Received: 23 November 2021 | Accepted: 12 March 2022

DOI: 10.1111/scs.13076

EMPIRICAL STUDIES

´You are not yourself anymore´: The place of the ethical demand in a practical home care context

Lena M. Jakobsen RN, Assistant Professor[1] | **Ranveig Lind RN, CCN, PhD, Associate Professor**[2]

[1]Department of Health and Care Sciences, Faculty of Health Sciences, UiT The Arctic University of Norway, Tromso, Norway

[2]Department of Health and Care Sciences, UiT The Arctic University of Norway and Research Nurse at Intensive Care Unit, University Hospital of North Norway, Tromso, Norway

Correspondence
Lena M. Jakobsen, Department of Health and Care Sciences, Faculty of Health Sciences, UiT The Arctic University of Norway, Tromso, Norway.
Email: lena.m.jakobsen@uit.no

Present address
Lena M. Jakobsen, Faculty of Nursing and Health Science, Nord University, Bodø, Norway

Funding information
No funding.

Abstract

The study's rationale: The Scandinavian nursing tradition is based on caring science as the ontological backdrop. This means that meeting the patient with openness and respect is essential in care. The experiences of an elderly woman receiving home nursing provide insight into a world many healthcare workers need to understand; meaning what is important in the encounter with the fragile old patient whose voice is not often heard in the society nor in research. Caring science with its person-oriented care clashes with the New Public Management's ideal for municipal health care in Norway, at the expense of the needs of the elderly patients.

Aims and objectives: This article aims to express the phenomenon of lived experience as presented by an elderly woman, more specifically her experience of care in home nursing run according to the principles of new public management.

Methodological design: The article is based on an empirical narrative in the form of an individual qualitative research interview.

Findings: The patient has needs that cannot be defined without the nurse having an ethical understanding of what may be important in the patient´s lifeworld. The core findings are: *Feeling disregarded as a human being, Broken agreements, Surrendering in anonymous relationships and Each day is a different day with altered needs.*

Conclusion: The system of New Public Management sets a strain on the time at hand for the nurse to develop a relationship that acknowledges and supports the patient´s life courage. The ethical demand and care ethics can explain how the patient´s will to live can be preserved, and provide knowledge of how the caregiver can best attend to the patient's ways of expressing what is important to her. Nevertheless, within the time at disposal, the nurse has an opportunity to either marginalize or strengthen the old person´s dignity.

KEYWORDS

caring ethics, dependency, dignity, disregarded, elderly, municipality, narrative, new public management, vulnerability

This is an open access article under the terms of the Creative Commons Attribution License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited.
© 2022 The Authors. *Scandinavian Journal of Caring Sciences* published by John Wiley & Sons Ltd on behalf of Nordic College of Caring Science.

INTRODUCTION

The expansion of New Public Management (NPM) as an ideology in the Norwegian welfare state in the last four decades is due to an idea that the public services and in particular health care should be managed like the private business sector with marked organized structures. The main goal is cost efficiency and public service quality enhancement [1]. In the light of this, several reforms have been introduced where NPM is the leading form of governance. The foremost reform is the Coordination reform implemented in 2012 in Norway as an answer to the increasing complexity in the health services. The reform led to elderly patients now being discharged from hospitals to municipal healthcare services while treatment is still ongoing in order for patient care being administered at the lowest cost-level [2]. This means subjecting the vulnerable oldest patients to rapid transitions between healthcare organisations [3], and is ideologically rooted in the principle of individual autonomy, aiming to strengthen the freedom of choice and the individual rights of each person as an actor in their own life [4]. Vabø (2006) describes how “contractual arrangements implemented in the name of the consumer run counter to established practices based on personal trust and continuous dialogue on needs” [4].

In the public health system, the patient is referred to in Norwegian as *the user*. This is linked to economic efficiency and business management thinking and culture [4]. Such a self-serving view of human capacity may stand in stark contrast to the need for health care of sick and fragile people, and it requires special attention from the nurse to care for persons who cannot communicate their needs [5–7]. The time available for the nurse to build the important relational contact with the patient is increasingly limited, despite many old patients having complex problems [8] and needing to feel valued [9].

