Fuchs' phenomenology of the embodied mind<sup>44</sup> and apply these in the study in combination with relationally phenomenological perspectives presented by the Danish philosopher and theologian K.E. Løgstrup<sup>45</sup> and the Austrian-born philosopher, Martin Buber.<sup>46</sup>

### *Theoretical concepts*

Building on Merleau-Ponty, Fuchs believes that 'there is no emotion without bodily sensations, bodily resonance, and affectability' (p. 222).<sup>44</sup> Most often, emotions concern issues of particular value. They are ways of perceiving where a person takes dominant aspects of a situation into account and attributes a meaning to these which they would not have attributed without the feeling. Fuchs argues emotions are experienced through *bodily resonance*, and therefore bodily reactions should not be understood as a side effect of an emotion, but as the very cause of affective intentionality.<sup>47</sup> Emotions are seen as interactions between the human body and the given situation; it is described with the notion of *embodied affectivity*. It refers to emotions being seen as a circular interaction between the embodied subject and the situation that is perceived through and affected by bodily resonance.<sup>47</sup> Fuchs also adds relational aspects to his phenomenological theory with the concept of *embodied interaffectivity*. In every relational encounter, the persons involved are intertwined in a process of bodily resonance, coordinated interaction, and 'mutual incorporation' that together form the basis for an intuitive empathic understanding. Fuchs describes this interaffectivity process in this way:

Our body is affected by the other's expression, and we experience the kinetics and intensity of his emotions through our own bodily kinaesthesia and sensation. Our body schemas and feelings expand and 'incorporate' the perceived body of the other. This creates a dynamic interplay which forms the basis of social understanding and empathy, and which I will describe as mutual incorporation. (p. 198)

Fuchs' conceptualization of the *embodied affectivity* and *interaffectivity* resonates well with Løgstrup's notion of *the sensory attuned impression*.<sup>48</sup> Løgstrup

believes sensory impressions from the surroundings impact humans, whether they be the aesthetics of a room or a painting or the tone of voice or body language in the relational encounter. The atmosphere or 'spirit' of our surroundings attunes our minds through the senses and gives rise to the ontologically given opportunities of what he calls the *sovereign manifestations of life* (*spontane livsyttringer*). Central manifestations are trust, compassion, frankness, the openness of speech, and/or love,<sup>49</sup> which are all basic human conditions in the relational encounter. Løgstrup<sup>45</sup> describes the sensory attuned impression in this way:

A person has never something to do with another person without having some degree of control over him or her. It may be a small matter, involving only a passing mood, a dampening or quickening of spirit, a deepening or removal of some dislike. But it may also be a matter of tremendous scope, such can determine if the life of the other flourishes or not. (pp. 15–16)

He emphasizes that if the atmosphere or 'spirit' (translated as 'attunement' elsewhere<sup>50</sup>) of our surroundings may not manifest the sovereign manifestations of life itself spontaneously in the relational encounter, *the ethical demand* should be carried out in the relationship as a substitute for the sovereign manifestations of life.<sup>45</sup> He hereby places ethical values in the relational sphere of his phenomenological theory; ethics are always situated in the interpersonal interaction between people. Løgstrup believes that we as people are interdependent and rely on the other person's way of encountering and relating to us. We are placing a part of our life into the hands of the other person and thereby surrendering ourselves in the encounter. This surrender has the capacity to alter the persons involved in the encounter.<sup>45,49</sup>

The transformational capacity of the relational encounter has also been described by the Austrian-born Jewish philosopher Martin Buber<sup>46</sup> who argues that a person being related to as a 'Thou' instead of 'It' in the relational encounter may alter both persons. In Buber's mind, every individual bears within an inherent 'Thou' that can only be a 'Thou' through the relationship with another human being. The health professionals' ability to relate to patients in the fullness of their humanity (I-Thou) rather than as to objects (I-It) is described as the *spiritual quality of interconnectedness*.<sup>51</sup> These I-Thou spiritual moments of interconnectedness between people

have also been described as the most important spiritual experiences of all.<sup>52</sup> Buber<sup>46</sup> adds that by becoming a Thou, the human being addresses the eternal Thou: ‘We look out toward the fringe of the eternal Thou; in each we are aware of a breath from the eternal Thou; in each Thou we address the eternal Thou’ (p. 78). The ultimate Thou is always Thou without being limited by the It in space and time. It is the eternal Thou that never becomes an It. Buber identifies God with this unlimited, eternal thou.<sup>46</sup>

The bodily and relationally phenomenological concepts are embodied affectivity, interaffectivity,<sup>47</sup> sensory attuned impression, sovereign manifestations of life, ethical demand,<sup>48</sup> and the spiritual quality of interconnectedness; I-Thou and I-Ultimate Thou<sup>46</sup> presented by Fuchs, Løgstrup, and Buber were applied in combination with methods of action research for generating, analyzing, and discussing data.

#### *Data generation process*

The data generation consisted of a combination of the two elements of action research: *reflection-on-praxis* and *action-in-praxis*<sup>53,54</sup> combined with the qualitative research methods of observations, semi-structured, and focus group interviews.<sup>55–59</sup> The action research project and data generation occurred during the period April 2017 to November 2018.

