Discussion Paper

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The feeling of being home when nearing end-of-life—the example of Norway: A discussion paper

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Abstract

Home is regarded as an important and safe place to be when nearing the end of life. However, for some, the home may be a place where people feel anxious and alone. The aim of this discussion paper is to reflect on the contextual and theoretical meaning of home. We will, based on a broader understanding of home, also suggest that home-deaths can take place both in a home-based care context and a facility-based care context, as the meaning of home belongs to the individual. We will end our discussion by concluding that the actions of care and nurses' attitudes are of vital importance, so that a feeling of home can be created for patients nearing the end of life, irrespective of their context.

Keywords

at-homeness, home-death, nursing, nursing facilities, palliative care

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Introduction

For most people worldwide, the significance of home seems to grow in importance as they get older.[1] When nearing the end of life, staying at home and dying there is preferred by the majority of the global population,[2,3] which is also the case in Norway.[4–6] An average of approximately 60% of the population name the home as their preferred place of death, yet there is also a great diversity.[2,7] In particular, socioeconomic aspects are considered less, and discrepancies are found in the views of the general public versus patients nearing the end of life.

Nevertheless, and despite a relatively high number of people preferring to spend their final days in their physical home, a low percentage of these may fulfil their wish.[5] In Norway, 13% of inhabitants died at home in 2013, of whom only 6% died at home due to a planned home-death.[8] Until 2021, these numbers remained approximately unchanged.[9] As for other Nordic countries, the number of home-deaths is slightly higher, particularly in Denmark.[10] To meet the wish to die at home, available and competent palliative home-based care in the municipality is a prerequisite for patients to feel safe at home.[10,11] This feeling of safety is often linked to achieving a home-death, as a quality indicator for palliative care[11–13] and the epitome of a 'good death'. On the contrary, a facility-based death promotes images of a technical, impersonal, and even inhumane death.[14,15] Studies have explored this phenomenon and present the low number of home-deaths as signs of failure.[5,8] However, questions concerning the physical home, as a judicial place of residence, and the substantial meaning of being or feeling at home are generally lacking in such research.

In accordance with the increased focus on the home as the preferred place of death, the context of home as a residence of care has also been increasingly emphasized. According to the World Health Organization,[16,17] more healthcare services should be transferred to primary healthcare and should be available where most people live, namely, in their homes. This requires easy access to support, as well as the development of a variety of choices regarding types of housing. First, staying at home implies staying in the house where one has lived for most of one's life, albeit complemented with home-care services – home-based care context – if necessary. Second, various forms of assisted living and specialized palliative care units – facility-based care context – are alternatives for housing in the municipality.[18] In spite of these different alternatives for housing, efforts to ensure equal access to healthcare services when nearing the end of life are challenged by geographical differences, particularly when depending on local healthcare structures, economic aspects, and healthcare resources.[19] Therefore, the low proportion of home deaths in Norway varies considerably between local communities.[5,8,20] Research implies that the likelihood of patients dying at home increases in municipalities with a population under 5000 while it decreases in municipalities close to a hospital.[5]

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In addition, being young, male, and married seems to increase the possibility of dying at home.[5,8] Despite the variety in the context of home concerning the place to stay for people nearing the end of life, the intentions of the government and the municipalities to increase the number of home-deaths appear to be good and well meant. However, they do not always match people's individual needs and preferences regarding the place of residence where they feel most at home.[21] We know that as people age, there is an increasing risk of morbidity and frailty, and managing life at home can be difficult.[22] Moreover, patients living with incurable illnesses, such as cancer, are defined as a vulnerable group of patients who need advanced home-care services when staying in their own home.[3] In such situations, to what extent may the meaning of home be affected? What might happen when the safe rhythm in life is becoming disturbed within the home-based care context?

Taking the above into account, it seems important that we, as both nurses and researchers, reflect upon the substantial meaning of 'home' and explore it as being more than the physical home for older, frail people or patients living with incurable illnesses. We believe that the meaning of home belongs to the individual; thus, our discussion will address how home-deaths can be possible in both a home-based care context and a facility-based care context. We put forward the need of a broader understanding, including both a contextual and theoretical perspective of home. Where the latter might add new and crucial perspectives to the wider debate concerning policies designed to support home-deaths as a success criterion for persons nearing the end of life.

