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Dealing with Ethical and Existential Issues at End of Life through Co-creation

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Abstract

Background: In research on co-creation in nursing, a caring manner can be used to create opportunities for the patient to reach vital goals and thereby increase the patient's quality of life in palliative home care. This can be described as an ethical cornerstone and the goal of palliative care. Nurses must be extra sensitive to patients' and their relatives' needs with regards to ethical and existential issues and situations in home care encounters, especially at the end of life.

Aim: The aim of this study was to explore nurses' experiences of dealing with ethical and existential issues through co-creation at end of life in palliative home care.

Research design, participants, and research context: The material consisted of texts from interviews with twelve nurses in a home care context. A hermeneutical approach was used and the method was inspired by a thematic analysis.

Ethical considerations: Informed consent was sought from the participants regarding study participation and the storage and handling of data for research purposes. Ethical permission to conduct the study was given by the organizations where the participants worked.

Findings: A main theme and four sub-themes emerged. The main theme was "Deep co-creative relationships are needed to manage ethical and existential issues at end of life". A model was created to display the findings and relations between ethical issues and situations and the need for a deep trustful caring relationship to solve problems in palliative home care.

Discussion: Together, the themes can be considered as a tool for learning and dealing with ethical and existential issues at the end of life in home care. The themes can also be seen as a part of nurses' ethical competence within this context.

Conclusion: The quality of life at the end of life can be improved through co-creation, despite difficult ethical and existential issues. Future research should focus on co-creation from the patients' perspective.

Keywords:

Co-creation, end-of-life care, ethical issues, existential issues, hermeneutics, nurses, palliative home care, thematic analysis

Introduction

The World Health Organization[1] highlights the importance of enabling high quality care in healthcare services that support patients who wish to receive end-of-life care at home. Worldwide, nurses in home care often face ethical issues in their daily practice, and at an increasingly rapid pace, and consequently ethical awareness in such encounters is required[2,3]. Ofstad[4] finds that in end-of-life home care the dying patient's environment, i.e., his/her home, is a place where the nurse is invited as a guest under special circumstances, which can create difficulties for the nurse, especially when it comes to ethical decision-making. When caring for dying patients at home, community nurses have become responsible for more complex tasks and are faced with difficult decisions[5]. Ethical issues in end-of-life care are of great significance[6,7,8], and nurses often encounter situations where difficult ethical issues emerge, but often fail to recognize the moral dimensions of such situations and also lack the skills needed to adequately resolve these issues[9]. Factors that hinder nurses from recognizing and meeting patients' existential needs include that nurses often feel unprepared to care for end-of-life patients[10,11]. Researchers have also found that even if patients at end of life are content with the physical and medical care they receive, that are not always content with the emotional and existential support they are given[12]. There is a gap in research regarding how the existential wellbeing of patients at end of life can be supported by nurses[13]. As seen in a study from the United States of America, the highest ranked end-of-life competency was the ability to discuss dying with patients and their families[14]. Consequently, health professionals should acquire the skills needed to engage patients and

patients' families in dialog on end-of-life choices[15]. There is a need for knowledge about how nurses in palliative home care experience dilemmas in ethical decision-making[16] and how co-creation can assist in their understanding of how to deal with ethically difficult issues in end-of-life home care.

Background

Dahlin states that unease in the care context can result from concealed or open conflicts about what constitutes "best care" for a patient[17]. In home care, community nurses often work alone and therefore often face ethical issues or ethical dilemmas by themselves[9,18,19]. While different terms are used to denote moral problems, e.g., "moral issues" or "moral conflict", moral problems are most frequently referred to as "ethical dilemmas" or "moral dilemmas'"[20]. Dilemma as a concept refers to involvement with a situation, an awareness of alternatives, the need to make a decision, and uncertainty about the best solution[21]. Therefore, one may state that the concept of an ethical dilemma is linked to choices and conflicts between values, principles and duties[21,22]. Barbosa da Silva[23] p. 154 describes an ethical dilemma as "a situation where a person experiences a conflict where he or she is obliged to perform two or more duties, but realizes that whichever action he or she chooses will be an ethically wrong one". Ethical dilemmas in end-of-life care are related to decisions on whether to withhold or withdraw interventions or treatment[24]. In most countries, patients cannot legally demand treatment that is not conducive to their best interests, and health professionals throughout the world follow the Hippocratic Oath, which includes treating the ill to the best of one's capabilities. One can therefore surmise that the assumption is made that life is to be preserved[25,26]. A person's right to self-determination is the basis from which many ethical dilemmas stem[27]. Ethics should not be confused with morality; an ethical dilemma is also distinct from a moral dilemma. According to the Code of Ethics of Nursing[28], morality is linked to individual or personal beliefs and values, and in ethics right and wrong are defined using an external source or code of behavior. Ethical issues comprise another closely related concept seen in home care nursing. Ethical issues are complex, but may concern situations where nurses experience uncertainty of what actions are appropriate[29,30] and questions regarding what is right or good in a specific situation[31]. These ethically difficult situations may concern issues such as behavior, treatment or resources[32], and pain management[33]. Additionally, Muldrew, McLaughlin and Brazil[34] reveal ethical issues experienced by nurses in palliative care in three domains: in practice, relational issues and organizational issues. Preshaw, Brazil, McLaughlin and Frolic[35] write that while ethical issues are unavoidable in nursing they can have a positive effect on improving care and work conditions. In a literature review on the ethical issues experienced by healthcare workers in nursing homes,