The volume and content of home care to be provided to the patient are decided by care managers from the municipal purchaser unit [10]. Vabø et al. (2012) claim that written instructions that tell the nurse what kind of help the patient needs do not work for elderly frail patients whose care needs may abruptly change [5]. Nurses have been deprived of the opportunity to assess the situation and take immediate care measures when the help to be provided is predefined [5]. In contrast to the NPM ideology stands the ideal of nursing care, which is based on a relational understanding that we as individuals are responsible for each other and have an extra responsibility for the weakest among us [11].

This caring philosophy is well known in the Scandinavian countries, and the Danish theologian and philosopher K. E. Løgstrup has inspired Norwegian and Danish nursing for more than 30 years. His approach to how we as humans touches each other´s lives is expressed in the ethical demand. The ethical demand sets the standard for what it means to relate to other people. He maintains that no encounters are of no significance. The ethical demand clarifies the nurse´s responsibility to the patient in a relationship where the nurse has the power to accept the appeal (or demand) from the patient, or ignore it [12]. The Danish Professor of Nursing C. Delmar states that caring morality is a prerequisite for good nursing, where compassion and love are the ethical foundations [13]. Delmar approaches the morality of care and life phenomena by expecting the nurse to be accountable for acquiring the knowledge necessary to understand the needs of the patient, regardless of whether these are physical or existential needs [14]. The patient-nurse relationship is built on mutual respect and trust, making the caring philosophy also a relational philosophy that contrasts with an individual and liberalist philosophy of life [15]. In reality, we are fundamentally and unconditionally dependent on each other [11].

Delmar explains that care is expressed in the way morality is present in what is said and done. In relationships, power is created, and power must be shaped and managed to enable trust to be maintained. The morality of care is to aim to heal without offending. It is to maintain the dignity of, and be attentive to, patients in order to enable them to live richer lives. The morality of care is to attend to and act on the patient´s demand for attention to expressed needs. This means that care will naturally follow when the nurse is not afraid to gain the patient´s trust through commitment and presence [15].

The aim of this paper is to present and discuss life phenomena narrated by an elderly woman receiving home care nursing within a healthcare system of pre-decided services.

METHOD

Design

The interview this article is based on originated from a larger qualitative study which explored the thoughts of elderly home care patients, based on an open interview process, asking what they needed their nurse to know to provide good care. From the larger project, this interview with an elderly woman in her mid-90s stood out as an “example narrative” [16] where the respondent organized her replies into longer stories about receiving nursing care in her home. The ways in which the respondent recapitulated what had happened and made a point of the inherent morality of the care provided inspired us to retell and analyse her personal narrative. In presenting her thoughts

and feelings, the woman wisely said that she made this effort because she wanted to help healthcare workers understand how they could provide better care.

Stories as a narrative method

The goal of describing lived experience is to address things we do not understand but try to understand through somebody else's experiences [17]. Although we can never truly understand the other person, we can accept our interrelationship as human beings, and through this perception make the other person's forms of expression meaningful to ourselves [16]. The narrative method is characterized by having a specific structure based on a plot. This is explained as six steps comprising an abstract, orientation, complicating action, evaluation, resolution and coda. By using this approach the unique meaning of the story becomes clear for the teller and the listener [18].

Storytelling as a research method is relatively new in an academic context. Here, reality and how we perceive and experience it is actively being constructed by ourselves [19]. Narrative inquiry is the approach closer to academic research, described as studying stories told by a person and retelling the stories with the intent to explore and uncover the hidden meanings underlying the stories [16,20]. Stories are like people, they change as time passes, and our understanding of the story we tell gives us a deeper understanding of the meaning behind it. Whoever listens to and accepts the story is a participant through the retelling that takes place afterwards [21]. The following definition of narrative inquiry has been provided by Connely and Clandinin: ´People shape their daily lives by stories of who they and others are and as they interpret their past in terms of these stories. Story, in the current idiom, is a portal through which a person enters the world and by which their experience of the world is interpreted and made personally meaningful´ [22].

Sample

The recruitment to the study was made by healthcare personnel when the old woman was admitted to a rehabilitation facility. After being discharged to home, her daughter called the interviewer and set the interview time and date on behalf of her mother.