In order to explore in collaboration with patients and staff at hospice, how they perceived, felt, lived, practiced, and understood spiritual care at hospice, and how spiritual care could be improved, the first author/researcher began the study by *being an observer* at hospice: For 2 months (April and May 2017) with 20h per week, she participated in the everyday life at hospice, being in dialog and relationship with the research field, patients, relatives, staff, and different situations with patients (e.g. taking care of patients together with the nurses). The researcher made observations and accounted for the practice she observed. Based on these observations, she arranged *reflection-on-praxis* with patients and staff. Reflection-on-praxis is a ‘mirror’ method where the researchers reflect their observations and perceived understandings of praxis together with actors embedded in practice.<sup>36</sup> These were conducted as 12 individual semi-structured interviews with patients and three focus group

interviews with staff about how they perceived, felt, lived, practiced, and understood spiritual care. Subsequently, she implemented an *action-in-praxis* with the hospice staff. Action-in-praxis is an experiment or intervention where praxis-oriented knowledge and change are facilitated.<sup>53</sup> The action-in-praxis was based on the knowledge gained from observations and reflection-on-praxis and focused on how spiritual care may be improved at hospice. The action-in-praxis was structured as four focus group interviews with the hospice staff, where the researcher facilitated discussions and initiatives on how to improve spiritual care at hospice. About 1–2 months after the actions-in-praxis, the researcher conducted two focus group interviews with hospice staff about the changes in practice they had gained through the action research process.

All in all, nine focus group interviews with hospice staff with 5–8 participants in each group were conducted (three reflection-on-praxis, four action-in-praxis, and two follow-up focus group interviews). The length of each focus group interview ranged from 57 min to 1 h 45 min (1 h 22 min on average). We applied a selection strategy for attaining ‘maximum variety,’ and group sizes where the participants would feel comfortable sharing their perceptions and experiences of spiritual care, as well as engaging in interactions and discussions with other participants.<sup>58</sup> The first author moderated the focus groups using a moderator guide. The individual interviews with 12 patients for the reflection-on-praxis took place in the patients’ own hospice rooms and lasted between 19 and 56 min (36 min on average). The first author conducted the interviews using a semi-structured interview guide. All interviews were recorded and transcribed in an anonymized way, with only sex appearing, after which audio files were deleted.

During the data generation process, the researchers evaluated the rigor and trustworthiness of the study by Lincoln and Guba’s criteria for qualitative research.<sup>60</sup> Credibility was established through prolonged engagement, persistent observation, peer debriefing, and member-checking which are techniques that are embedded in the present action study design. Transferability was established through thick descriptions of data. Dependability and confirmability were upheld by reflexivity, as well as involving external audits of authors not involved in the research process.

The first author conducted the study and drafted the work. The last author was involved in establishing relationships with the research field and designing the study. The first and last authors coded data to ensure reliability in the themes, and all authors revised and discussed the data. It is important to keep awareness of the different motivations, interests, and goals as well as personal beliefs, values, and preconceptions of both researchers and field of practice. These were written in notes during the different aspects of the research process and discussed between the authors, who were also aware of being as transparent as possible about own preconceptions concerning spiritual care and being embedded in a specific caring paradigm. The authors represented different fields within health care: psychology, anthropology, medicine, and theology.

#### *Study site and participants*

The study took place at two hospices in Denmark. Both hospices accommodate 12 patients and have approximately 45 hospice staff, including nurses, doctors, physiotherapists, chaplain, kitchen, and operating staff. Hospice staff was strategically selected to attain variation within age, years of working at hospice, and interdisciplinarity. Nurses, doctors, physiotherapists, chaplain, kitchen, and operating staff were all involved in the action research study, as interdisciplinarity is highly emphasized at hospices in Denmark. All staff, and not just health care staff, have contact with patients and are encouraged to care for all patients' spiritual needs. It was, however, not possible to attain variety in sex, as a very low percentage of staff were men.

Based on ethical concerns, participating patients should fulfill inclusion and exclusion criteria. The inclusion criteria were patients at hospice that volunteer freely to participate after receiving thorough 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. There was attempted variation in sex (eight women and four men) and age (mean age: 61 years) among the participating patients. The patients had various terminal cancer diagnoses.

#### *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, that they could withdraw from the study at any time, and that all personal data would be made anonymous. Only the name of the two hospices has 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 followed the standards for good research practice of the Danish Cancer Society, version 12.12.2011<sup>61</sup> and met the criteria for ethical guidelines for nursing research of the Nordic Nurses Federation.<sup>62</sup> The project was registered and approved by SDU Research & Innovation Organisation (RIO) and the Research Ethics Committee (REC) of RIO (Registration No. 10.467) and carried out in accordance with the instructions of the RIO and Danish legislation on personal data. The REC checks whether your research project meets certain ethical standards.

#### *Validity*

When addressing validity in qualitative research, we are concerned about whether we study what we intend to study and whether the methods applied achieve what they intend.<sup>63</sup> Hillary Bradbury and Peter Reason (2003) describe six principles for validity in action research. The researchers should ask themselves whether the study is (1) grounded in lived experience; (2) developed in partnership; (3) addressing significant problems; (4) working with, rather than simply studying, people; (5) developing new ways of seeing/theorizing the world; and (6) leaving infrastructure in its wake.<sup>64</sup> For this study, we could answer all six questions of validity: (1) the grounding of lived experiences was sought throughout the study by keeping the lived experience of patients and staff central; (2) the understandings and knowledge were gained from close collaboration between research and field of practice and involving them in all facets of the study; (3) spiritual care concerns optimizing care for dying patients, which we believe is a significant problem of interest; (4) the study was conducted in close relationships with the participants who were involved in generating, analyzing, and discussing data; (5) the knowledge gained from the study was discussed with theoretical perspectives of sensing and relational phenomenology to obtain a broader understanding of how patients and staff perceive, feel, live, practice, and understand

spiritual care at hospice; and (6) this study aimed at implementing some lasting capacities among the staff involved in the study and influencing future policies for how to improve spiritual care at hospice.

### Data analysis

This action study is based on the epistemology of phenomenology of perception,<sup>40,41</sup> and the analytical approach focused on patients' and hospice staffs' subjective experiences of spiritual care as a practice-related and lived phenomenon, and on how spiritual care could be improved in hospice practice.

