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An Autoethnography on Being the Daughter of a Frail, Sick Mother in Transitional Care

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ABSTRACT

The article reflects on and explores a daughter's experience of being the relative to a frail, sick elderly mother in Norway. Recent reforms of the Norwegian healthcare services have had a major impact on the relationship between patients, their families and healthcare workers. The daughter's experiences elucidate the failure of the primary healthcare service to interact with the specialist health service and the patients' family. The article has a qualitative design and is based on one of the authors' autoethnographic accounts. The researchers are inspired by collaborative autoethnography (CAE). The co-authors reflect on and explore the daughter's experiences in order to increase the understanding of the interplay between personal and experiential aspects on the one hand and the social, cultural and political context on the other. The article is evocative and analytical, and investigates critically the ways in which system routines, procedures and practices restrict the opportunities for real user involvement and partnership. We address frail older people in transition between various levels of the health service and explore the opportunities of the relative to voice their expectations for user participation in nursing care.

KEYWORDS

Autoethnography; relative; frail elderly; transitions; health care; healthcare services/system; collaboration; palliative care

Introduction

Norway has a public healthcare system, with hospital services funded by the central government and community services (nursing homes and home care) funded by the local government. Basic palliative care (PC) is provided in hospital wards, nursing homes, and municipal home care services as an integrated part of general patient care. Specialist PC is provided by hospital-based, ambulatory PC teams serving hospital wards and community services, in designated hospital inpatient units, and in designated units or beds in nursing homes (Sommerbakk et al. 2016). Norway is by WHO (2014, 39) named as a country where hospice-PC services are at a stage of advanced integration into mainstream service provision. Although frail older people with more than one chronic disease may

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share the experiences of patients who need palliative care, this patient group is not given priority and the same access to PC (Meld.St.24 2019–2020).

In 2012 Norway implemented a coordination reform in the healthcare service to achieve coordinated care and treatment, which is especially crucial for the palliative care of frail older people (NOU 2017:16, 2017). Still insufficient coordination between the healthcare service levels continues to be documented (Haukelien 2015; Wyller 2015). Internationally studies show that older people who suffer from chronic diseases and are in transition between primary health care and the specialist health service, constitute a neglected group (Kendall and Reid 2017). Transitions between nursing homes and hospitals are associated with adverse events related to information transfer and course of treatment (LaMantia et al. 2010; Wyller 2015).

Taking care of relatives is a key goal in PC (WHO 2014). The relatives' situation might be related to emotions and ambivalence, for example, the satisfaction of fulfilling obligations and responsibilities can be intertwined with dissatisfaction with not being able to cope with situations. According to a Norwegian study (Lindén 2018) relatives have been considered the invisible help corps because they have neither been recognised nor focused on. Caregivers often feel uninformed about the patient's situation and lack guidance and support from health professionals. Relatives are further concerned about whether the care for the patient is good enough and struggle to prepare for the fact that the situation may change from day to day (Melin-Johansson et al. 2012).

Relatives have in recent decades both in Norway (Jenhaug 2018) and internationally (Ott, Sanders, and Kelber 2007; Tuomola et al. 2016) gained a more prominent role in the debate on treatment and care for the elderly, and are of great importance for the patient's experience of dignity (Östlund, Brown, and Johnston 2012). When the older person's own resources fail, family members can play a key role in safeguarding care needs and patient rights. Recent reforms of the Norwegian healthcare service give frail older people's close relatives the right to user participation and partnership with health personnel (Jenhaug 2018). In accordance with Norwegian legislation, the relative have the right to participate in the implementation of healthcare services together with the patient, to contribute to the choice between available and secure methods, and to receive information on behalf of the patient.

Recent reforms provide no clear indications of how the role of the families will be affected. It is therefore essential to explore how the patient's family members are 'something more than various caregiver roles in relation to the staff' (Whitaker 2009). Taking into consideration that family members play a key role in safeguarding care needs and patient rights, it is crucial to investigate the ways in which structural factors can affect this relational context (Puurveen, Baumbusch, and Gandhi 2018).

Personalisation and citizens' rights are on the political agenda in Western health policy (Kendall and Reid 2017; Lloyd 2010). Although personalisation takes different forms in European countries (Christensen and Pilling 2014; Rummery 2011), the right to have influence over one's own life, by virtue of being a fully worthy citizen, is a *shared* principle. The democratic understanding of user participation is a step in the direction of a general trend towards democracy and rights in the welfare sector. However, the ideal of user participation could also represent a consumerist and individualist orientation, in which the focus on freedom of choice is a core component (Askheim 2017; Rummery 2011). In particular, this discussion is associated with the development of New Public Management (NPM) in the healthcare

sector in Norway and a number of other European welfare states (Lloyd 2010; Rummery 2011). The healthcare service is increasingly dominated by market mechanisms that prioritise efficiency and cost-cutting (Tronto 2010). Government regulations and forms of funding fail to provide sufficient support to a community that prioritises care, and health personnel report that insufficient resources limit the time that can be spent with patients and increase pressure and moral stress (Kendall and Reid 2017; Woods, Phibbs, and Severinsen 2017).

