The impact of existential vulnerability for nursing home doctors in end-of-life care: A focus group study

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\textbf{A R T I C L E I N F O}

\begin{tabular}{|l|}
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Article history: \\
Received 28 October 2015 \\
Received in revised form 22 May 2016 \\
Accepted 12 July 2016 \\
\hline
\end{tabular}

\textbf{Keywords:}
Nursing home
End-of-life care
Doctor
Existential

\textbf{A B S T R A C T}

\textbf{Objective: }Explore the impact of existential vulnerability for nursing home doctors’ experiences with dying patients and their families.

\textbf{Methods: }We conducted a qualitative study based on three focus group interviews with purposive samples of 17 nursing home doctors. The interviews were audio-recorded, transcribed, and analyzed with systematic text condensation.

\textbf{Results: }Nursing home doctors experienced having to balance treatment compromises in order to assist patients’ and families’ preparation for death, with their sense of professional conduct. This was an arduous process demanding patience and consideration. Existential vulnerability also manifested as powerlessness mastering issues of life and death and families’ expectations. Standard phrases could help convey complex messages of uncertainty and graveness. Personal commitment was balanced with protective disengagement on the patient’s deathbed, triggering both feelings of wonder and guilt.

\textbf{Conclusion: }Existential vulnerability is experienced as a burden of powerlessness and guilt in difficult treatment compromises and in the need for protective disengagement, but also as a resource in communication and professional coping.

\textbf{Practice implications: }End-of-life care training for nursing home doctors should include self-reflective practice, in particular addressing treatment compromises and professional conduct in the dialogue with patient and next-of-kin.

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\textbf{1. Introduction}

Illness, loss of function, and the prospect of death make all human beings vulnerable to existential suffering. This may include challenges such as dependency, meaningless in present life, hopelessness, burden on others, loss of social role functioning, and feeling emotionally irrelevant [1]. Little is known about professional palliative care providers’ experiences supporting other people in existential suffering [2]. The doctor’s vulnerability is central in Vetlesen’s existential approach to the clinical encounter. Acknowledging vulnerability as a basic element of humanity common to both patient and doctor, he argues, is a precondition for accessing the patient’s perspective [3]. Although intuitively viewed as a weakness, the doctor’s vulnerability may be valuable to successful patient communication [3,4]. Doctors’ own existential vulnerability facing matters of life and death has been underestimated [5], and it is unclear how such vulnerability should be viewed as part of a professional identity.

Kissane suggests eight types of existential challenges for patients with advanced illness: 1) death anxiety, 2) loss and change, 3) freedom with choice, 4) dignity of the self, 5) fundamental aloneness, 6) altered quality of relationships, 7) meaning, and 8) mystery [6]. To each of these, he offers a suggestion to doctors on how to facilitate adaptive responses. Kissane’s typology might also be useful to understand the challenges of doctors working in EOL care, given the common human nature of patients and doctors. However, the doctor’s professional role is defined as a contrast to the patient role, thereby potentially also alienating itself from the vulnerability of its counterpart. Such an opposition may have consequences for the experiences and expressions of existential distress, adaptive responses, and facilitation strategies for doctors.

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http://dx.doi.org/10.1016/j.pec.2016.07.016
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About 45% of deaths in Norway occur in nursing homes [7], making them the most common provider of end-of-life (EOL) care in the country. Nursing home doctors are central team-members in EOL care responsible for treatment decisions such as initiation and withdrawal of drug therapy, and hospital admission. These decisions are often difficult. Nursing home doctors value a well-functioning relationship with the nurse [8]. They also value consensus about the patient’s health status and an appropriate care plan between staff, as well as with the patient and family [9]. They perceive themselves to provide less emotional support to families compared to nurses and aides [10], and family members call for their increased involvement in EOL care [11,12]. Discordance between the demand from staff for medications and the patients’ actual need of nursing care is reported, in particular when not being able to fulfill the existential needs of the nursing home patients [8].

As experienced nursing home doctors, GPs (KJ and SR), and a hospital doctor (MAS) with a key interest in improving EOL care, and studying existential conversations and interactions (KM and MAS), we therefore set out to explore the impact of existential vulnerability for nursing home doctors’ experiences with dying patients and their families.

2. Methods

We conducted a qualitative study based on three focus group interviews, each including five to six nursing home doctors, conducted in two Norwegian municipalities.