The interview

Asking open questions during a conversation elicits a story that is the person´s own and minimally influenced by the person who receives it [19], but stories are still always communicated in a dialogue [23]. The conversation with the elderly woman took place in her home. She was informed by phone about the topic for the interview and was explained the confidentiality rules and opportunity to withdraw. This was repeated at the start of the interview when she also signed a written consent to participate. The woman was comfortably seated in a good chair during the conversation, with a soft drink at hand, while the interviewer was seated on the sofa opposite her.

After some initial everyday small talk, an open interview question was asked: *Could you share your everyday experiences of receiving nursing care and help in your home?* This was followed by: *What do you find important to you in this context?* These questions led to a longer coherent narrative in which the interviewer showed empathy through body language and acknowledging the woman´s statements. The interviewer was attentive to her utterances and paid special attention to signs of tiredness during the interview. Towards the end of the story, prepared and spontaneous sub-questions led to elaboration of what had already been told. After almost 1 h of talking, she closed her telling by acclaiming that now there was nothing left to add to her story. Following some small talk, the interviewer asked her again if she had something more to tell and then invited her to make contact if needed.

The story was recorded with a digital audio recorder before being transcribed by LJ; the recording lasted for 50 min.

Analysis

We performed a dialogical narrative analysis of this single interview. A dialogical narrative analysis understands stories as representations of lives, bringing the past to the present, illuminating or foreseeing a possible future. Stories are told within dialogues, and are recipient designed, and thus also co-constructed by the responses from the listener [24]. In this interview, the story was told to an experienced nurse, which assured the storyteller that specific care aspects would be understood.

When starting the analysis, we considered the story as a whole. Then throughout the analysis, we asked the text three main questions: Why is the story told in that way? What is at stake for the person? and How does the storyteller seek to maintain her worth and identity? A dialogical narrative approach imagines life as primarily a condition of vulnerability [24], which was useful in our attempt to approach the core of the narrative.

After re-reading the transcribed text several times, the text was subject to analysis inspired by Riessman. We started the analysis by dividing the text into segments

where the underlying meaning in each segment was identified. At this stage, the text is ′cleaned′, making it easier to encode the different meanings into categories and themes. Riessman explains how a text becomes a narrative by how events are *selected, organized, put into context and considered to be meaningful to the reader* [25].

Ethical considerations

Elderly fragile people are considered vulnerable and can experience rapid changes in their condition. The interviewer was an experienced nurse and paid extra attention to this. The woman was given oral and written information about the study, including the possibility to withdraw at any time. The study was approved by the NSD (reference number 60960).

FINDINGS

This is a narrative of a woman in her mid-90s, who lives alone in a house in a small town in Norway. She has until recently managed her daily life with some help from her family who lives many miles away. A fall resulting in a broken hip with some additional complications has now made her dependent on home care services for cooking and everyday care.

The analysis of the text identified four themes. All of them made an impact on us and revealed the woman′s voice through the text. The findings are presented through these themes: *Feeling disregarded as a human being*, *Broken agreements, Surrendering in anonymous relationships* and *Each day is a different day with altered needs*.

Feeling disregarded as a human being

It is important to feel somewhat independent in everyday activities. She has felt strong and independent all her life and is now experiencing the transformation from being independent to having to receive help. She reveals that this is a difficult change for her. She describes it as *not being myself anymore*. She says she feels she has become someone else, someone who requires care but who must manage daily life alone.

> *When you first get in that situation, you get frustrated and full of despair. You're used to being independent and managing yourself, and suddenly you don′t get anything done. So, it′s not a situation you are happy about. It′s the adjustment as well, from being a fit well-functioning person who has cared for herself most of the time, to suddenly not being yourself anymore.*

The woman reports often feeling down and full of despair, but at the same time, she finds that many nurses are nice and show that they listen to her and care about her. They sometimes take the time to chat and sit down and provide a little extra help such as watering a pot plant that the woman notices has begun to wither. Other nurses, however, are perceived as sharp or edgy and these nurses make her feel small. These nurses say they are not allowed to water the plant, because it is not in the instructions.