The aim of this study is to draw attention to frail older people in transition between various levels of the healthcare service and explore the opportunities of the relatives to voice their expectations in care of frail elderly. We describe how we have used autoethnography as a research method, followed by the daughter's narrative and the colleagues' responses. Finally we discuss the opportunities of patients' families to speak their mind about their expectations for involvement in healthcare services.

Autoethnography as a research method

The article has a qualitative research design inspired by collaborative autoethnography (Chang, Ngunjiri, and Hernandez 2012; Ellis, Adams, and Bochner 2011). Autoethnography is a post-modern research method that emphasises the potential for insight that can be found in the interaction between personal experiences on the one hand and the social, cultural and political context on the other (Ellis, Adams, and Bochner 2011). This method is recognised as having the potential to develop new knowledge in the health and social sciences (Bath 2017; Chang 2016; Peterson 2015).

We describe and systematically analyse (graphy) personal experience (auto) to understand cultural context (ethno) (Baarts 2015; Chang 2016). The autoethnographic material is based on an autobiographical narrative about a daughter's experience of palliative nursing care for a frail older person. The narrative is based on her recollections of her perceptions and experiences. Openly and self-reflectively, she has written and explored her own experiences. This is in line with the requirement for quality in autoethnography, where the researcher is assessed in light of their ability to be reflective and open and to provide credible descriptions (Chang 2016). The writing of the narrative took place in stages. Brief notes on topics were gradually assembled into a coherent narrative. Two of the daughter's siblings read the first draft and made suggestions for changes. The narrative was rewritten and abridged over many rounds. The final version appears more distanced and is not as detailed as the first drafts. In analysing the narrative, the daughter uses the internal dialogue method.

Autoethnography provides an opportunity for drawing on personal experiences to better understand a specific culture (Ellis, Adams, and Bochner 2011), and therefore directs its gaze both inwards to the vulnerable ego and outwards to the sociocultural setting. Thereby, the researcher seeks to elucidate an experience from within and in a way that addresses and moves the reader (Ellis, Adams, and Bochner 2011). Accordingly, the researchers have made reflections that seek to involve and invite the reader to a dialogue and reflective meetings, rather than provide explanations.

Collaborative autoethnography and reflective research

Autoethnography has met with criticism that self-exploration is of little use to anyone other than the researcher in question (Karlsson et al. 2019). Since the researcher and

owner of the narrative may be prejudiced, critics call for an alternative perspective on the topic being studied. One strength of this study is its basis in *collaborative autoethnography* (in contrast to single-authorship research). In this article, collaborative autoethnography means that three researchers have contributed by their reflections and jointly analysed the material. Through dialogue and reflection, the co-researchers have contributed experiential knowledge, theoretical concepts and perspectives, and by this the narratives have turned into personal insight and scientific knowledge (Baarts 2015).

The researchers are colleagues who have been engaged in academic collaboration for several decades in the training of nurses at the basic and further education level, as well as in a variety of projects and publications. In contrast to the daughter's personal account of the past, the two co-researchers' reflections are 'self-reflective and self-analytical' in their responses to the daughter's narrative, cf. Chang, Ngunjiri, and Hernandez (2012). The researchers have chosen a hybrid model consisting of individual reflections and group dialogue. The co-researchers have played a key role as a reference group ('sounding board') (Chang, Ngunjiri, and Hernandez 2012), and have read all versions of the narrative and added their reflections to the data basis. This shifting between independent reasoning and interaction in the research team gave rise to valuable group synergies.