Data comprised 12 individual semi-structured interviews with patients and three focus group interviews with staff about how they perceived, felt, lived, practiced, and understood spiritual care (reflection-on-praxis); four focus group interviews with the hospice staff on how spiritual care may be improved at hospice (action-in-praxis); and two focus group interviews with staff about the insights about spiritual care and changes in practice they had gained through the action research process. Individual and focus group interviews were transcribed by the first author, and the content of the sentences was weighted in the transcripts; speech sounds and repetitions emanated, while pauses and expressions of emotion were included, so that interviews emerged with an understanding of patients' expressions, experiences, and meanings about spiritual care. The first author's observation of practice informed reflection-on-practice, and these informed action-in-praxis, wherefore transcribing, analyzing, and interpretation of data were ongoing processes in close collaboration between researcher and hospice practice.

The focus group and individual interviews of the reflection-on-praxis were thematically analyzed according to Kvale and Brinkmann.<sup>59</sup> The researchers would read and reread the interview transcripts in order to become familiar with the data set. The researchers wrote comments attempting to summarize or paraphrase, make associations or connections, and make preliminary interpretations. Each researcher did this individually. Then, transcripts were closely read, while we wrote comments in the text where the participants expressed particular experiences and meanings on their perception of spiritual care. Hereafter, transcripts were reread and the comments from each interview reworded into themes

across all interviews. These were presented to the staff during action-in-praxis where they were discussed, elaborated, and validated.

The new focus group interviews of the action-in-praxis were also thematically analyzed according to Kvale and Brinkmann<sup>59</sup> and added to the body of analysis. Then, themes across the compiled individual and focus group interviews were compared, and connections and groupings between them were explored to gain a more analytical and theoretical understanding of the themes. We assigned the groupings of themes to overall names, and a structure emerged about how spiritual care is perceived, felt, lived, practiced, and understood, and how spiritual care can be qualified and augmented in hospice practice. These themes were presented to the staff during two evaluating focus group interviews, where hospice staff participated in validating, changing, elaborating, and interpreting the presented themes. This action research process led to four themes of analysis that aim to explore the two research questions.

### Analysis

The four themes concern four aspects of spiritual care through which patients and staff seemed to perceive, feel, live, practice, and understand spiritual care at hospice, and from where spiritual care may be improved in hospice practice. The four themes are (1) relational aspects of spiritual care, (2) individualistic aspects of spiritual care, (3) embodied aspects of spiritual care, and (4) verbal aspects of spiritual care. We will present the phenomenological analysis of the four themes involving the bodily and relationally phenomenological concepts presented.

#### Theme 1: relational aspects of spiritual care

The first theme, *relational aspects of spiritual care*, concerns how patients and staff at hospice experienced relational interconnectedness as important when being cared for spiritually or caring for someone's spiritual needs. It concerns the perceived experience of interconnectedness in the relational encounter between patient and staff. For example, a patient expressed how the staff at hospice were able to relate to her in ways where she experienced being cared for in the fullness of her humanity (cf. Buber<sup>46</sup>):

Well, it's all about their way of being. The way they enter through the door and sit down. Sometimes

next to me on the bed, they put their hand on my hand. Or take me by the shoulder, or ... and the way they can say 'how are you?' And then I can hear that it's not just 'do those pills work?' No, I know they think about all of me.

The patient explains how she can sense in the staff's tone of voice, their entrance into the room, their touch, and the words spoken that she is cared for as a whole being. Through the relational encounter, she perceives that the staff relate to all of her and not just the medical aspects of being a patient at hospice. The patient perceives the intentions of the staff and the staff respond to the patient through the process of *embodied affectivity* and *sensory attuned impression*. *Interaffectivity* and the *sovereign manifestations of life* manifest in the relational encounter, and the patient perceived being related to *in the fullness of her humanity (I-You)*.

When the hospice staff were interviewed about their interactions with patients, they explained that they bodily 'sensed' how to interact relationally with different patients (*embodied interaffectivity*). They described that with some patients they asked in a general way how they were doing, with others they touched their hands or shoulders physically, and with others again they would ask them about something very specific. Both patients and staff emphasized the importance of the staff's relational 'senses' for practicing spiritual care (i.e. *embodied interaffectivity* and *sensory attuned impression*), where the staff's bodies are affected by the patients' expressions. Fuchs<sup>47</sup> describes this as the *interaffectivity* process, where both staff and patients incorporate expressions and emotions, and actual bodily sense the emotions and needs of the other person.

During the reflection-on-praxis, the staff explained how they would bodily sense and know how to respond to and interact with each patient. For example, a nurse in a focus group interview gave an example of how they related to a patient:

There was this one patient; we just had to contain his silence; we should be in the room with him in silence ... for some of us it was very difficult ... but it was the only way to 'reach' him ... To get to know him, you had to be present in his silence.

During action-in-praxis, staff members agreed and explained how they would rely on their embodied, relational ability to feel, sense, or

perceive the right approach to relate to every patient. They discussed how they all did that in relation to patients and expressed their conviction that by being more aware and by trusting their embodied, relational abilities spiritual care would augment at hospice. The action-in-praxis helped staff becoming professionally aware of these relational aspects of spiritual care.

The staff also explained how relational aspects of spiritual care were closely linked to seeing and caring for each patient as an individual human being. The second theme concerns this.

### *Theme 2: individual aspects of spiritual care*

The second theme, *individual aspects of spiritual care*, concerns how patients and staff at the hospices believed spiritual care should be sensitive to the needs and personality of each patient individually. This was related to their emphasis on spiritual care concerning caring for the entire patient as a person and not only caring for the medical aspects. In a reflection-on-praxis focus group interview, a hospice staff explained,

We sometimes forget what illness the patients have. We see the person, not the illness...We care for who she or he is, the issues they might have ... but that also means that you really have to know each person before you can provide spiritual care.