Exploring the literature regarding the theoretical concept of home implies that 'home' is primarily considered a positive word, evoking positive feelings. Being home implies being in one's own place, where one feels secure and protected, and where privacy is respected. Home is regarded as the central point in our lives, a place that we as individuals cherish and rely on.[23] These images fit the context of the governmental presentation of the home and the way we have interpreted this concept for decades.[10] Moreover, identity, security, memories, and nurture are other words related to the notion of home. Such words indicate an affective bond between people and their homes, which relates to both the fundamental character of the home itself and the meaning people assign to it.[15,24] This bond between person and home is a common finding in studies related to the meaning of home. For example, Hilli and Erikson[25] claimed that being home entailed being at home in oneself. Fæø et al.[26] found that those living at home with dementia described an interdependency between their home and their lived life, while Molony[27] pointed to the home as a place of empowerment, mastery, and being in control.

Consequently, the above reveals that the concept of home has a much deeper meaning for us as individuals and as social beings, than simply being a place of residence. Martinsen and Kjerland[28] describe how the various aspects of being home are conditioned by rhythms, and how sickness and disease might disturb these rhythms. This applies to the rhythms and phases of life and death, the seasons of the year, the daily chores, and everything in between. Martinsen also stresses the importance of paying attention to these rhythms when providing care and support. Therefore, for those in need of healthcare services in their own home, it is crucial that this care is provided by people who are willing to understand the home-owner's individual rhythm of daily life, otherwise the patient's understanding of home will be distorted, as will his/her feeling of security. This perspective is consistent with that of Silverglow et al.,[21] who advocate that home-care services play a critical role in enabling frail, older individuals to feel safe at home. They point out that when older people maintain their independence, are able to influence everyday life, and have control in life, they are able to trust staff and, as such, have a feeling of at-homeness.[21] This concept can be identified as a sense of being metaphorically at home, while experiencing well-being[22,29] and also feeling safe, connected, and centered.[30] The concept of at-homeness is also emphasized by Hilli and Eriksson,[25] who view the home as embodying the ethos for caring, meaning that the home can be seen as an abstract room where the human being lives and interacts with others. In order for nurses to demonstrate that their trust is real and genuine, they should invite the patient into this room and establish a caring relationship. This viewpoint helps us understand how patients, who are in connection with their ethos and their self, and are able to feel at home, can experience at-homeness.[25] Hence, we argue that feelings of at-homeness or feeling at home, in the case of patients nearing the end of life, are experienced when their rhythms in life are being upheld and nurses show a genuine interest in each individual by establishing a caring relationship.

By contrast, even when patients prefer to be in their own home and receive home-care services, the atmosphere can be negative. Martinsen and Kjerland[28] show how nurses can either contribute to creating harmonious homes or further disrupt the rhythms of home when the support is not sufficiently adapted to what constitutes 'home' for the individual patient. According to Hilli and Eriksson, this can lead to feelings of homelessness.[25] A study by Hemberg et al.[31] presents similar results and highlights how frailty and vulnerability may lead to existential loneliness, which increases the chances of feeling homeless at home. Their study contributes to an interpretation of experiences of suffering from aloneness among older people receiving home care. In particular, a lack of interaction with others and few meaningful social activities in daily life led to the feeling of homelessness. Such relational connections in the home environment of patients receiving palliative care are defined as a complex matter.[32] This is especially the case when the home is converted into a place for care, a place to which the patient and family members generally have an emotional connectedness. Lindahl et al.[33] found that the space is experienced as both a home and a workstation, which constitutes tensions between the patient, the family, and nurses. Further, they stress the importance of retaining the physical character of a home, while integrating the elements crucial for a workplace. This can be understood by the symbolic view of the doorstep, a portray by Borch[34] who emphasizes the homes' symbolic, material, affective, and multivocal aspects. In particular, Broch highlights the doorstep that represents the boundary between the home and everything that is outside of the home. In a broader sense, she describes the

doorstep as being both a barrier and a protector of one's life, as well as a border between what is private and what is public. When patients need healthcare services in their own homes, their doorstep or barrier in life may lose its function as providing protection. As a nurse, it seems of importance to question whether the loss or compromise of this protective barrier can cause the patients to lose their feeling of being home. Regardless, we suggest that nurses need to know about and understand this symbolic boundary of what is considered private and public. In particular, acknowledging what nurtures the sense of meaningfulness and security in their lives, their feeling of being at home might be maintained despite receiving end-of-life care in their home.