researchers found that the most common ethical issues experienced were related to clashing ethical principles, communication, a lack of resources or quality of care provision[35]. Nurses are responsible for alleviating patients' suffering, which corresponds to the philosophy of end-of-life care[4]. One reason why nurses may have problems dealing with ethical issues could be related to behavioral issues, such as lack of respect for patients' self-determination[36,37,38] or confidentiality and integrity[39,38]. Fry and Damrosch[40] found that nurses mostly experienced ethical issues related to, e.g., protecting patients' rights and human dignity, respecting/not respecting informed consent during treatment, providing care that constituted a possible health risk, use/nonuse of physical or chemical restraints and "staffing patterns that limit patient's access to nursing care". Ethical issues that nurses in intensive care units face include end-of-life issues related to, e.g., prolonging the dying process through unnecessary procedures[41,42]. The different backgrounds and experiences that nurses have, e.g., in relation to age, gender, education, knowledge of ethics or work experience, affects their capacity to identify ethical issues in clinical contexts[19,43].

People nearing the end of their lives and older people with severe illnesses often have more complex needs than those in other age groups[44]. Palliative care is defined as an approach that improves patients' quality of life (QOL) and that of their families through prevention, early identification, assessment, treatment of pain and other physical, psychological and spiritual needs[1]. The concept palliative care has been used interchangeably with, for example, terminal care, end-of-life care or hospice care[45]. Palliative care concerns a complex caring practice[46,47,48], where nurses are expected to deliver high-quality care. While hospital settings have traditionally been the main "location of death", a shift from giving care in hospital to community settings has occurred, which allows individuals to die at home[49]. Nurses have a multifaceted and complex role when caring for a dying person[50,51] and especially with regard to palliative home care, because adequate support and resources are often lacking[52]. Rainer, Kranzale Schneider and Lorenz[53] have also found that most ethical dilemmas in care contexts surface from end-of-life issues and decisions[9]. Fromme[54] mentions that ethical issues in palliative care, are concerned with legalities of end-of-life care, advanced care planning, inappropriate use of medical interventions and symptom-specific issues. Ethical issues at end of life may also concern questions about palliative sedation[55], often mentioned as the most delicate and ethical issue in end-of-life care[18]. Ethical issues can be related to a lack of family understanding or relatives' unrealistic treatment expectations and demands[36,56,16,34]. These demands give nurses experiences of powerlessness[16]. Frustration in palliative care arises when nurses feel that the patient's next-of-kin do not have confidence in them[16]. Another difficult issue can be confidentiality, meaning situations when next-of-kin pressure nurses to disclose patient information[36]. Hernández-Marrero, Fradique and Martins Pereira[18] have found that

communication is a sensitive ethical issue. Ethical issues may surface from conflict with physicians or organizational limitations[53]. Different opinions regarding end-of-life care and gaps in communication between nurses and other professionals can be a source of stress for nurses[52]. Ethical issues in palliative care can be that nurses experience conflict between what their duty is and what they feel is right[34]. Ethical issues also emerge when nurses are worried about a possible lack of consensus among colleagues regarding about how to care for the patients, e.g., with regard to pain relief[16]. Nurses can experience a sense of powerlessness when physicians are the sole decision-maker[57] and they can feel obliged to continue treatment and tests if they are dependent on the physician[16]. Powerlessness can give rise to frustration, and nurses can feel powerless if they are unable to solve ethical dilemmas[9]. In end-of-life care, the most frequent ethical issues that nurses face include advanced care planning and surrogate decision making[19]. Respecting patients' autonomy has limits, and health professionals need to be aware of these limits in relation to their responsibility to do what is best for the patient, use resources fairly, respect patients' autonomy, and engage in truth telling[27]. Patients' right to independently make decisions about their end-of-life treatment must be respected ethically and given consideration in relation to the use of advance treatments and prognosis[58]. Patients' right to independent decision-making has some limitations, and therefore includes ethical dilemmas[58]. Health professionals must respect patients' autonomy while also considering the limitations of such and performing caregiver duties to patients' advantage, while also not causing any harm[27]. A central challenge that nurses and physicians face is witnessing the suffering of patients and patients' families during end-of-life experiences[59].

In nursing, the concept of co-creation is defined as deep nursing: a solicitous and considerate co-created nursing process that entails a personal nursing practice enabled through perceptiveness and attention to patients, spending time with patients and reflecting on nursing encounters[60,61]. According to Palumbo[62], co-creation relates to that patients should be involved in honest and comfortable relationships with their healthcare providers, because patients are effective members of the healthcare team. Co-creation in nursing care is more than simple collaboration with patients[63]. It is also the joint creation of vital goals for patients through the process of sharing knowledge, with the aim to enable the creation of opportunities and achieve the best possible essential goals for patients[64,61]. All team members, nurses, patients and their next-of-kin should share knowledge in the caring relationship so that they jointly contribute to the striving to fulfill the patients' goals[60,61]. If nurses perceive patients as experts on how to live their lives they can utilize their expertise and experience through engaging them in dialogues through co-creation[65], through attentive listening and plan the best possible care goals[66]. In home care, co-creation can be understood as the relationship between healthcare providers, patients, and informal family