> *For example, I asked one of the nurses to look at two pot plants in the window there and give them some water: 'I′m not allowed to!' she answered. And another time there was something similar, just a few small things: 'That′s not in the instructions!' So, you get a smack in the face. It′s so indescribable and means so much if someone just says: 'Yes of course I can do it!'. Some do of course, but the day is kind of... you're vulnerable in this situation... it hurts so much...*

The woman felt hurt by the nurse's refusal to water the plant. She understood that the nurse did not realize how important it was to her.

> *I feel like I′m not that important anymore. It′s just the old hag who can now just take what she gets, like a withered flower. It′s all about feelings, you know. It′s probably the fact that you've fallen out of society, then you must accept for yourself - you get what you get...*

Broken agreements

The woman says she becomes frustrated when nurses come to see her at an unscheduled time. She has informed them about when her daughter will be visiting her. She does not need help when her family is present.

> *And about the fact that they don′t keep up with messages. There are messages they ignore or that just get lost. A lot of times, they′re here completely unnecessarily. Like today, someone comes and wakes me up in the morning even*

though I have a visit from my family here and should not be on their worklist.

The woman says she feels guilty when the nurses waste their precious time visiting her when they could have helped someone else instead. She is upset because this means they disregard instructions about patients, so how can she trust them to pay attention to important information from, for example, her GP? Or if something changes in her condition that requires special attention?

Surrendering in anonymous relationships

It was important to the woman to be able to remember the names of the nurses who come to her house. She says that by knowing and using their names, she shows the nurses respect and courtesy. In return, they address her by her name. She expresses the need to have a good relationship with the nurses. She loves the one who is her primary nurse and had a good dialogue with her. Then all of a sudden, she learns that she will no longer come. Instead, there is a new nurse.

Now I just got a new primary, and I don't like it. They could have asked me, are you happy to get this one or that one? Imagine if there´s a person you can´t stand? Then you should be able to ask for someone else! So now I´ve got a new primary and secondary nurse but neither of them was up to date on my situation. They just came and rang the doorbell and wanted to make me tell... it´s not easy, you know...

Despite her efforts to remember the names, she no longer knows the healthcare workers' names and occupations, because there are just too many of them visiting her home. She has no idea who is a nurse, assistant nurse or assistant. A healthcare worker is a professional title in Norway, which she does not understand: *When they come to my home, I don´t know who they are if they don´t have a name tag. I don´t know what they are... care worker - what does it even mean? I don´t know who they are anymore.*

Each day is a different day with altered needs

She spends considerable time just managing her daily life on her own, and she now realizes that she needs more help to avoid wearing herself out completely. *It takes so much effort to get some clothes on, that I have somehow... well, I have no more energy left to go on the rest of the day.* The old woman spends all her energy on the morning routine, while the rest of the day she spends just sitting in a chair without energy to move. When she feels every day as a burden, she becomes depressed.

If I get good practical help, it won't be so overwhelming. Because, when every step you take is exhausting, then your energy soon gets drained and then your mood goes down. And I do get into a dark mood often, sitting here with no energy to get up.

The old woman needs to experience some self-sufficiency, also because she does not want to burden the home care nurses. It is important for her that she can claim some independence, even though it cost her the energy of the day.

DISCUSSION

This study aimed to emphasize the woman's experience of needing home care nursing. It will be discussed in the tradition of caring science, and by contrasting lived experience as a contradiction to the ideology of new public management.

The voice of a single woman can have an impact, reaching out and enhancing care practices. The woman had a clear voice and a mission: she wanted the nurses to understand what was important not just to her, but for all frail elderly people in the hands of nurses. The discussion will be rooted in Løgstrup´s "The Ethical Demand" and Delmar's work on the ethical demand in caring science.

Dignity measured in terms of time

Dignity is to be free to be who you are, even if you receive help to deal with everyday life. Providing help without offending means maintaining the patient´s dignity [15]. Care provision requires calm and patience in order to understand and not to abuse [26]. In Norway, home nursing is a municipal service. The assessment of the patient´s needs is made by a team of professional care managers in a local office. Based on the care managers' evaluation, the tasks and the time needed with the patient are calculated, and a concrete decision is made [10]. The resources available for home care nurses are considered inadequate to provide elderly patients with care that preserves dignity [27]. We ask ourselves how the nurse-patient relationship is affected by the written instructions based on the care managers' decision, rather than the patient´s own assessment of what is

important. Delmar encourages nurses to pay attention to how life-enriching needs can differ from rational needs. If a nurse meets an elderly person with an attitude of only wanting to meet the person's physical needs, as in this narrative, the nurse will not pay attention to the importance of the person´s will to live [15].