When interviewing the patients about feeling cared for individually, they expressed how they felt they were 'known' by the staff and it made them feel good. They also, however, explained that the staff only could know them and their situation individually to a limited extent. For example, a male patient said,

I'm being treated as a human ... I cannot see any different way to be treated, 'cause to treat me differently would require so much more knowledge which they don't possess, and that I myself don't even possess. Based on their qualifications I believe this is a really good way to be treated. They remember my name every time they come into the room.

This patient expressed gratitude for the care he experienced from the staff, but he also described immanent limitations of that care. This quote points to immanent conditions of dying that patients at hospice are facing; no one has knowledge or experience about dying, neither staff nor

patients. The patient, however, clearly states being related to as a 'Thou' and not an 'It' when he explained the importance of him being treated as a human and the staff remembering his name. It could seem that the patients' idea of being cared for individually was closely linked to the staff's ability to relate to patients in the fullness of their humanity (*I-Thou*), and this *spiritual quality of interconnectedness* was an important individual dimension of spiritual care, regardless of the staff's immanent lack of understanding of the individual patient's experiences of dying.

When addressing this individual aspect of spiritual care in action-in-praxis, the staff expressed caring for each patient as an individual with individual needs, understandings, and values about living and dying was important for improving spiritual care at hospice. It also, however, became clear how individual aspects of caring for patients' spiritual needs were inhibited by the fact that sometimes patients died before the staff had time to get to know them individually. A hospice staff explained,

We have developed this contact-nurse system, where each patient has closer relationships with a few nurses. They get to know them well ... but sometimes they (patients) are just too sick ... and die too fast...

It required time for the staff to get to know each patient to be able to care for the individual needs of the patients, and often that time was not available, despite having developed the contact-nurse system. During the action-in-praxis, the staff became aware of this difficulty of the individual aspect of spiritual care. A nurse commented, 'Perhaps, we have to accept that it [the individual aspect of spiritual care] is just not always possible.'

During the focus group interviews, the staff discussed how they, during the research process, had become aware of the limitations of the individual aspects of spiritual care and how it may not always be attainable in practice. They, however, pointed to how caring for embodied aspects of spiritual care could be an available approach in those situations.

### *Theme 3: embodied aspects of spiritual care*

The third theme, *embodied aspects of spiritual care*, concerns physical aspects of spiritual care. The patients and staff at the hospices expressed how

they perceived physical care needs (e.g. pain relief) and the touching of the patients' bodies as a highly important aspect of spiritual care. This third theme comprises aspects of spiritual care where the way the staff cared for and touched the patients' bodies was considered spiritual care in itself as well as how touching the bodies of the patients opened for other aspects of spiritual care, for example, conversations about spiritual and existential issues. A hospice staff explained,

I touch their bodies, and often it is an opening for other things; they relax and feel free to talk about whatever ... I show them that it is okay that I see their skinny bones and their cancer ulcer; they shall not feel ashamed. I still see them as the person they are.

The way the staff touched the bodies of the patients would create an opening for talking about issues that the patients would not have opened up about if the staff hadn't touched their bodies. Through the touching of their bodies, the patients sensed an understanding and empathy from the hospice staff; it facilitated *embodied affectivity*. Touch facilitates *interactivity* and *I-Thou interconnectedness* between patient and staff. This bodily resonance of the relational encounter was also present in the above quote where the patient said, 'Well, it's all about their way of being ... they put their hand on my hand. Or take me by the shoulder, or ...' The embodied interactivity process facilitated *sovereign manifestations of life* such as trust, openness of speech, and perhaps even love in the relational encounter between staff and patients. Patients, for example, would say about the staff: 'They (hospice staff) are so incredible, good at being humans' and 'They make me feel safe and cared for.'

When addressing embodied aspects of spiritual care in action-in-praxis with the staff, it became evident that the staff experienced embodied aspects as 'easy.' For example, a nurse said,

We easily just asked the patients about bodily things ... like how is your stomach today? We don't forget the other things, it's just the body we tend to notice first.

When discussing this during the action-in praxis, the staff talked about how embodied aspects of spiritual care often would open for verbal aspects of spiritual care. They, however, explained how they found verbalizing spiritual care more difficult and how they would sometimes 'hide' behind



the embodied aspects of spiritual care because it made them feel more confident. As a staff said,

We notice the body first ... but it is also what we do. What we are trained to do. What we do best. When it comes to the patient's body ... I know what to do, and I do it. It is harder with talking ... so I tend to the body first.

During the focus group interviews, the staff expressed their hesitations and insecurities about the verbal aspects of spiritual care and how it had facilitated a shared awareness of increasing this bodily aspect of spiritual care, with a shared openness among the colleagues about tendencies of 'hiding' behind patients' physical needs.

#### *Theme 4: verbal aspects of spiritual care*

The fourth theme, *verbal aspects of spiritual care*, concerns patients' and staff's understandings about spiritual care also being dialogical. Both patients and staff expressed how embodied aspect of spiritual care could facilitate verbal dialogue about spiritual issues. The embodied aspects of spiritual care seemed to open verbal aspects. As illustrated in the above quote, however, staff also explained how sometimes the physical care would hinder verbal aspects of spiritual care. The hospice staff expressed feeling more confident and comfortable in the physical aspects of patient care than opening for dialogue about patients' spiritual thoughts and needs. The patients also pointed to staff often initiating conversations about general issues but caring for the patients' spiritual needs through conversation was less frequent. For example, a patient explained,

They always ask about me ... not in a curious way, but ... they are just like my children. They are very caring, and they let me do the talking. It means a lot to me ... they care for me about everything and they talk to me about everything. They ask about my family. Most of them know the names of my great-grandchildren, and it's so touching ... they may not go that deep when talking ... it's mostly general talk about family and stuff ... and it's nice, but it's not like... for example, I thought this place was more spiritual or how shall I say it ... That it was more based on the Christian faith, but I have not felt that. Not at all ... we don't talk about spiritual stuff...