caregivers, and these relationships can be seen as the growth of a professional friendship where all parties meet the other as an individual[67]. Karlsson, Roxberg, Barbosa da Silva and Berggren[16] have found that nurses in a palliative care context took their duties seriously, e.g., their responsibility toward their patients and for providing high quality care for them at end of life[51]. Co-creative processes are multifaceted and include main-, sub- and microprocesses[60]. Time has been found to play a particularly important role in co-creation[61,68]. Many patients wish to receive comprehensive information about their health status, but as patients come closer to the end of life this may decrease[69,70]. Research shows that existential issues are more profoundly present in end-of-life and palliative care than in any other care context[71]. Faced with new and unexpected life situations, patients need not only their physical and medical needs addressed but also their emotional and existential needs[72,73,74,75]. Yalom[76] and Van Deurzen[77] find that existential dimensions (issues) are always present in human life. Existential issues can include the meaning of life, loneliness, death or freedom and are commonly experienced by all humans, regardless of context or background[76]. Nelson-Becker[78] defines existential issues as challenges associated with an individual's beliefs, values, behaviors, and experiences that are related to ultimate meaning and which often involve subjective experience and contemplation on the nature of human existence, formulated from the perspective of secular and humanistic thought. Religious issues can be considered challenges associated with values and beliefs that are related to an individual's perspective on the meaning of life[79]. Spiritual issues can be considered an umbrella concept encompassing both existential and religious perspectives[79]. Kallenberg[80] notes that for patients in palliative care, existential issues are questions associated with the meaning of life, death, guilt, and reconciliation. Addressing patients' existential issues is a fundamental element of all-embracing palliative care[1], yet researchers have found that nurses often find it challenging to talk with patients about existential issues[81,82,83]. Cancer and palliative care patients often have existential concerns and a desire to discuss existential issues[84,10,85,86]. Nurses can help patients avoid unnecessary anxiety by showing compassion for each patient's uniqueness through acknowledgement of the patient's personal issues[87,88]. Also, if patients' feelings related to a sense of meaninglessness are acknowledged and patients are supported by nurses in their ethical questions, patients can cope better with their illness and cure[84,89]. If nurses do not acknowledge such feelings, patients' QOL may be affected in a negative way[90,91].

McSteen and Peden-McAlpine[92] highlight that the need for patient advocacy often arises in ethically difficult situations, and for nurses to act as strong advocates for dying patients means that they are guides, liaisons, and supporters. Ethically difficult situations might also be differences between nurses' and patients' opinions regarding what to do or if the patients do not follow staff recommendations[21,38].

End-of-life care can also be ethically difficult for nurses[34], because being constantly confronted with death in palliative care reminds them of their own mortality, and such stress factors as grief is common[91] and also moral distress[93]. Karlsson et al.[16] mention reflection as a means of reducing this kind of difficulties or stress factors, or feelings of powerlessness and frustration for nurses. In fact, reflection can strengthen nurses' ability to remain close to the dying patient[16]. Nurses need continuous support for reflecting on ethics in order to enhance quality assurance in healthcare[94]. Jacobs[95] also states that support regarding moral sensitivity, critical thinking and trans-professional working should be part of their professional development as nurses. However, research indicates that nurses are not always aware of ethical dimensions in their work[96]. Sometimes nurses might even ignore ethical issues or avoid them by adjusting their work procedures[96]. Molewijk, Abma and Stopler[97] suggest that dealing with concrete ethical issues requires knowledge of complex and highly specific circumstances. Wilson, Avalos and Dowling[44] state that a high level of palliative care knowledge provides nurses with more positive attitudes toward the care of patients at end of life.

Nurses come close to patients in different situations and are allowed to touch the patient and be touched both physically and spiritually in these encounters[16]. Ethical issues in palliative care can emerge from conflict with families and patient privacy concerns[53]. The nurse's work can be particularly difficult in palliative care since the care can involve the whole family[98] which, amongst other things, involves being faced with ethical dilemmas as a result of the close relationship with the parties involved[99]. Relational issues, for example with residents and families, cause the greatest distress amongst nurses in palliative care[34]. Relational issues involve, for example, conflicts within the relationships of staff, families and residents, including attentiveness to resident care needs[34].

This concerns, for example, communication with the patient about the diagnosis/prognosis and also communication with relatives is mentioned as complex. Rasoal, Kihlgren, James and Svantesson[100] have showed that ethically difficult interactions with patients and next-of-kin can make nurses feel powerless. Powerlessness is comprised of feelings of insufficiency, difficulties to respond or manage the emotional needs of the patient or next-of-kin. Other reasons for a sense of powerlessness are uncertainty regarding who should have power over life and death, disclosing the truth or how much power next-of-kin should have[100].

Building on previous research, the co-creation of vital goals for the patient in home care is important[48] and time is considered to be highly important[60]. Previous research shows that co-creation can also be seen as an aspect of caring[68] or compliance and that nurses' role is to create conditions for co-creation as well as provide patients with the space to enjoy the freedom to choose[68,101]. Therefore we seek to explore co-creation as a means for dealing with ethical and existential issues at end of life in palliative home care from a qualitative perspective.

Aims

The aim of this study was to explore nurses' experiences of dealing with ethical and existential issues through co-creation at end of life in palliative home care.

Methodological aspects

This study was inspired by a hermeneutical approach in accordance with Gadamer[102]. The data material consisted of texts from in-depth interviews with twelve nurses. The method was inspired by thematic analysis[103].