The professor of nursing and philosophy K. Martinsen explains how people in the Western world have become the owners of time, which is understood in terms of money and economics. The stopwatch organizes and disciplines. The watch has become a symbol and measuring instrument for efficiency and production [28], and the focus has shifted from individual- and person-oriented care towards task-oriented care [29]. The elderly woman explains this in her own words when she feels disregarded as a human being, having to take what she gets, like a withered flower in the window.

Nurses who feel able to influence how they work can strengthen the patient´s self-esteem [30] and perhaps help the patient to understand herself in a context where she still perceives herself as part of society [31]. Recognising the patient´s vulnerability is a pathway to strengthening hope and courage [14]. For the nurse, this sometimes means disobeying the time and tasks allotted to the patient in the written instructions [32]. A caring moral attitude assumes that the nurse is courageous and attentive to individual situations that may arise [14]. Understanding the lifeworld of the patient may sound like a philosophical and distant way of explaining the significance of listening to what the patient regards as important. If one does not try to understand the patient´s perspective, one will also not be fully present in the nurse-patient encounter. The nurse will then inflict unnecessary suffering on the patient instead of relief [33]. Thoughtful communication is important to develop a good relationship and try to understand what is important for the patient [34]. The nurse´s condescending tone in the dialogue is an example of morally irresponsible nursing [15]. The asymmetry of the nurse-patient relationship can constrain or enhance the patient´s autonomy, and a dismissive attitude will darken the patient´s world. Trust is a key aspect of any relationship. We expect the other to accept the trust shown and respond to it. The sensitivity of the nurse in being able to understand the various situations that arise requires attentive presence [35]. Although the available time with the patient may be perceived as too short [36], the nurse´s attention to the needs of the moment can clearly make the patient´s day good or bad [37].

The ethical demand places the power in the encounter in the nurse's hands, the power to choose an ethical approach to the patient, to be caring, or to be dismissive. Trust must develop in such a way that it can be maintained in the relationship [37,38]. The elderly woman expresses a sense of powerlessness. A feeling of vulnerability makes it difficult to maintain trust. Vulnerability increases when trust is challenged [37].

Trusting the unknown

Care means building relationships that promote joy of life [15]. The many meetings that take place in one´s life consist of both good and bad encounters, and good nurse-patient interaction is appreciated by elderly patients [29,39]. The good encounters will provide more autonomy, while the bad ones will limit it [40]. In the meeting with the other, our identity and dignity can be strengthened, along with our well-being [41]. A home care nurse is a guest in the patient´s home, but unintentionally the patient becomes a guest within her own four walls [42].

New healthcare workers are perceived as representing a lack of continuity making it challenging to establish a close relationship between patient and caregiver [36,43], especially if the caregiver is not fully informed about the patient´s situation [44]. Relationships that are forced upon the patient, as a patient-nurse relationship is, can be experienced as healing but may equally well be devastating [42]. A good patient-nurse relationship involves equitable and empathic communication [34], and nurses use all their knowledge in the dialogue and interaction with the patient to be able to achieve a healing and therapeutic relationship [14].

Fixed care – a menace for the elderly patient

Nurses learn how important it is to work to help patients to retain as many functions as possible, by encouraging self-activity in everyday life. This also involves a responsibility to understand what values matter for the patient and prioritize these [45,46]. Not being able to employ autonomy can have a negative impact when in need of help, and damage the patient´s self-image and sense of dignity [47]. Delmar says that it is a form of neglect to equate the autonomy of a healthy person with that of a sick person and expect the latter to have the resources and capacity to take responsibility for her situation as if she was functionally healthy. That would leave her without the care and protection she needs [15].