During action-in-praxis, the staff discussed how to improve caring verbally for patients' spiritual needs and considerations. There seemed to be a

general consensus among the staff about waiting for the patients' initiative and thereby making sure that patients voluntarily engaged in conversations about their spiritual concerns. For example, in a focus group discussion, it was said,

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...

Among the staff, there was a shared understanding about how patients should freely and voluntarily choose if they wanted to talk about spiritual issues such as death, faith, hope, and so on with the staff. They believed it was not the staff's job to confront those issues by initiating spiritual conversation. Furthermore, the staff explained how they would bodily sense that some patients did not want to talk with them about their spiritual concerns. During action-in-praxis, however, we found that sometimes patients did want to share spiritual thoughts and needs with the staff, although the staff had sensed otherwise. For example, a specific patient was discussed:

It wasn't like you could not ask him about death or anything like that ... but then late at night he would come up and want to drink a cup of coffee with the night nurse ... I remember he said that a person should always fight to the end or always ought to fight or something like that ... He actually wanted to talk about dying and stuff ... especially at nighttime. When he couldn't sleep.

The patient presented in this action-in-praxis did actually want to talk with the staff about his thoughts on dying, although the staff had sensed they could not ask him about that. It seemed as if the staff had sensed the spiritual needs of this patient incorrectly. During the action-in-praxis, the staff continued discussing patients' needs for talking with staff about spiritual issues, and how verbal aspects of spiritual care could be improved. Staff from both hospices made clear that they believed facilitating spiritual communication with patients was an important aspect of spiritual care at hospice, but they also pointed to certain difficulties. They were highly concerned about not violating the autonomy and boundaries of the patients, and they discussed how that affected how they sensed the needs of the patients; they

described themselves as ‘being tuned into preserving patients’ boundaries.’ One staff said, ‘It’s like ... I can feel it in my body how wrong it is (to cross patients’ boundaries)...’ However, they continued discussing how solely waiting for patients’ initiative and *not* initiating conversation about spiritual concerns also could hinder sufficient patient care, and how patients would often also worry about crossing staff’s boundaries and therefore neither initiate conversations.

During focus group interviews, that staff pointed to the importance of these discussions and improving all four aspects of spiritual care. The two hospices, however, responded in different ways. At one of the involved hospices, the staff found consensus about waiting for patients’ initiative before addressing their spiritual concerns but increasing their ability to notice this initiative. Whereas among the staff at the other involved hospice, these insights into their spiritual care practice led them to start a 2-year development project about spiritual care for all the staff.

### Discussion

The analysis indicate that patients and staff perceive, feel, live, practice, and understand spiritual care at hospice as a concept involving four aspects; spiritual care is relational, individual, embodied, and verbal. The theme of *relational aspects* pointed to staff relying on their ability to bodily sense (*embodied interaffectivity*) how to interact relationally with patients. Furthermore, *interaffectivity* and the *sovereign manifestations of life* seemed to manifest themselves in the relational encounter between patients and staff, and the patient perceived being related to *in the fullness of her humanity (I-You)*. During action-in-praxis, staff realized how being professionally aware of and trusting their embodied, relational abilities could improve spiritual care at hospice.

Relational aspects were closely connected to *individual aspects* of spiritual care. Despite patients being aware of their situation and nearness of death, and thereby the immanent limitations of staff understanding and caring for them individually, patients experienced the *spiritual quality of interconnectedness* of being related to as a ‘Thou’ instead of ‘It.’ Also, during the action-in-praxis, it seemed as if the staff came to the realization of some of the immanent limitations of practicing individual aspects of spiritual care. Based on

Buber’s thinking, however, every patient becomes a Thou because staff relate to him or her in the fullness of their humanity, and by being a Thou, patients also always relate to the eternal, Ultimate Thou. This philosophical perspective brings a broader understanding to individual aspects of spiritual care. When staff is confronted with the immanent limitations of caring individually for each patient, the Ultimate Thou who is not limited by space and time may take over, as patients ‘are aware of a breath from the eternal Thou.’ It becomes enough that staff relate to patients as a ‘Thou’ instead of ‘It,’ and that it also possible in situations where there is not enough time to get to know patients individually because the spiritual qualities of interconnectedness are still at work despite the immanent limitations of individual aspects of spiritual care.

Both patients and staff expressed the importance of *embodied aspects* of spiritual care. These were also connected to *embodied interaffectivity* and could open for conversation about patients’ spiritual concerns. It can be argued that, however, staff were so good at the embodied aspects that it would hinder *verbal aspects* of spiritual care. Staff explained how they unknowingly would primarily ask about and care for patients’ bodily needs, and they felt less comfortable and confident caring for the patients’ spiritual needs through conversation. During action-in-praxis, it became clear that staff were highly concerned about not violating patients’ autonomy and boundaries by initiating spiritual conversation. They believed patients should freely and voluntarily choose if they wanted to talk about spiritual issues with the staff. Furthermore, a staff explained how this concern was bodily sensed. It seemed that the staff bodily sensed (*embodied interaffectivity*) the patients needing to voluntarily initiate spiritual conversation. Despite staff being *attuned* to the patients’ needs in a highly sensory manner, somehow their understanding of the importance of patients’ autonomy blended with feeling unconfident and uncomfortable in initiating spiritual dialogue and this could lead to staff sensing the spiritual needs of patients incorrectly. During action-in-praxis, staff realized that they might have to initiate spiritual conversation in order to care for patients’ needs for talking about spiritual issues, despite them bodily sensing otherwise. This bodily sensation of not initiating spiritual dialogue might be explained by Danes in general culturally exhibit a high degree of privacy concerning spirituality,<sup>17-19</sup> and the staff being

embedded in the Danish culture may have embodied this sensation of spiritual privacy.