The researchers have chosen an *evocative ethnography* to invite a rich and more expansive appreciation of the possible. For the evocative ethnographer emotionally arousing discourse plays a central role in order to engage the reader in a more fully embodied experience (Gergen and Gergen 2018). In the evocative part of the article, we present the daughter's narrative and co-researchers' reflections associated with this. The purpose of the writing is to represent the story as realistic as possible, and emphasises the researchers' feelings and experiences. At an early stage, the researchers chose a wide focus in their approach to the narrative, without any systematic planning of the further direction of the collaborative research. The dialogs and reflections focused at that stage mainly on palliative care to frail elderly. Stories/narratives have the advantage of being open to innumerable interpretations, and numerous problematic areas were identified in the palliative area. We engaged in conversations face to face, and reflected on the lack of a palliative care approach. We also reflected on the daughter's fundamental position as vulnerable and dependent. The colleagues have for many years known the daughter as a person who speaks her mind. But as the narrative stems from her experience as a daughter and the process of outing herself, they came to know her as a vulnerable person. And we also reflected on the co-researchers being affected by the fact that the narrative brought to life both previous experiences and more existential questions related to the care of their own frail / dying family members. As responsible for educating nurses we also reflected on a dilemma connected to the discrepancy between values conveyed in teaching nursing and the reality the daughter experienced being a daughter of a frail elder.

Our agreed-on topic with the purpose of gaining a deeper understanding was focused on the opportunities of the relatives to voice their expectations in care of frail elderly. Falling within the analytic part of this article, the researchers combine personal experience with theory and knowledge as described by Chang, Ngunjiri, and Hernandez (2012). The search for meaning inspired us to view these reflections in a sociocultural context, and in the discussion, we regard these experiences in light of recent healthcare reforms that call for greater efficiency and cost-cutting.

Ethical considerations

In autoethnography, ethical concerns are associated with the values in interpersonal relations (Ellis 2007). Respect is an overarching value in our reflections and discussion of the narrative. The researchers have reflected on how to describe the persons involved, and a fundamental idea is that those involved should be able to read the article without feeling offended.

The daughter's narrative involves the mother, the narrator's siblings and the personnel in the primary healthcare service. In their final, critical review of the narrative, the researchers rewrote particular characteristics of the personnel and the ward. Autoethnography gives rise to challenging ethical considerations, and the requirement for informed consent in research is especially controversial (Ellis 2007; Lapadat 2017).

The daughter's siblings gave their consent to the publication of the narrative. The mother is dead and cannot therefore give consent. The daughter's siblings believe that their mother would have consented to the narrative had she been alive. The mother was herself a nurse, and in the daughters' opinion, she would have wanted to contribute to further developing the understanding and knowledge pertaining to the needs of frail older people.

The daughter's narrative

My mother was more than 90 years of age and living at home when one day she fell on the bedroom floor and remained there the entire night. Old age had brought various ailments with it. She suffered from a cerebrovascular disease and had realised that a stroke might end her life. The fall and subsequent encounter with the healthcare service became a turning point. She sustained a painful wound on the dorsum of her foot, which was treated with a skin graft and ended in a crural amputation. Over a period of four months, my mother alternated between two stays in hospital and two stays in an intermediate primary care unit. My narrative here is limited in time to these four months.

To me, my mother's stay at various levels of the healthcare service appeared to be full of contradictions and ambiguities regarding the goals and intensity of treatment and nursing. Our impression was that while the specialist healthcare service undertook active symptomatic treatment of my mother's wounds, the personnel of the intermediate primary care unit believed that my mother's wish to be left in peace should be respected. The state of my mother's health improved after the stay in the specialist healthcare service, but the lack of follow-up in the intermediate primary care unit was a burden on us. I asked many questions about nourishment, analgesics, the personnel's lack of attention to my mother's remaining functions and her shifting consciousness, but was met with little response. Why was the wound treated with a skin graft and observation in the outpatient clinic if the primary healthcare service left her in peace to die? How would the wound on the dorsum of her foot heal if she was not given sufficient nourishment? My mother found it meaningful to be helpful when receiving nursing care and being able to move herself in bed. When we asked for a lifting pole to be attached to the bed, our request was denied. The nurse referred to the physiotherapist, who believed that a lifting pole makes patients lazy. I insisted that to my mother, a lifting pole would be helpful. In the end I prevailed, but not without a fight. We were present at mealtimes and

asked for an overview of our mother's fluid intake to monitor what she was taking in, but with no luck. The personnel communicated that we daughters should not pester my mother any more with food. Moreover, one day when my sister tried to help our mother have some yoghurt, she was stopped with the words: 'We don't force people to eat here'. Did the personnel see us as wanting to keep our dying mother alive? I recall being paralysed by the moralising attitude that we were pestering our mother. Despite my familiarity with the institution and my competencies in geriatrics, no collaboration on my mother's treatment and nursing care was initiated. We lost confidence in the health personnel, and with a mixture of despair and anger I made my opinion clear when my emotions ran high. We did not want to be a nuisance. When the personnel were unable to answer the daughters' questions, we stopped asking because we felt embarrassed on the personnel's behalf.