2.1. Study context and participants

Norway spends a higher share of total health expenditures in long-term care facilities than most countries in the world [13]. In 2014, doctors were available on average 0.49 weekly hours per nursing home bed [14]. Nursing home doctors in Norway are a blend of general practitioners providing a part-time service, and increasingly, dedicated nursing home doctors commonly working at larger nursing homes.

Participants were recruited by email correspondence, with senior consultants in the municipalities providing contact information. The first focus group was invited directly by email to the nursing home doctors. In further recruitment this approach did not prove fruitful. Local groups of nursing home doctors meeting for Continuing Medical Education purposes therefore provided starting points for recruitment for the last groups.

We included a purposive sample of 17 nursing home doctors based in two Norwegian municipalities, aiming for variation in gender (10 women, 7 men), age (33–65 years), clinical experience (3–29 years), part-time or full-time engagement (14 versus 3), and specialty background (3 doctors were specialists in general practice, 3 hospital specialists, the remainder had no specialty background). The first author knew several participants in the first and second focus groups from earlier work as a nursing home doctor in the same municipality. Most doctors did not declare any particular religious background, seven doctors declared a Christian faith, and two described themselves as agnostic.

2.2. Data collection

The moderator (KJ) asked participants to share an episode treating seriously ill or dying nursing home patients that they found challenging. After the first interview, in an attempt to facilitate stories of vulnerability or challenges while also allowing for stories of success, participants were invited to share an experience that had made a profound impression on them. These stories were starting points for an open exploration of participant’s experiences, using a brief interview guide covering issues such as prognostication, own relationship to death, and talking about dying.

The interviews lasted for 90 min. The first author served as moderator in all interviews, the last author as secretary taking field notes. The first author taped and transcribed the interviews verbatim. Data collection was closed after three focus group interviews, as we assessed the data sufficiently rich to illuminate the research question.

2.3. Analysis

All authors participated in the analytical process following the steps according to Systematic Text Condensation [15] (Fig. A1) [16]. First, we read the transcripts for an overall impression, identifying preliminary themes. Second, units of meaning were identified and coded independently by all the authors, representing different aspects of challenging experiences in EOL care and how these were dealt with. Third, the content of the code groups and subgroups was abstracted into condensates, each illustrated by a quotation. Fourth, generalized descriptions of experiences with dying patients associated with existential vulnerability were developed in an iterative process. Theoretical perspectives from Kissane [6] and Veliers [3,17] sharpened the interpretative focus [18] of the final analytic stages on experiences concerning existential vulnerability. At each step, the code groups were reflected upon and renegotiated in the author group. A decision trail documented the choices during the analytic process [19].

2.4. Ethics and approval

The Western Regional Committee for Medical and Health Research Ethics (2012/1091) and Norwegian Social Science Data Services (#31098) approved the study. Pseudonym participant names were used in the transcription and analysis.

3. Results

Nursing home doctors experienced having to balance treatment compromises in order to assist patients’ and families’ preparation for death, with their sense of professional conduct. This was an arduous process demanding patience and consideration. Existential vulnerability also manifested as powerlessness mastering issues of life and death and families’ expectations. Standard phrases could help convey complex messages of uncertainty and graveness. Personal commitment was balanced with protective disengagement on the patient’s deathbed, triggering both feelings of wonder and guilt. These findings are elaborated below. Selected quotations have been chosen to illustrate the findings.

3.1. Doctors balance treatment compromises in order to assist patients’ and families’ preparation for death, with their sense of professional conduct

The doctors unanimously emphasized the importance of preparing patients and their families for death. They described advance care dialogues, grief work and joint decision-making in many occasions to be a slow and arduous process for all parties. They experienced a duty to take into account the requests of next-of-kin in decision-making, as these would later have to live with the consequences. Doctors sensed that family members needed to see the patient be given “a chance” to realize that the patient’s life could not be saved. Accepting futile treatment in order to ease the grief process for the next-of-kin could oppose the patient’s wishes as well as the doctors’ professional standards. In such situations, doctors felt the need for difficult compromises, revealing and
challenging their own vulnerability. These compromises included administering intravenous fluids, nutrition and antibiotics in discord with the doctors' professional and personal opinion. An experienced doctor described how he yielded to pressure from relatives for further treatment, in a patient with metastasized lung cancer who did not want treatment:

«And then there came a moment when the family and his wife said: yes, but isn’t he going to get nutrition? And at that point nutrition wasn’t medically relevant, but just to do something good. ( . . . ) And I did go so far, then, that I ordered intravenous nutrition. ( . . . ) I have many times been in situations where . . . we actually have to yield quite a lot.» (Nathan)

The participants said that it was essential to them to adopt an attitude of patience and carelessness in these challenging processes. They would encounter widely different patients and families, with varying degrees of acceptance of their situation, need for information and preparedness for death. Doctors described treading gingerly, sometimes taking a step back, listening and not pushing things. One doctor told about his negotiations with the family of a seriously ill stroke patient who repeatedly pulled out his feeding tube. It took many conversations with the whole family before they accepted not giving the patient yet another feeding tube. Another doctor had a similar story regarding intravenous drips:

«What makes this so hard? I think it’s . . . We see that we can’t do what’s best for the patient, what we think is the best for the patient, and what the patient says that he wants. ( . . . ) And that I think is quite a difficult ethical dilemma.» (Sarah)

3.2. Doctors’ vulnerability manifested as feelings of powerlessness mastering life and death, and families’ expectations

Several participants described situations where they felt powerless and uncertain in their professional role. This could be with patients that were difficult to palliate, striving to find words to console the patient or families, or when they could not uphold their assurances to the patient or families. A young nursing home doctor spoke of her meeting with an old patient with grave and deteriorating heart failure. She was overwhelmed by the task of both having to console both the patient and her family:

«I was unsure if she was dying, if she knew who was around her, and if she could hear anything at all. Then I spoke to her, while her daughter was crying, and I felt that I fell short of helping both of them. I tried speaking to the patient, the dying woman, but didn’t know what to say to the daughter. It was hard. I couldn’t find any comforting words.» (Trish)

Another challenge for the doctors was to respond to patients’ or next-of-kin’s inquiries about prognosis, reflecting an uncertainty regarding diagnosing dying patients. They feared a «Lazarus-effect», whereby the patient suddenly would improve after having removed their regular medications and their families having been informed of imminent death. To deal with this, the doctors employed standard wording that would convey the seriousness of the situation and at the same time the uncertainty, such as: «I have stopped guessing», «this is no longer in our hands», or «we will let nature take its course». They would seldom use religious allusions, but a doctor who himself was not Christian would sometimes say «God has a plan with us all». Even in the cases where death was clearly near, the doctor could feel guilty of being the «bad informer» explicitly revealing the patient her dire prognosis. An experienced female doctor speaking to a patient with senile dementia illustrated this vulnerability:

«And we knew he would die. And we had agreed that if he asked, I would be the bad guy informing him, and the nurse would comfort him. ( . . . ) But then he lay there in bed, breathing heavily, and then he says to me, because he knew I was a doctor: ‘Out of breath’. I say: ‘Yes, you are ill’. Then he looks at me and says: ‘is it serious?’ And I answer ‘Yes’. And then he asks: ‘Will I die?’ And he had dementia, and it was a little difficult to answer straight out ‘Yes’ to that. I felt. ( . . . ) I answered: ‘Yes’, and then I had a little break, and then I said: ‘We are all going to die’. (Mary)

3.3. Balancing personal commitment and protective disengagement on the patient’s deathbed

Several participants expressed their own acquaintance with death as difficult. Conversations about death at the ward were demanding, and they would often hesitate to engage in them. They said that the death of a patient could remind them of the eventuality of their own parents or children falling in a similar situation. A male doctor felt guilty about not showing as much feeling as the nurses would after his patients had passed away, even though he had participated in several patients’ funerals. He interpreted this as self-protection against personal involvement, similar to when he sometimes referred to the local vicar service instead of himself talking with the patient about death. Several participants experienced seemingly contradictory feelings, as they witnessed the end of a prolonged trajectory of suffering – a feeling of compassion could alternate with, or change into, relief:

«I remember once, to see them not have to suffer any more, for example to see them the next day lying nicely cleaned in bed . . . . There was a sailor here who died, he had a terrible last year after a stroke, and suddenly he lay in bed completely relaxed, with seagulls crying in the background – because they always have seagulls and baby seagulls here in the summer – it was incredible! There’s something about it, that it can be good to let go, and in a way have a peace about it.» (Elisabeth)