This study also points to that the four areas of total pain<sup>12</sup> may overlap when staff care for patients' spiritual pain. This may also increase our understanding of the health care professionals' barriers and why dying patients do not experience their spiritual needs being adequately met.<sup>8–10</sup> The study indicates that if this underdeveloped fourth aspect of total pain<sup>13–15</sup> is to be increased in health care, the barriers of the health-care professionals should be addressed with an understanding of the presented four aspects of spiritual care that were found in this study. The practice-relevant knowledge of this study about how relational, individualistic, embodied, and verbal aspects of spiritual care may overlap and be addressed differently in practice may be helpful when addressing the barriers of health professionals for caring spiritually for seriously ill and dying patients and their caregivers.

We applied an action research design combined with the phenomenology of perception<sup>40,41</sup> which has elsewhere been successfully applied for studying a field where death and dying are impending.<sup>39</sup> The goal of action research is to improve practice and facilitate new insights and knowledge through experimenting collaborative research processes between researcher and field of practice.<sup>38,39</sup> The action research process of the current study was fourfold: observation in practice, reflection-on-praxis, action-in-praxis, and evaluation of the action research process. We believe this study has facilitated changes in practice; the staff's insights into different understandings, experiences, and practices of spiritual care as well as discussions have led to an improvement of spiritual care in practice at hospice. The method of action research seems adequate when aiming at both studying and improving a practice-related phenomenon such as spiritual care. The changes in practice were mostly generated by an increase of awareness and shared verbalization among the staff about existing understandings and practices of spiritual care, both those aspects of spiritual care that staff felt easy to address (e.g. embodied aspects of spiritual care) and those they felt more reluctant and insecure about (e.g. verbal aspects of spiritual care). It also became clear, however, how the verbal aspects of spiritual care seem assigned to values about preserving patients' boundaries in ways which relational, individual, and embodied aspects of spiritual care were not.

These values highly affected staff's reluctance for initiating the verbal aspects of spiritual care. We believe further action research processes focusing on values and how these may affect and inhibit changes in practices are warranted. The findings of this study, however, may also be relevant when addressing the barriers of health professionals for caring spiritually for seriously ill and dying patients and their caregivers.

### Limitations

The 12 patients interviewed for the study were selected based on their energy and interest in the study; therefore, they may not be representative of patients at hospice in general. Variation within age, sex, and type of illness, however, was attempted. Furthermore, the themes identified in the data reflected the authors' interpretation, and aspects of the participants' experience could have been omitted. The findings of this study, however, have been presented for the staff at both involved hospices; at about 1–2 months after the actions-in-praxis, the researcher conducted two focus group interviews with staff about the insights about spiritual care practice they had gained through the action research process. The staff have also verified their quotes. This was, however, not possible for patients' quotes, which constitutes a limitation.

### Conclusion

In this study, we applied an action research design to explore how spiritual care at Danish hospices was perceived, felt, lived, practiced, and understood by patients at the end of life and health care staff. Two research questions were explored: (1) How do patients and staff perceive, feel, live, practice, and understand spiritual care at hospice? and (2) How can spiritual care be improved in hospice practice?

Action research seeks to improve and facilitate changes in practice through experimenting collaborative research processes between researcher and field of practice. The present action research process was designed with four consecutive stages: observation in practice, reflection-on-praxis, action-in-praxis, and evaluation of the action research process. The data material presented comprised 12 individual interviews with patients and nine focus group interviews with the staff. Data were thematically analyzed and the staff at hospice participated in validating,

changing, elaborating, and interpreting themes. The research process led to four themes on how patients and staff perceive, feel, live, practice, and understand spiritual care: (1) relational aspects of spiritual care, (2) individualistic aspects of spiritual care, (3) embodied aspects of spiritual care, and (4) verbal aspects of spiritual care.

During action-in-praxis, staff realized how being professionally aware of and trusting their embodied, relational abilities could improve spiritual care. They also came to the realization of some of the immanent limitations of practicing individual aspects of spiritual care. Spiritual qualities of interconnectedness, however, may still be at work despite these immanent limitations, and staff can still meet patients' spiritual needs without knowing each patient individually. We also found that embodied aspects of spiritual care could open for verbal dialogue about patients' spiritual concerns, but staff had a tendency to primarily tend to patients' bodies and be reluctant to initiate verbal aspects of spiritual care. During an action-in-praxis, it became evident how staff would bodily sense this reluctance, but they also realized that they might have to initiate spiritual conversation in order to care for patients' spiritual needs, despite them bodily sensing otherwise. This bodily sensed reluctance seemed to be assigned to values about preserving patients' boundaries in ways which relational, individual, and embodied aspects of spiritual care were not and it might also be embedded within a Danish culture where spirituality is considered private and highly individualistic. Further action research focusing on and changing this reluctance to practice verbal aspects of spiritual care is warranted. Furthermore, the study points to implications for practice on how to address relational, individualistic, embodied, and verbal aspects of spiritual care when caring spiritually for seriously ill and dying patients and their caregivers.

### Acknowledgements

The authors wish to thank all the participants in the study: patients and all the staff at Arresødal Hospice and Hospice Sydfyn.

### Author contributions

The first author conducted the study and drafted the work. The last author was involved in establishing relationships with the research field and designing the study. The first and last authors coded and analyzed the data. All authors ensured reliability in the themes, and also revised and discussed the final manuscript.

### Conflict of interest statement

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

### Funding

The authors disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: A warm word of gratitude for the financial support securing the study: JaschaFonden, Helsefonden, Academy of Geriatric Cancer Research (AgeCare), M. L. Jørgensen og Gunnar Hansens fond, Arresødal Hospice, and Hospice Sydfyn.