Data material and data collection

Twelve nurses, one man and eleven women, between 23 and 64 years of age in Finland were interviewed about their experiences of ethical sensitivity and co-creation in a home care context. The participants were from both urban and rural areas in a bilingual area of Ostrobothnia and shared the same socioeconomic background (see Table 1). They all worked in home care contexts, and one of them also worked on a clinical ward. The participants were recruited from two public care organizations and one private home care organization in Ostrobothnia in cooperation with the head nurses. The in-depth interviews took place in 2018, either in the previously mentioned home care contexts or at the university where one of the researchers worked. The interviews lasted between 60- and 90 minutes and were transcribed by the first researcher.

Insert Table 1 here.

Thematic analysis

The researchers analyzed the data material by using a thematic analysis inspired by Braun and Clarke[103]. First, both researchers individually analyzed the material through a repetitive process in recurrent movements of close reading and with openness to allow the substance to emerge bit by bit. Second, they regularly engaged in discussions. Third, they generated the final analysis together. The researchers categorized the data material into one main theme and four subthemes. The interpretation, carried out in a spirit of hermeneutics, moved between interpretation and understanding, and the whole-parts-whole. The material was approached with alert

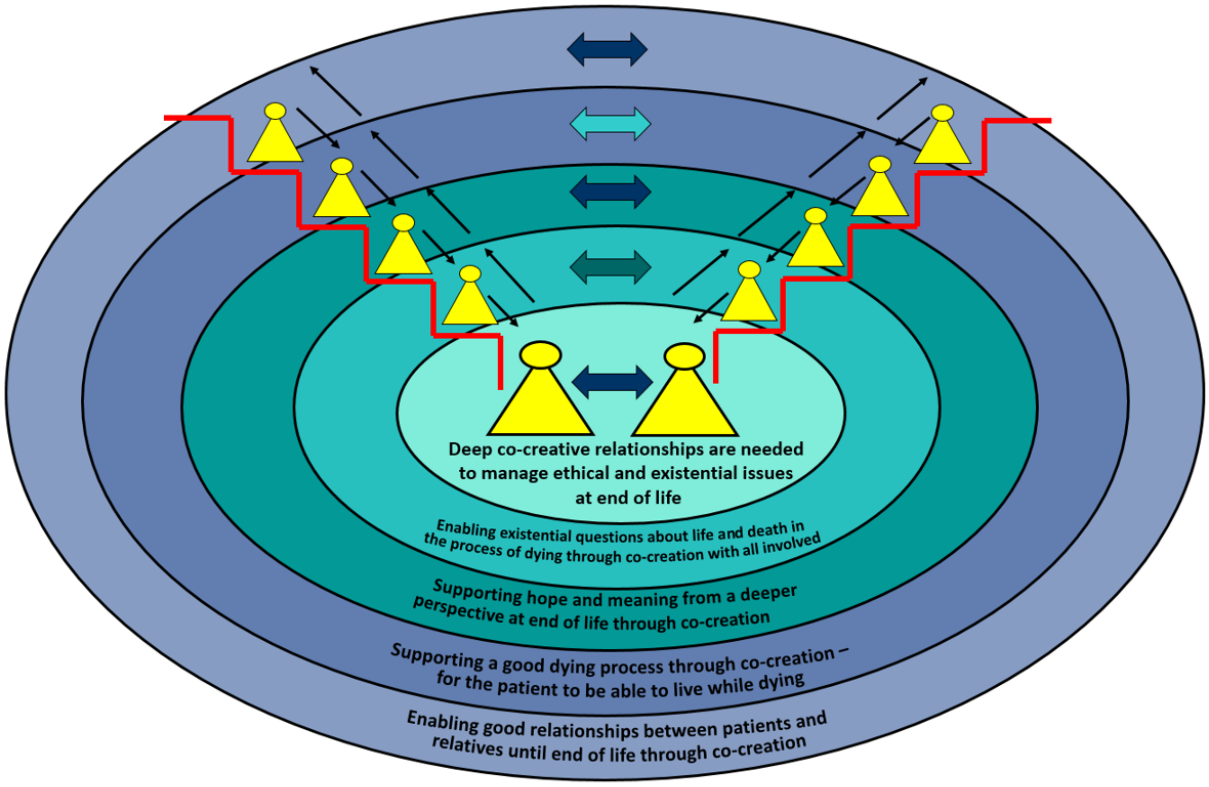
watchfulness. For the purpose of guaranteeing mastery of their pre-understanding, the researchers were careful to formulate it during the interpretation. In this way, they also prevented their pre-understanding from guiding the interpretation. As the reading challenged the pre-understanding, the researchers invited it, together with the substance of the material, into the scientific dialogue.

Ethical considerations

This study is conducted according to the guidelines outlined by The Finnish National Advisory Board on Research Ethics[104]. One of the researchers personally contacted (through e-mail) the nurses that were chosen for participation in this study. The nurses were provided information about the study purpose, confidentiality, withdrawal of consent and intent to publish, in both oral and written form. The researchers sought informed consent from the respondents regarding study participation and storage and handling of the data for research purposes. Moreover, ethical permission to conduct the study was given by the organizations where the participants worked.

Findings

The analysis revealed one main theme and four subthemes. The main theme was "Deep co-creative relationships are needed to manage ethical and existential issues at end of life" and the subthemes were: "Enabling good relationships between patients and relatives until end of life through co-creation", "Supporting a good dying process through co-creation – for the patient to be able to live while dying", "Supporting hope and meaning from a deeper perspective at end of life through co-creation" and "Enabling existential questions about life and death in the process of dying through co-creation with all involved". Finally, at the end of the analysis process a model was created (see Figure 1).