The doctors expressed that by daring to take off their white coat and making themselves accessible as fellow human beings, time spent with the dying and their relatives could feel sacred, meaningful and rewarding. Several participants described touching encounters with patient and families. A dying patient with dementia would in a clear moment share a dream of her deceased husband with the doctor. The doctors described a sense of awe to sit by the patient deathbed, holding the dying person’s hand, and feeling a peace and calm unique to dying. They sometimes felt deep gratitude in patients when futile treatments were abandoned, and were happy when they managed to comfort patients by talking and not only prescribing medications. The joy of seeing the patient as a person and not just for their illness also gave a greater perspective on their own lives, and an opportunity to cope better in a difficult profession, some of them remarked. A young doctor expressed how daring to be a buddy with an alcoholic patient with liver cancer in his last two months had facilitated their interaction when the day came that the patient was dying, and words were more difficult to find:

«He was not one of those I followed for years. However, in a way it was hard for me not being able to contribute so much. Just being present. But on the other hand . . . with him I didn’t have to say so much. He recognized me when I came in. And we were both at ease with the fact that he had complaints that we could not fully palliate. And that things were going downward. I felt that was something positive, too.» (Gary)

4. Discussion and conclusion

4.1. Discussion

Feeling at times powerless before the palliative and communicative challenges surrounding death, doctors balance both personal commitment with protective distance, as well as treatment compromises with their sense of professional conduct,
in an arduous, integrated process of decision-making and grief work. Below, we discuss strengths, limitations, and interpretations of these findings.

4.1.1. Validity and transferability
Focus-group interviews are preferable in seeking information on attitudes, viewpoints, and personal experiences in environments of cooperation and interaction [20,21]. Even though exposing vulnerability of the participants could have called for the more intimate setting of individual interviews, the group seemed well able to admit shortcomings and share challenging experiences, successful or not. We believe that the participants, facilitated by group reflection, were presenting their experiences without excessive concern about making a favorable impression. Contributing to this may have been the fact that most of the participants knew each other [22,23], and all including the moderator and secretary shared the same profession, as well as familiarity dealing with life-and-death issues. The fact that the first author knew several of the participants in the first and second focus groups, may also have contributed to this. However, we did not notice any substantial difference in the ease of discussion nor subjects raised between the groups. The purposive sample of participants represented a rich variation in age, gender, working experience, and nursing home institutions. Although EOL care is a team effort, our study focused on nursing home doctors, as compared to other staff groups or care providers. This is because factors considered important at the end of life are known to differ by professional role [24]. Also, we consider the voice of nursing home doctors faint in previous literature, and their existential vulnerability an underexposed issue.

Although we believe international comparisons to our results are reasonable within a Western cultural setting, doctor’s experiences are likely to be influenced by factors such as doctor availability and EOL care competence, role of nursing home in health care, and cultural differences in attitudes and communication. In particular, doctor availability and staff resources are likely to allow more time for patient and family dialogue, as well as the reflection and self-care that have been shown central to coping with the emotional, physical, and existential demands of EOL care [25–28]. Norway’s health expenditures in long-term care facilities are privileged in a global perspective, comparable mainly to the Netherlands, Switzerland, Belgium, Denmark, and Sweden [13]. The authors’ preconceptions are an integral element of interpretation in qualitative studies. The nature of EOL care as burdensome yet rewarding was part of the authors’ preconceptions from own experience. Nursing home medicine and EOL care have low-status in healthcare. As a nursing home doctor and general practitioner, the first author has firsthand experience of a complexity and sense of importance to this work that feels to deserve otherwise. We may therefore have had a special awareness for aspects of EOL care that are personally and professionally challenging yet rewarding.

4.1.2. Doctors’ existential vulnerability – what does this study add?
Our study adds to existing knowledge by presenting the concrete impact of existential vulnerability in the context of nursing home doctors working in EOL care, such as how they balance personal commitment with protective distance, and professional conduct with treatment compromises. Furthermore, our analysis adds to the understanding of nursing home doctors’ experiences in EOL care, where emotions such as powerlessness and guilt, and strategies such as standard phrasing, are further interpreted in an existential context below.

In Kissane’s existential typology, the perceived powerlessness of doctors facing the dying patient may be viewed as a threat to their need of control, and in prolongation, to their professional freedom and autonomy [6]. Nursing home doctors positively value freedom and autonomy [8,25]. The need to know the timing of death nevertheless seems more important to patients and family than doctors [29]. Standard expressions of uncertainty of prognosis, such as “we will let nature take its course” may help situate the doctor on the side as an onlooker, a position that relieves their responsibility for the ensuing course of illness. Our analysis demonstrated how protective disengagement from the situation of dying could be balanced by experiences of personal presence and a sense of awe. Such a feeling of reverence for the mystery of death, points to the spiritual significance of EOL care. The adaptive responses of doctors here swing between peaceful presence and guilt-laden distance, illustrating that professional conduct in this specific context is not straightforward.