Naturally, ageing reduces bodily functions. The experience of increased bodily constraints can give a sense of hopelessness and loss of meaning [48]. When the body changes, one´s experience of the world also changes, and one can feel alienated and alone with less motivation to

live [49]. Living alone can reinforce this feeling, especially when coupled with adversity [50]. Being able to maintain a certain level of self-care despite the need for help allows the woman to preserve her dignity [49,51]. However, there are also days when the nurse does not see the patient´s needs and expects her to practice self-care, which is then a burden for the patient. The patient then somehow becomes invisible [52]. The nurse must assess each situation individually; sometimes the patient does not have the capacity, while at other times she only needs a little support [15]. Patients who need specialized medical care and assistance to meet their immediate needs receive more attention from nurses than elderly ones who need help in coping with everyday life at home. This means that care built on relationships must give way to task-oriented work [53]. Delmar highlights the importance of a close relationship with the person who is chronically ill, which applies to many elderly patients [54].

CONCLUSION

This woman´s story is a strong voice that needed to be heard. These were her lived experiences and her lifeworld phenomena of trust, hope and joy. The most important factor for her is the relational, to be seen and respected by the one who comes to help her. She wishes to be acknowledged as a person who matters because she exists, and because she has also been young and busy, just like the nurses. Care and respect reveal themselves in the details, the little things, such as watering the thirsty pot plant in the window. This is an example of complying with the ethical demand.

Strengths and limitations

It could be considered a limitation that the interview was originally conducted for another purpose than as a single narrative provided by an elderly patient. Nevertheless, we have argued for the validity that one person´s voice of experience can give a significant impact, as history shows us. On the other hand, if there had been several participants, other themes might have arisen in the analysis, giving space to different phenomena.

ACKNOWLEDGEMENTS

The authors are eternally grateful to the woman for telling her story with its important impact.

CONFLICT OF INTEREST

None.

AUTHOR CONTRIBUTIONS

LJ conducted the interview and drafted the manuscript; RL has contributed to all parts of the writing and analysis.

ETHICAL APPROVAL

Norwegian centre for research data, project number 60960.

ORCID

Lena M. Jakobsen https://orcid.org/0000-0002-3659-7895
Ranveig Lind https://orcid.org/0000-0003-3513-9419

REFERENCES

1. Strømmen-Bakthiar ATK. Introduction: A farewell to new public management? 2021 07.01.2021. In: Strømmen-Bakthiar A, Timoshenko K, editors. Revisiting New Public Management and its effects- Experiences from a Norwegian context [Internet]. New York: Waxmann Verlag. p. 9–18.
2. Gautun H, Syse A. Earlier hospital discharge: a challenge for Norwegian municipalities. Nord J Soc Res. 2017;8. https://doi.org/10.7577/njsr.2204
3. Hestevik CH, Molin M, Debesay J, Bergland A, Bye A. Older persons' experiences of adapting to daily life at home after hospital discharge: a qualitative metasummary. BMC Health Serv Res. 2019;19(1):224.
4. Vabø M. Caring for people or caring for proxy consumers? Eur Soc. 2006;8(3):403–22.
5. Vabø M. Norwegian home care in transition–heading for accountability, off-loading responsibilities. Health Soc Care Community. 2012;20(3):283–91.
6. Waerness K. The rationality of caring. Econ Ind Democr. 1984;5(2):185–211.
7. Szebehely M, Meagher G. Nordic eldercare–weak universalism becoming weaker? J Eur Soc Policy. 2018;28(3):294–308.
8. Fjørtoft AK, Oksholm T, Førland O, Delmar C, Alvsvåg H. Balancing contradictory requirements in homecare nursing—A discourse analysis. Nurs Open. 2020;7(4):1011–9.
9. Hauge S, Kirkevold M. Variations in older persons' descriptions of the burden of loneliness. Scand J Caring Sci. 2012;26(3):553–60.
10. Tønnessen S, Ursin G, Brinchmann BS. Care-managers' professional choices: ethical dilemmas and conflicting expectations. BMC Health Serv Res. 2017;17(1):630.
11. Martinsen K. Løgstrup & sygeplejen (Logstrup and nursing). Aarhus: Klim; 2012.
12. Løgstrup KE. Translated as The ethical demand, Bjørn Rabjerg, Robert Stern, (trans). Oxford: Oxford University Press; 2020 (1956).
13. Delmar C. Scandinavian caring science. In: Rosa W, Horton-Deutsch S, Watson J, editors. A Handbook for Caring Science: Expanding the Paradigm. Springer Publishing Company; 2018: p. 461–74.
14. Delmar C. Beyond the drive to satisfy needs: in the context of health care. Med Health Care Philos. 2013;16(2):141–9.
15. Delmar C. Omsorg og ansvar som to sider af samme sag (Caring and responsebility as two sides of one story). Tidsskrift for Omsorgsforskning. 2018;4(3):322–9.