Deep co-creative relationships are needed to manage ethical and existential issues at end of life

The main theme concerned the need for nurses in palliative home care to establish deep co-creative relationships in order to gradually reach a patient's inner thoughts to be able to help the patient manage ethical and existential issues at end of life (see Figure 1). Important aspects for establishing this deep co-creative relationship are: trust, time, attentiveness, responsiveness, sensitiveness, closeness, touch and continuously asking questions. Co-creation within the palliative home care context means that the nurse follows the patient in an oscillation between hope and despair, seriousness and play, humor and closeness, in distance and depth. By being responsive and attentive, nurses may follow in this journey, close to the patient and sometimes the patient's relatives, in a deep relationship to help create solutions to ethical issues.

> *"...it becomes an oscillation in this way* [uses hand to show a wave movement]*... that sometimes takes you up a little* [from the depths of despair] *and then I use some humor and ... and try to mix in something* [light-hearted]*... in all this heavy ... and then we are up on the surface trying to get some air and...then we must dive down again in the difficult issues* [deeper]…" (P9)

Using humor can be a way of easing a patient's situation and connecting with the patient in a natural way. Humor is not always beneficial nor is it suitable for all situations, but if the nurse and patient share a sense of humor its use can be quite positive. Humor not only helps deepen the caring relationship, it also increase the chances of

completing tasks. Humor can therefore be used for more than improving a patient's mood. As one participant notes:

> *"Or if you [as a nurse] say that, 'now tell me a story you remember, something nice…' Then [the patients] say, 'yes, but can't you start…'. So I say… 'Yes, why not? To…tell [something] that I would like to hear…' So that is also a way. And also in [something that is] hilarious, so a little humor lightens the mood and you can perhaps more easily get things done."* (P10)

One participant mentioned that it was natural for experienced nurses to involve themselves in the patient's situation and try to create a sensitivity and closeness to be able to establish a deeper relationship with the patient in order to address ethical and existential issues.

> *"Yes, this is exactly the way it is … in some way it comes to you and you sense or recognize her…* [the human being in the patient] *…how she feels… and you sense if she does not feel well … And it somehow comes to you when you talk to and associate closely with the patient…* [that you become closer and closer]*…"* (P2)

In certain situations, when faced with ethically difficult questions or existential issues, nurses who associate closely with patients and together with the patient discuss and reflect on various solutions can experience moments where the patient suddenly opens up, resulting in the nurse and patient becoming closer and the relationship deepening. In relation to the model presented in this study, once can metaphorically view such as the nurse and patient simultaneously stepping down and meeting the other in the innermost circle (see Figure 1).

> *"Something happens when one gets really close to a person… 'But what should we do, then?'* [the patient asked during a deeper conversation at end of life] *and I said that 'well, you have the port-a-cath … we will use it if we need to' …but from that moment on we could talk to each other on a deeper level."* (P2)

Through touch nurses may sometimes deepen their relationship with patients so that the latter more easily can begin to talk about the deeper and existential issues that have a tendency to emerge during the palliative phase. Nurses can broach a specific issue to see if the patient follows and begins to talk about it. The participants indicate that nurses can see if patients hesitate and become quiet or if they open themselves for discussion. If they do, the nurse can, through co-creation, continue to elaborate on the theme and follow the patient: *"is there something you*

are thinking about? [‘death’] *They are often very honest...”* (P6). If they notice that the patient needs to talk about difficult issues and seems anxious, it is best to ask. Here time and the depth of the relationship play an important part.

> *"And if they are hesitant* [patients open up a little] *... then I am open. I also put out small ‘bait’ and perhaps say ‘I was thinking ...have you ever thought or wondered about this* [for instance, what it will be like at death]*?”. And sometimes I get a reply ...‘Yes, perhaps a little…’”* (P10)

Nurses need to be vigilant and responsive to the signals that indicate whether a patient is ready to talk about ethical or existential issues; they need to respect the patient and tread carefully. "*...I think, OK ...and we let it go, if they do not want to talk about it anymore. And the next time, I lay out the bait…. and with time…. time is what is needed”* (P10) Closeness is key, sitting with and listening to patients or only holding their hand might mean that they can open up about difficult issues. Nurses do not have to be able to provide an answer when difficult existential issues arise, but must dare to listen to them: *“To have the courage to listen also to difficult questions. I do not have to be able to answer them, but I must be able to listen to them.”* (P10)

Enabling good relationships between patients and relatives until end of life through co-creation

This subtheme concerned the possibility of supporting good relationships between patients and their relatives through co-creation at the end of life. This not only includes, for instance, to make next-of-kin understand the patients’ perspective regarding the end of life, but also to make patients see things from the point-of-view of their next-of-kin. This is to avoid, for instance, that next-of-kin "drain" the patients’ energies by forcing them to go to medical examinations and treatments although they no longer wish to do so. In this situation it is important to broach the topic with the patients’ next-of-kin and explain that much valuable time is maybe wasted because the patients instead want to enjoy the time they have left in their own way. Nurses become mediators between patients and their next-of-kin in co-creation, where they discuss ethical difficulties and together create opportunities on the journey toward the end of life. Yet, cooperation may be difficult if patients and their next-of-kin do not have the same understanding of the illness. If patients and their spouse suffer separately and do not have the courage to talk about difficult issues, but instead experience anxiety, nurses need to intervene, for instance, in the following way: *"...I concretely bring it up and say ‘now you are both equally miserable and you think about the same things, have you thought about talking to one another about it…?’”* (P1) The participants mention that one becomes closer and have a deeper relationship if one has the courage to show each other one’s own vulnerability. Paradoxically, being

"weak" leads to well-being. It is not helpful to refrain from showing sadness to avoid that the other person should feel bad, and here nurses can be a support.