In long-term care doctors may know patients for months or years. This could make doctors feel closer to and more easily be vulnerable in front of their patients, or more easily be touched. Nevertheless the story of being a devil’s advocate of an explicit message of death that nobody wants to be associated with, demonstrates the stigma of death, and the doctor’s instinct to preserve dignity for herself and her patient. The doctor may fear removing hope, adding to the burden of the patient, or making the prognosis self-fulfilling [29]. Participants also felt guilty for not showing feelings before the patients and their families, at the same time needing a protective distance. A need for emotional control is clearly not unique to doctors relating to dying patients or their families. In view of Kissane’s perspectives, however, a need for distancing from death and dying is also an expression of human beings’ anxiety of death [6].

Doctors’ vulnerability may on the other hand be more linked to their sense of responsibility than to death itself, consistent with what has been shown in interviews with hospital doctors [5]. Sharing responsibility helped these doctors create a supporting alliance with their patients similar to the joint decision-making processes and compromises with patient and next-of-kin described by our participants. Our findings support Aase Schaufel’s idea of a “vulnerable responsibility” of nursing home doctors in EOL care [5]. This is demonstrated by the difficult balance of treatment negotiations with next-of-kin, and the doctors’ sense of professional conduct. The powerlessness experienced by the doctors may in part also be viewed as a consequence of assuming a vulnerable responsibility for the challenging, and one must assume often unsuccessful, task of palliating existential suffering. While there is a broad range of manualized interventions for treating existential distress in patients [30], limited empirical research exists on the effectiveness of these [26].

A central concern for medical professionalism is patient welfare [31,32]. In contrast, participants told many stories of next-of-kin centered decision-making. Next-of-kin are important proxy responders in EOL decision-making. Many barriers have been reported to proxy decision-making for people with dementia, and end of life decisions are considered particularly difficult to make as such [33]. The views of cognitively able nursing home patients and their relatives have been reported to differ [34]. Although the insistence of patient and family on interventions that the doctor considers futile is not a surprise [35], treatment decisions possibly aggravating the suffering of the dying patient raise important questions of ethical focus and legal acceptability. Doctors would not be vulnerable to this dilemma had they not experienced a conflicting moral obligation of beneficence and non-maleficence [36] toward next-of-kin.

Showing emotions and personal commitment may be considered unacceptable with professionalism to the extent that it reflects respect for the patient and next-of-kin, and does not hamper good judgment [32]. As exposed by Vetlesen [3] and further elaborated in later studies [4,5], doctors in the present study express how
compassionate engagement and revealing a shared human vulnerability may even be desirable in strengthening the partnership with patient and next-of-kin.

4.2. Conclusion

Existential vulnerability in the experiences of nursing home doctors working in EOL care is on one hand encountered as a burden. This is shown in feelings of powerlessness and guilt facing prognostic and palliative challenges, the difficult balance of treatment compromises with next-of-kin with professional conduct, and the occasional need for protective disengagement from difficult situations. Powerlessness may be enhanced by the doctors’ own need for control. The shared human anxiety for death, the stigma of death, and doctors’ sense of responsibility contribute to vulnerability. On the other hand, existential vulnerability is also experienced as a resource in communication and professional coping, by allowing for meaningful experiences.

4.3. Practice implications

Existential vulnerability plays an important role in understanding EOL care communication and in furthering professional self-care and reflection. Professional conduct in EOL care is not straightforward but needs to take into consideration both the doctor’s vulnerability as well as that of the patient and next-of-kin. EOL care training for nursing home doctors may benefit from including self-reflective practice, and in particular address treatment compromises and professional conduct in the EOL dialogue with patient and next-of-kin.

Conflicts of interest

None declared.

Funding

This study was supported by the Norwegian Medical Association’s Fund for Research in General Practice.

Acknowledgements

We are in debt to the all the study participants for sharing their time and insights.

Appendix A.

See Fig. A1.

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Please cite this article in press as: K. Jansen, et al., The impact of existential vulnerability for nursing home doctors in end-of-life care: A focus group study, Patient Educ Couns (2016), http://dx.doi.org/10.1016/j.pec.2016.07.016
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