16. Riessman CK. Narrative Analysis, Vol. 30. Newbury Park, Calif: Sage; 1993.
17. James D, Komnenich P. Dilthey's philosophy and methodology of hermeneutics: an approach and contribution to nursing science. Nurs Philos. 2021;22(3):e12353.
18. Labov WWJ. Narrative analysis: oral versions of personal experience. J Narrat Life Hist. 1967/1997;7(1–4):3–39.
19. Holloway I, Freshwater D. Narrative Research in Nursing. Oxford, UK: John Wiley & Sons; 2009.
20. Bleakley A. Stories as data, data as stories: making sense of narrative inquiry in clinical education*. Med Educ. 2005;39(5):534–40.
21. Caine V, Estefan A, Clandinin DJ. A return to methodological commitment: reflections on narrative inquiry. Scand J Educ Res. 2013;57(6):574–86.
22. Connely FM, Clandinin DJ. Narrative inquiry. In: Green JCG, Elmore P, editors. Handbook of Complementary Methods in Education Research. Mahwa, NJ: Lawrence Erlbaum; 2006. p. 375–85.
23. Frank A. Practicing dialogical narrative analysis. In: Holstein JA, Bubrium JF, editors. Varieties of Narrative Analysis. Thousand Oaks, CA: SAGE publications, Inc; 2012; 33–52.
24. Frank AW. Letting Stories Breathe: A Socio-Narratology. Chicago and London: University of Chicago Press; 2010.
25. Riessman CK. Narrative Methods for the Human Sciences. Los Angeles: Sage Publications; 2008.
26. Martinsen K. Øyet og kallet. (The Eye and the Vocation). . 2nd ed. Bergen: Fagbokforlaget; 2002.
27. Slettebø Å, Kirkevold M, Andersen B, Pedersen R, Halvorsen K, Nordhaug M, et al. Clinical prioritizations and contextual constraints in nursing homes – a qualitative study. Scand J Caring Sci. 2010;24(3):533–40.
28. Den MK. øknomiske tidsforståelsen, og tiden i helsevesenets rom (The economic understanding of time, and the time in the health care system's space). In: Øye C, Øvre Sørensen N, Martinsen K, editors. Å tenke med Foucault (Thinking with Foucault). Bergen: Fagbokforl; 2018.
29. Strandås M, Wackerhausen S, Bondas T. The nurse–patient relationship in the New Public Management era, in public home care: a focused ethnography. J Adv Nurs. 2019;75(2):400–11.
30. Spence laschinger HK, Gilbert S, Smith LM, Leslie K. Towards a comprehensive theory of nurse/patient empowerment: applying Kanter's empowerment theory to patient care. J Nurs Manag. 2010;18(1):4–13.
31. Pickard S. Health, illness and frailty in old age: a phenomenological exploration. J Aging Studies. 2018;47:24–31.
32. Strandås M, Wackerhausen S, Bondas T. Gaming the system to care for patients: a focused ethnography in Norwegian public home care. BMC Health Serv Res. 2019;19(1):121.
33. Svanström R, Sundler AJ, Berglund M, Westin L. Suffering caused by care—elderly patients' experiences in community care. Int J Qual Stud Health Well-being. 2013;8(1):20603.
34. Höglander J, Eklund JH, Eide H, Holmström IK, Sundler AJ. Registered Nurses' and nurse assistants' responses to older persons' expressions of emotional needs in home care. J Adv Nurs. 2017;73(12):2923–32.
35. Åberg C, Berglund M, Hallgren J, Gillsjö C. Older persons' experiences of reflective STRENGTH-giving dialogues – 'It's a push to move forward'. Scand J Caring Sci. 2021;35(3):779–87.
36. Ernsth Bravell M, Bennich M, Walfridsson C. "In August, I counted 24 different names": Swedish older adults' experiences of home care. J Appl Gerontol. 2021;40(9):1020–8.
37. Delmar C. The excesses of care: a matter of understanding the asymmetry of power. Nurs Philos. 2012;13(4):236–43.
38. Tarlier DS. Beyond caring: the moral and ethical bases of responsive nurse–patient relationships. Nurs Philos. 2004;5(3):230–41.