> *"I* [the next-of-kin] *may not want to show that I am sad, so that the other* [the patient] *will not feel bad… but it is quite the opposite…but you* [the next-of-kin] *are sad because you care…and that is comforting for the other* [patient]*."* (P1)

When first establishing a relationship with a patient entering the palliative phase, it may be productive to refrain from talking about the patient's illness or ethical issues.

Supporting a good dying process through co-creation – for the patient to be able to live while dying

This subtheme emphasizes that supporting a good dying process through co-creation can enable the patient to live while dying. This means supporting wishes of, for example, not dying alone. Sometimes humor while handling difficulties was something that could alleviate the dying patients' suffering. Participants point out that they strive to fulfil the patients' wishes until the end of life. One participant relates: "They often say *'I do not want to be alone …when I die…'"* (P7) Co-creation also means that if the nurse has promised the patient that the patient can die at home the nurse also has to ensure in an ethically sensitive way that this is what will happen. Nurses should regularly ask whether the wish to die at home is the same or if it has changed, because no patient should be forced to die at home if that suddenly makes the patient feel unsafe. In order to support a good dying process through co-creation the nurse has to listen to the patients' goals, wishes and questions and instill a feeling of security, and also enable pain relief at the end of life. Being able to express their wishes together with the nurses may sometimes alleviate the patients' suffering.

> *"But it is important that someone is there, holding your hand, that you do not need to die alone… And they have an infusion pump for the delivery of pain relief and pain so that no one should die in pain. There is medication that we can give them, and everything is according to doctor's order. But many times… just being able to talk about it… and to express this wish, can alleviate suffering… Knowing that someone else knows your wish."* (P7)

Co-creation also involves advocating for patients if they do not wish to talk about ethical difficulties or existential issues such as death. Sometimes it is the relative who needs to talk about death and dying, and insists on talking about this with the patient who may not have such a need and does not wish to talk about it, or even does not have

the ability or energy to do so at the time. Nurses can in this situation use co-creation and tactfully attempt to address this issue by helping next-of-kin to understand that patients may need to rest from the thought of their own imminent death: *"Then we need to say that 'well, but he* [the patient] *does not feel the need to talk perhaps … Do you have anyone else to talk to?"* (P1)

Patients should have the right to choose to do what they want with the time they have left and what kind of atmosphere they want. Many wish to remain cheerful with the help of humor until they die or during the whole process of dying, and this means that nurses must perceive, understand and follow this oscillation up or down (see Figure 1). Humor from both nurses and patients can be one way of "playing with" each other and the situation, but it always has to be on the patients' terms. This is what one participant says: "and they do not expect you to be sad when you arrive but they want you to be *a little cheerful and cheer them up."* (P1) Humor can be important for many patients to be able to deal with difficult issues at the end of life and it can be a significant part of palliative home care because, paradoxically, it can enable patients and nurses to discuss difficult and deep issues. It can also be a relief because it makes it easier to deal with difficult issues, and gives new strength.

> *"… you also notice that patients may try to joke a little… and then you need to catch on right away and relieve the atmosphere and… because you cannot be there* [in the deep] *all the time. You have to lighten things up…"* (P9)

Supporting hope and meaning from a deeper perspective at end of life through co-creation

Encouraging hope and meaning from a deeper perspective is essential at end of life. This can be done by encouraging patients' hopes of fulfilling goals and wishes about what they find meaningful in life. Especially in end-of-life situations it is common for patients and their next-of-kin to have completely different goals with regard to care or compared to the caring team. For instance, some relatives feel that treatments should be given until the end even though the patient does not share this goal. In such situations it is important that nurses discuss with the patient's next-of-kin and explain the patient's perspective, who needs to feel meaning and hope at end of life. Nurses who respectfully use co-creation to enable the patient to participant in and influence the decision-making related to treatment can provide meaning in end-of-life care. As one participant says:

> *"No, from the beginning I thought that we use a PEG [feeding] tube…so that [the patient] could receive nourishment…But…[the patient] refused because she did not want to go to a hospital. So the alternative was to insert [a tube] in a vein. So it became in this way a little different, and*

according to her wishes…she was the one steering. She to be sure steered very well all the way. So she got to have [her care] patient-centered all the way. So in this way she got to contribute and feel the meaning in care…" (P2)

Through co-creation nurses can also help instill hope in patients and create meaning through, e.g., focus on someone else. One participant expresses:

"In some way I [as a nurse] must of course also instill a certain hope, when I come. Not hope to be [cured], but joy and hope to feel a little better or a sense of wellbeing…Because I perceive this of course often when I call my patients. They often say, 'Thank you for calling, now I got to talk about this…that you made my day.'" (P12)

At the end of life, patients often experience difficult situations of hopelessness and meaninglessness. Nurses can, however, through co-creation, help to create hope for patients: the patients leave something that can comfort their children or grandchildren and that also can create meaning for the dying patients themselves.