If the concept of home has a much deeper meaning for us as individuals and as social beings than simply being a place of residence, how can we as nurses foster a feeling of home within a facility-based care context. This urges us to question whether a patient must be in his physical home to stay in homely surroundings. Dekkers[23] metaphorically describes the home as the 'patient's coming home'. On the one hand, this implies getting the patient back to his/her own physical home; however, on the other hand, it can also mean an attempt to create a new home for the patient, in which he or she feels at home both physically, bodily, and psychosocially. This relates to the viewpoint of Heidegger[35] and the notion of homelikeness, who emphasizes the meaning of home as being closely interrelated to the sense of self, the sense of being in the world, in a place where one feels cherished and protected. When being ill or feeling anxious, Heidegger described the opposite as 'being-unhomelike-in-the-world'. Acknowledging and exploring such notions can increase the understanding of how to interpret the feeling of being home and how we, as nurses, can contribute to this meaning of home.

Research supports our belief that home is more than your place of residence. For example, a study by Fæø et al. among home-dwelling individuals with dementia[26] maintains that the home they live in is not important by definition, but the role the home plays within a larger existential foundation is significant. For example, this could be freedom to continue habitual behavior, to enjoy everyday life, and to find satisfaction in the fundamental routines of life. Likewise, Staats et al.[36] found that the value of care was seen as more crucial than the physical accommodations for elderly women living with incurable cancer. Even when the women had a strong desire to spend their last days in familiar surroundings with their family, admittance to an institution could provide relief and may be necessary. In view of these references, one may suppose that the attention on improving end-of-life care should not only be restricted to facilitating the preferences of home-deaths but should also focus on the quality of end-of-life care in a facility-based care context.[6] When supporting patients requesting to die at home, maintaining the patients' existential being at home should be paid as much attention as the physical being at home. From this perspective, we may support the person dying at home, metaphorically, even in an institution, and may prevent them from dying homeless in their place of residence. Therefore, a holistic understanding of both social and individual characteristics, as well as the environment, such as the building and the interior design, will optimize the sense of home. Care should be tailored as much as possible to each individual, in order to feel as though they still matter and to ensure that they feel safe in a homelike environment. A study by Saarnio et al.[29] found that individuals who had made the choice to move when they were still capable to organize the move themselves, were influenced by the sense of at-homeness all through the move and afterwards. Therefore, time appears to be particularly valuable in relation to relocating and becoming attached to new places and new people. Besides time, rhythm also seems vital for the sense of home. A continuous creation of the home, according to the shifting needs and possibilities of life, is a view also shared by Martinsen and Kjerland,[28] who urge that nurses should focus on upholding the rhythm and a harmonious tone in a patient's room, wherever this physical room is situated. Like Martinsen and Kjerland, we acknowledge the importance of being attentive to a patient's rhythms when the patient's home stops being a home, and to 'tune in' to these rhythms when caring for patients, in order to maintain their feeling of being home despite their illness.

We end by concluding that the national intention of policymakers and municipalities is to increase the number of home-deaths as well as to ensure that those in need of end-of-life care are able to remain in homely surroundings. The known incongruency among the desired and actual place of death and the importance of the feeling of being at home for patients nearing the end of life are vital factors to consider if these intentions are to be fulfilled. However, for clinical nurses as well as for the educational programs for nursing students, this has several implications. The first is the need to raise the public and professional awareness and knowledge base of the meaning of home as an important point in any discussions about home-deaths. In addition, nurses should follow the patient's and their family's rhythm in life to be able to create a more individual approach than is the case in today's healthcare services. To achieve such an individual approach in care, the ethical training of nurses, as well as of nursing students' educational programs, need to promote reflections and theoretical knowledge of what constitutes home for patients nearing the end of life. The actions of care and nurses' attitudes are of vital importance so that a feeling of home can be created for patients nearing the end of life, irrespective of their context. Thus, we, as nurses, need to address this issue with patients and their families, so that the feeling of being at home can be adapted to the actual context of residence while taking the notion of theoretical understandings of concepts such as doorsteps, time, and rhythm into account. Being in a safe and caring environment is essential for all human beings when nearing the end of life, and deciding where to end your life is not something that can be determined by policies or politicians alone.

Conflicting of interest

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