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

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ABSTRACT

Objective: Explore the impact of existential vulnerability for nursing home doctors' experiences with dying patients and their families.
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.
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.
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.
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.

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, meaninglessness 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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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 Vetlesen [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