"Once I had a younger male patient who was single …he had a boy and he was dying and…this was difficult for him [that he would die and leave his son]*… but then I suggested that he would begin to try and create memories for this boy and to write down everything in a book and do as many things as possible and…it turned out great…*[in this way the father could also have a sense of meaning] *and he had written so much in this book and such a good speech to the boy for the funeral … and he died in November, but in December his friend called and told me that he* [the patient] *had decided that everyone should receive Christmas gifts from him despite him being dead…so in this way he got to be present that Christmas…"* (P1)

Co-creation can also mean that patients and their next-of-kin are made aware that talking about ethical issues and showing how they feel can give them both strength and provide meaning. Patients who suffer may gain strength and a sense of meaning from their next-of-kin's tears.

"And I know this because I had a female next-of-kin [to a patient] *who became weak and cried … then her husband* [the patient] *became strong … it is like a teeter-totter all the time… and this was good for him when he could be the strong one* [in the midst of his own suffering]*… that gave him meaning, he was not just the weak and ill person…"* (P1)

Co-creating with the patient or patients' relatives by asking questions in order to enable answers to ethical issues may help patients find hope and meaning if they are feeling hopeless and see no meaning in suffering.

> *"And she sat there on the couch and said no I do not want to live I do not want to live … I took her hands and said let's calm down. I am here now… Try to feel… And she said no I do not want to live! And I tried to ask her 'Why not?'…Then I asked 'What do you have left?". She said 'I have my friends and the children'. 'They need you', I said. Then she said 'Yes, this is true'. This was just such a little thing, and I was probably there for two hours* [and she had recreated meaning and hope]*… My being there* [and I did not abandon her gave her hope] *made her feel safe."* (P10)

Enabling existential questions about life and death in the process of dying through co-creation with all involved

This subtheme concerns co-creation in the palliative stage as enabling deeper existential questions about life and death in the process of dying with patients and their next-of-kin. After a good relationship in the palliative stage has been created and nurses become close to patients they can broach deeper issues in a natural way.

> *" …so you sit there close next to each other and suddenly you start reflecting together … and I may ask 'What do you think about the future…?' and perhaps they say that 'I take one day at a time …and I know that I do not have much to look forward to.'* [and you enter deeper into the topics]*… And in this way you can ask do you think about death? That these questions emerge from a sense of calmness in a way…that you first have to create trust and then these issues appear gradually in a natural way…* [as the relationship deepens]*"* (P2)

If the nurse notices that the patient ponders on death and spiritual issues and seems to need to talk about it, the nurse can ask questions.

> *"Well, …you can ask 'What do you believe in?' or 'What do you think about and how?' And they have a lot about forgiveness of sins and I usually say that 'you know… I believe you are forgiven* [for possible sins]*… and I think this will be OK…"* (P9)

The participants indicate that it is important to support patients if they want to talk about spiritual and existential issues, but this always has to occur on the patients' terms. The participants mention that patients may not always see the situation in the same way as their next-of-kin. Sometimes the patient's next-of-kin may wonder about some

ethical issues and need support and help although the patient may not have any difficult questions. If patients have not been involved in the ethically difficult discussions regarding the end of life and the process of dying, nurses may ask them questions.

> *"…You can ask 'Would you like to include your next-of-kin in these discussions?' And then, often the following day, you can continue the discussions with them. Because they do not want to share these things, because they do not want their next-of-kin to be sad. Often it has to do with 'You know and I know… but we do not talk about it because we do not want to hurt each other…' And then I ask 'Do you want us to talk with your next-of-kin about this?' It usually turns out that already the following day you sit down and say that yesterday we had this discussion..."* (P7)

Discussion

The aim of this study was to explore nurses' experiences of dealing with ethical and existential issues through co-creation at end of life in palliative home care. The most important conclusions are that co-creation can be seen as the nurse's focus and role, to enable nurses to become more like a fellow traveler, a caring companion during the patient's oscillations between flourishing moments and adversities, between hope and despair during the journey to the end of life in palliative home care. This compliance may enhance a deeper caring relationship in the co-creative process at end of life. The study also reveals that co-creation in a palliative home care context involves using humor, and creating hope and meaning from a deeper perspective for the patient.

This study shows that the close and deep relationship between nurses and patients includes more touch and closeness and opens up moments where it is possible to solve, uncover or manage ethically difficult situations or existential issues. Co-creation may enable nurses to be more responsive, open and attentive toward the patient, in turn allowing nurses to read signals indicating whether a patient wishes to discuss difficult issues and allowing nurses the possibility to compose an ethical response. This study also highlights that nurses do not need to answer such questions but instead merely to listen to them. Research shows that all caring encounters are not characterized by nurses fulfilling patients' wishes in palliative home care[60]. Perhaps this is the case if the nurse is not open and chooses to take "the easy way" to avoid facing and handling ethically sensitive issues[96]. Perhaps the nurse also lacks competence for dealing with these ethical issues[96,29] or are not always aware of these dimensions or lack respect for the patient's self-determination[36,38,37].