39. Claesson M, Josefsson K, Jonasson L-L. 'My registered nurse': older people's experiences of registered nurses' leadership close to them in community home care in Sweden. Int J Older People Nurs. 2021;16(5):e12399.
40. Delmar C. A call for phronesis in caring ethics. In: Johns DC, Christopher J, editors. The Good, the Wise and the Right Clinical Nursing Practice. 1st. edition 2008. 1.st edition ed. Denmark: Aalborg Hospital, Århus University Hospital, Charlotte Delmar, Aalborg hospital Science and Innovation Center, Forskningens Hus, Sdr. Skovvej 15, 9000 Aalborg; 2008. p. 19–24.
41. Sæteren B, Nåden D. Dignity: An Essential Foundation for Promoting Health and Well-Being. In: Haugan G, Eriksson M, editors. Health Promotion in Health Care-Vital Theories and Research. Switzerland: Springer Nature Switzerland AG; 2021. p. 71.
42. Jarling A, Rydström I, Ernsth-Bravell M, Nyström M, Dalheim-Englund AC. Becoming a guest in your own home: home care in Sweden from the perspective of older people with multimorbidities. Int J Older People Nurs. 2018;13(3):e12194.
43. Westerberg K, Hjelte J, Josefsson S. Understanding eldercare users' views on quality of care and strategies for dealing with problems in Swedish home help services. Health Soc Care Community. 2017;25(2):621–9.
44. Gjevjon ELR. Kontinuitet i hjemmesykepleien–vanskelige vilkår, men gode muligheter (Continuity in home care- difficult conditions, but good opportunities). Tidsskrift for Omsorgsforskning. 2015;1(1):18–26.
45. Sundler AJ, Eide H, van Dulmen S, Holmström IK. Communicative challenges in the home care of older persons - a qualitative exploration. J Adv Nurs. 2016;72(10):2435–44.
46. Hupkens S, Goumans M, Derkx P, Oldersma A, Schutter T, Machielse A. Meaning in life of older adults in daily care: a qualitative analysis of participant observations of home nursing visits. J Adv Nurs. 2019;75(8):1732–40.
47. Fox BM. Looking behind the fear of becoming a burden. HEC Forum. 2021;33(4):401–14.
48. Sjöberg M, Beck I, Rasmussen BH, Edberg A-K. Being disconnected from life: meanings of existential loneliness as narrated by frail older people. Aging Ment Health. 2018;22(10):1357–64.
49. Matthiesen HN, Delmar C. Trøst og livstruende sygdom – en differentieret forståelse af betydningsfulde relationer (comfort and life-threatening illness- a differentiated understanding of meaningful relationships). Nordisk Sygeplejeforskning. 2016;6(3):233–46.
50. Kitzmüller G, Clancy A, Vaismoradi M, Wegener C, Bondas T. "Trapped in an Empty Waiting Room"—The existential human core of loneliness in old age: a meta-synthesis. Qual Health Res. 2018;28:213–30.
51. Witsø AE, Vik K, Ytterhus B. Participation in older home care recipients: a value-based process. Act Adapt Aging. 2012;36(4):297–316.

52. Clancy A, Simonsen N, Lind J, Liveng A, Johannessen A. The meaning of dignity for older adults: a meta-synthesis. Nurs Ethics. 2021;28(6):878–94.
53. Fjørtoft A-K, Oksholm T, Delmar C, Førland O, Alvsvåg H. Home-care nurses' distinctive work: a discourse analysis of what takes precedence in changing healthcare services. Nurs Inq. 2021;28(1):e12375.
54. Delmar C. Nære relationers indvirkning på livsmodet (Close relation´s impact on life-courage). Nord Magazine Health Res. 2019;15(2):14-undefined.

How to cite this article: Jakobsen LM, Lind R. ´You are not yourself anymore´: The place of the ethical demand in a practical home care context. Scand J Caring Sci. 2022;00:1–9. https://doi.org/10.1111/scs.13076