### ORCID iD

Dorte Toudal Viftrup  <https://orcid.org/0000-0002-8254-6001>

### References

1. *Anbefalinger for den palliative indsats* [Recommendations for palliative care]. København: Sundhedsstyrelsen, 2017.
2. Best M, Leget C, Goodhead A, *et al.* An EAPC white paper on multi-disciplinary education for spiritual care in palliative care. *BMC Palliat Care* 2020; 19: 9.
3. Etiske Råd D. *Åndelig omsorg for døende – Udtalelse fra Det Etiske Råd*. København: Det Etiske Råd, 2002.
4. Assing Hvidt E, Søndergaard J, Hansen DG, *et al.* 'We are the barriers': Danish general practitioners' interpretations of why the existential and spiritual dimensions are neglected in patient care. *Commun Med* 2016; 14: 108–120.
5. Lundmark M. Attitudes to spiritual care among nursing staff in a Swedish oncology clinic. *J Clin Nurs* 2006; 15: 863–874.
6. Boston P, Bruce A and Schreiber R. Existential suffering in the palliative care setting: an integrated literature review. *J Pain Symptom Manage* 2011; 41: 604–618.
7. Buxton F. Spiritual distress and integrity in palliative and non-palliative patients. *Br J Nurs* 2007; 16: 920–924.
8. Assing Hvidt E, Søndergaard J, Ammentorp J, *et al.* The existential dimension in general practice: identifying understandings and experiences of general practitioners in Denmark. *Scand J Prim Health Care* 2016; 34: 385–393.

9. Balboni TA, Balboni M, Enzinger AC, *et al.* Provision of spiritual support to patients with advanced cancer by religious communities and associations with medical care at the end of life. *JAMA Intern Med* 2013; 173: 1109–1117.
10. Bruce A and Boston P. Relieving existential suffering through palliative sedation: discussion of an uneasy practice. *J Adv Nurs* 2011; 67: 2732–2740.
11. Moestrup L. *I dødens nærvær – En kvalitativ undersøgelse af, hvordan patienter på hospice og deres pårørende forholder sig til eksistentielle aspekter af livet og døden* [In the presence of death: a qualitative study on how patients at hospice and their relatives approach existential aspects of life and death]. Odense: University of Southern Denmark, 2015.
12. WHO. *National Cancer Control Programmes: policies and managerial guidelines*. 2nd ed. Geneva: WHO; Health & Development Networks, 2014.
13. Mako C, Galek K and Poppito SR. Spiritual pain among patients with advanced cancer in palliative care. *J Palliat Med* 2006; 9: 1106–1113.
14. Delgado-Guay MO, Hui D, Parsons HA, *et al.* Spirituality, religiosity, and spiritual pain in advanced cancer patients. *J Pain Symptom Manage* 2011; 41: 986–994.
15. Gijsberts M-JHE, Liefbroer AI, Otten R, *et al.* Spiritual care in palliative care: a systematic review of the recent European literature. *Med Sci* 2019; 7: 25.
16. Zuckerman P. *Society without God. What the least religious nations can tell us about contentment*. New York: NYU Press, 2008.
17. Viftrup DT, la Cour P, Buus N, *et al.* Religious transformation among Danish Pentecostals following personal crisis and group psychotherapy: a qualitative study. *J Spirit Ment Health* 2016; 18: 1–23.
18. Viftrup DT, Hvidt NC and Buus N. Religious coping in a Christian Minority Group: a qualitative study among Pentecostal Danes. *Nord J Relig Soc* 2017; 30: 115–135.
19. Hvidt NC, Nielsen KT, Kørup AK, *et al.* What is spiritual care? Professional perspectives on the concept of spiritual care identified through group concept mapping. *BMJ Open* 2020; 10: e042142.
20. Jones JM, Cohen SR, Zimmermann C, *et al.* Quality of life and symptom burden in cancer patients admitted to an acute palliative care unit. *J Palliat Care* 2010; 26: 94–102.
21. Thune-Boyle IC, Stygall JA, Keshtgar MR, *et al.* Do religious/spiritual coping strategies affect illness adjustment in patients with cancer? A systematic review of the literature. *Soc Sci Med* 2006; 63: 151–164.
22. la Cour P. Existential and religious issues when admitted to hospital in a secular society: patterns of change. *Ment Health Relig Cult* 2008; 11: 769–782.
23. Pedersen CG, Christensen S, Jensen AB, *et al.* In God and CAM we trust. Religious faith and use of complementary and alternative medicine (CAM) in a nationwide cohort of women treated for early breast cancer. *J Relig Health* 2013; 52: 991–1013.
24. El Nawawi NM, Balboni MJ and Balboni TA. Palliative care and spiritual care: the crucial role of spiritual care in the care of patients with advanced illness. *Curr Opin Support Palliat Care* 2012; 6: 269–274.
25. Paal P, Brandstötter C, Lorenzl S, *et al.* Postgraduate palliative care education for all healthcare providers in Europe: results from an EAPC survey. *Palliat Support Care* 2019; 17: 495–506.
26. Agora scgwg. *Spiritual care nation-wide guideline, version 1.0*. Amsterdam: Integraal Kankercentrum Nederland, 2013, [www.oncoline.nl](http://www.oncoline.nl)
27. van de Geer J and Leget C. How spirituality is integrated system-wide in the Netherlands Palliative Care National Programme. *Prog Palliat Care* 2013; 20: 98–105.
28. WHO. Definition of palliative care, <http://www.who.int/cancer/palliative/definition/en/>
29. Puchalski C and Romer AL. Taking a spiritual history allows clinicians to understand patients more fully. *J Palliat Med* 2000; 3: 129–137.
30. Puchalski CM, Lunsford B, Harris MH, *et al.* Interdisciplinary spiritual care for seriously ill and dying patients: a collaborative model. *Cancer J* 2006; 12: 398–416.
31. Paal P, Roser T and Frick E. Developments in spiritual care education in German-speaking countries. *BMC Med Educ* 2014; 14: 112.
32. Greasley P, Chiu LF and Gartland M. The concept of spiritual care in mental health nursing. *J Adv Nurs* 2001; 33: 629–637.
33. Martinsen K. *Care and vulnerability*. Oslo: Akribes, 2006.
34. Martinsen K. *Skønnet og evidensen* [Sense-estimating and evidence]. København: Gyldendal, 2006.
35. Steinfeldt VØ. Åndelig omsorg. En introduktion [Spiritual care. An introduction]. In: Steinfeldt