Patients can have more faith in nurses if nurses engage in close continuous contact with them and if nurses also promise to follow the patients "down", without abandoning them. Nurses' compliance becomes a condition for creating the faith and trust, i.e., deep relationship, needed for nurses to be able to broach ethical issues at end of life. Sharing difficult moments may enable nurses in a natural way to ask sensitive questions about ethical or existential issues or practical arrangements at end of life, because the nurses may already have been invited into "the innermost circle in the deep relationship", and this is important with regard to existential issues or existential suffering, which is a widespread phenomenon at end of life[71]. This is why we argue that a caring approach through co-creation can enable the creation of a deep relationship with the potential of alleviating this suffering and thereby enhancing the QOL for patients at end of life. For example, Fagerström and Eriksson[105] state that nurses' awareness and knowledge of the existential and spiritual needs and desires of patients assist them in understanding and interpreting the caring needs of the patient in their striving to alleviate suffering. QOL in end-of-life care may also enable patients to die at home if they wish to do so[106] and this can, in turn, strengthen their sense of dignity. Enabling people to die at home may be done by empowering families and public education, balanced with a continuing effort to improve home-based models of care and training in palliative care for staff[106]. The stepwise model created in this study (see figure 1) can be used as a tool for nurses in order to understand how to use co-creation in order to become close to the patient and deal with ethical issues in end-of-life palliative home care[61]. Other research also indicates that nurses can use co-creation for empowering the patient[107].

Sometimes end-of-life care can be difficult to deal with for nurses because they are constantly faced with death[34] and as a consequence their stress and grief levels can increase. Research shows that humor may be a coping mechanism for nurses when dealing with their professional grief[108]. One way of enhancing co-creation competence amongst nurses would therefore be to provide possibilities for reflections in groups and supervision in the work team on a regular basis[61]. In healthcare settings, for example in Sweden, moral case deliberation (MCD), meaning ethical reflections or ethical rounds, are used for strengthening the nurses' competence and well-being[109,110,111]. With support from clinical nursing supervision, nurses can reflect on different situations and view these from a broader perspective[112,61] in order to be able to make ethical decisions and deal with the patient's desires and needs.

This study also shows that humor used on the patient's terms can constitute a way of handling ethical and existential issues or topics in a co-creative manner. Humor is often used as a "break in proceedings", allowing both the nurse and patient to cope with heavy and difficult aspects of end-of-life care through resting in "the spice of humor". Humor in healthcare settings is usually described as being dark[113] and researchers maintain that such dark humor has a protective function because it promotes the expression of emotions[114,115,116].

This study reveals that through co-creation nurses have the opportunity to provide for a good dying process and enable patients to live while dying, and promote hope and meaning at end of life from a deeper perspective. The nurse may, through co-creation, help the patient, for instance, by focusing on something else than self, including those who are left behind after the patient dies. Patients may experience difficult existential suffering at end of life because of unaddressed ethical or existential issues that they cannot find someone to talk to about these concerns. Boston, Bruce and Schreiber[117] also mention that difficult aspects in end-of-life in palliative care can be, e.g., existential suffering regarding how to understand and heal. Here the nurse, through co-creating, may establish a relationship with the patient and become more aware of the patient's outspoken needs and desires and enable possibilities for expressing them which potentially may alleviate the suffering.

The present study demonstrates that deep co-creative relationships are needed for nurses to "stepwise" come closer to and reach deeper into helping the patient handling ethical issues at end of life[118]. Important aspects for establishing this deep relationship with the patient are: trust, time, attentiveness, responsiveness, sensitiveness, closeness, humor and touch. Attentiveness and time are aspects that are also mentioned as important in the relationships between the nurses and the patients by Southall[119]. One can ask whether all nurses who care for dying persons at end of life have the ability or the time to create these deep relationships. Kaiser, Kohlen and Caine[120] state that nurses can have feelings of disgust when caring for a patient with, for example, open and difficult wounds due to cancer and at the same time be obligated to carefully protect the patient and relatives from feelings of disgust in palliative care. From an ethical perspective, this can be seen as a special issue and something that needs more attention and careful consideration in the future and shows how complex this care can be due to the intensive relationship-building with patients and their families that is essential in the field of palliative care and hospice care[120].

McSteen and Peden-McAlpine[92] state that end-of-life care and ethically difficult situations require a profound developed partnership between the patient and the nurse where the nurse acts as a guide, liaison, and supporter. However, focus should not only concern the nurses' abilities to be open, attentive and responsive and have a holistic view of patients and families in need of palliative care. Sandsdalen, Hov, Høye, Rystedt and Wilde-Larsson[121] found in a systematic mixed studies review-study that responsiveness for palliative care must permeate care in its entirety. This is needed to enable the promotion of the meaningful life that patients need, a need that distinctly manifests in palliative home care, and this responsiveness is required not only of healthcare personnel, but also of the care environment and the organization for palliative care.

Strengths and limitations

The results might have been different if the participant group had included, e.g., more male respondents. Consequently, this may represent a source of bias that may limit the generalizability and comparability of the results. This study is, however, reliable and includes a nuanced representation of the subject matter. Additionally, the interviews generated rich data on nurse's experiences of encountering and tackling ethical and existential issues through co-creation in palliative home care. From an ethical perspective, this study is defensible as the experiences related by the nurses can potentially be of help for others in developing a more profound understanding of co-creation in palliative home care. While interviews were used in this study, observation studies should be conducted in the future.

Conclusions

Ethical and existential issues related to end-of-life home care can be understood as an oscillation, with ups and downs between hope and despair. This difficulty can be managed by establishing deeper relationships through co-creation which thereby can provide the means for enhancing QOL for patients and patients' relatives in palliative home care. Future research should focus on co-creation from patients' perspectives.

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