- VØ, Viftrup DT and Hvidt NC (eds) *Åndelig Omsorg* [Spiritual care]. København: Munksgaard, 2019, pp. 17–30.
36. Kildedal K and Laursen E. Professionsudvikling – udvikling ad professionel praksis gennem aktionsforskning [Development of professional practice through action research]. In: Duus G, Husted M, Kildedal K, et al. (eds) *Aktionsforskning – en grundbog*. København: Samfundslitteratur, 2014, pp. 81–96.
  37. Nielsen KA and Nielsen BS. Kritisk-utopisk aktionsforskning [Critical-utopian action research]. In: Jensen TB and Christensen G (eds) *Psykologiske og pædagogiske metoder – kvalitative og kvantitative forskningsmetoder i praksis* [Psychological and pedagogical methods – qualitative and quantitative research methods in practice]. Frederiksberg: Roskilde universitetsforlag, 2005, pp. 155–181.
  38. Eikeland O. Action research – applied research, intervention research, collaborative research, practitioner research, or praxis research? *Int J Action Res* 2012; 8: 9–44.
  39. Hansen FT. *At Undres ved Livets Afslutning* [To wonder at the end of life]. København: Akademisk Forlag, 2016.
  40. Merleau-Ponty M. *Phenomenology of perception*. Reprinted 2005 ed. London: Routledge, 2002.
  41. Fuchs T. *Ecology of the brain: the phenomenology and biology of the embodied mind*. 1st ed. Oxford: Oxford University Press, 2018.
  42. Fuchs T and Koch SC. Embodied affectivity: on moving and being moved. *Front Psychol* 2014; 5: 508.
  43. Koch SC, Caldwell C and Fuchs T. On body memory and embodied therapy. *Body Mov Dance Psychother* 2013; 8: 82–94.
  44. Fuchs T. Depression, intercorporeality, and interaffectivity. *J Consciousness Stud* 2013; 20: 7–8.
  45. Løgstrup KE. *The ethical demand*. London: University of Notre Dame Press, 1997.
  46. Buber M. *I and Thou* (Original ed. 1937). London; New York: Bloomsbury, 2013.
  47. Fuchs T. Intercorporeality and interaffectivity. *Phenomenol Mind* 2017; 11: 194–209.
  48. Løgstrup KE. *Kunst og erkendelse: kunstfilosofiske betragtninger* [Art and realization: contemplation of philosophy of art]. 3. udgave ed. Aarhus: Klim, 2018.
  49. Løgstrup KE. *Opgør med Kierkegaard* [Breaking with Kierkegaard]. 4. udgave ed. Aarhus: Klim, 2013.
  50. Timmermann C, Uhrenfeldt L and Birkelund R. Ethics in the communicative encounter: seriously ill patients' experiences of health professionals' nonverbal communication. *Scand J Caring Sci* 2017; 31: 63–71.
  51. Scott JG, Scott RG, Miller WL, et al. Healing relationships and the existential philosophy of Martin Buber. *Philos Ethics Humanit Med* 2009; 4: 11.
  52. Lomax JW, Kripal JJ and Pargament KI. Perspectives on 'sacred moments' in psychotherapy. *Am J Psychiatry* 2011; 168: 12–18.
  53. Laursen E. Aktionsforskningens produktion af viden [Action research and its production of knowledge]. In: Duus G, Husted M, Kildedal K, et al. (eds) *Aktionsforskning – en grundbog* [Action research – a textbook]. København: Samfundslitteratur, 2014, pp. 97–112.
  54. Viftrup DT, Hvidt NC and Prinds C. Dignity in end-of-life care at hospice: an action research study. *Scand J Caring Sci* 2021; 35: 420–429.
  55. Creswell JW. *Qualitative inquiry and research design: choosing among five approaches*. London: SAGE, 2013.
  56. Green J and Thorogood N. *Qualitative methods for health research*. London: SAGE, 2004.
  57. Liamputtong P. *Focus group methodology: principle and practice*. Thousand Oaks, CA: SAGE, 2011.
  58. Halkier B. *Fokusgrupper* [Focus groups]. 3rd ed. Viborg: Samfundslitteratur, 2016.
  59. Kvale S and Brinkmann S. *InterView: Introduktion til et håndværk* [Interview: introduction to a craftmanship]. 2nd ed. København: Hans Reizels Forlag, 2009.
  60. Lincoln YS and Guba EG. *Naturalistic inquiry*. Newbury Park, CA: SAGE, 1985.
  61. Danish Cancer Society. Standarder for god forskningspraksis, vs 12.12.2011. BC Copenhagen, 2011, <https://www.cancer.dk/dyn/resources/File/file/6/8086/1562575521/den-danske-kodeks-for-integritet-i-forskning.pdf>
  62. Ethical guidelines for nursing research in the Nordic countries, 2003. [https://ssn-norden.dk/wp-content/uploads/2020/05/ssns\\_etiske\\_retningslinjer\\_0-003.pdf](https://ssn-norden.dk/wp-content/uploads/2020/05/ssns_etiske_retningslinjer_0-003.pdf)
  63. Duus G. Validitet [Validity]. In: Duus G, Husted M, Kildedal K, et al. (eds) *Aktionsforskning – en grundbog* [Action research – a textbook]. København: Samfundslitteratur, 2014, pp. 113–128.
  64. Bradbury H and Reason P. Action research: an opportunity for revitalizing research purpose and practices. *Qual Social Work* 2003; 2: 155–175.