After the skin graft, we accompanied our mother to the outpatient clinic at the hospital and were informed about the doctors' assessment of the wound. For my sisters and me, this waiting period brought hope that the transplanted skin would settle and that our mother could go home again. We were not waiting for the decision to let her die, and this choice was never stated explicitly. In retrospect, I think that this was implicit in the personnel's attitude to my mother. As a primary healthcare patient she became increasingly fatigued and apathetic, brought on by analgesics and lack of nourishment. To us, letting our mother die in this way was disgraceful. Occasionally, I had the impression that the personnel believed that my mother's condition was poorer than it really was; that she was dying more than living.

When the pain in her foot increased, we welcomed the relief that opiates could bring. Gradually, however, I witnessed an emaciated and apathetic older woman with whom it was hard to establish contact. Was the dosage correct? She did not say much, but asked to be left in peace as she lay there tight-lipped and pale in bed with deep furrows between the eyes, picking on her duvet. Apathetic delirium became part of my mother's illness picture. What amazed us, though, was how the situation could change from one day to the next. I was astounded by her ability to mobilise energy. We could see her anxiety and apathy, but also her vitality. On good days we would take her out in a wheelchair, have some ice cream and watch the birds in the park.

As a result of the failures in primary health care, my mother's general condition was dismal when the specialist healthcare service 'threw in the towel' and offered her a crural amputation. On the operating table, her poor condition caused complications that nearly killed her. However, she recovered quickly after receiving treatment for her poor nutritional status, and to our joy she perked up after the surgery. During her two weeks in hospital, my mother gradually got a new lease on life. The analgesics that we suspected to be the source of her apathy were gradually reduced and finally terminated completely. We could see her recovery progress on a daily basis. She was awake when I came to see her, sitting on the bed with her leg amputated, and we all had coffee and food that we had brought with us. After returning to the primary healthcare service her condition deteriorated. She suffered from nausea, ate little and started picking on her duvet again, with deep furrows on her forehead. One day as we were helping make her comfortable in bed, we discovered the analgesic patch. Our mother had mistakenly been given analgesic treatment that the hospital had ceased.

What my mother thought of the situation we can only guess at. After the fall, her sense of reality became distorted. She could not recall what had happened, and filled the void with nightmarish thoughts. Her comments and questions testified to horrendous fantasies of how she had gone to hospital to die and that she now was in a morgue. When we came to see her she was often confused and wondering what had happened. By repeatedly giving her details about the events that had unfolded we could help her sort out what had happened, and she wondered: 'Was this how it was all supposed to end?' We were glad we were there to explain the reality, comfort her and remind her of the things we knew were important to her.

We spent a lot of time in the ward corridor in the primary healthcare unit trying to come in contact with the personnel. When we finally could find someone, they were unable to answer our questions. Spending time searching for personnel eventually became pointless. For us sisters, finding a meaning in this chaotic situation meant being actively involved in maintaining my mother's dignity. We established our own schedule to allow us who knew her best to spend as much time with her as possible. My sisters and I organised ourselves and ensured continuity for our mother. We were with her at mealtimes, looked after her oral hygiene, moistened her lips and took her out into the fresh air on good days. We kept each other informed by telephone, text messages and brief meetings. Everything revolved around my mother's situation, and our main sources of information were our mother and each other. We were dependent on the personnel, however, and we were worried when none of us were with my mother. Could the personnel see how unstable and changeable her situation was? I was desperately worried about her situation during the night. Could the personnel understand her questions and North Norwegian temperament? How could they get to know my mother, who in general was a very private person who preferred not to establish any bonds with strangers?

As it turned out, my mother's time was not yet up. She died at the age of nearly 94 – three years after her fall.

Response to the daughter's narrative from co-researcher no. 1

I feel it is a strength in this context that the daughter has been a close and good colleague of mine for many years. My ideas and emotions will obviously be coloured by the fact that I have devoted large parts of my professional life to working with patients in need of palliative nursing care and their families. I have a strong and intense desire to meet the families of dying patients, recognise their needs and encounter them in perhaps what is the most vulnerable stage of life.

What strikes me is that the daughter, a fearless, reflected, skilled and committed nurse, who for years has devoted her attention to taking care of older, vulnerable people, becomes so vague and to some extent absent when it comes to calling attention to reprehensible conditions associated with the care and treatment of her mother. I know the daughter as a spokesperson for nursing ethics, but here she appears to be 'reduced to silence'. I am amazed by what is happening. I try to recall all those patients' families I have met who were in a situation similar to the daughter's. Did I, as a professional, behave in a way that made them feel offended and robbed them of the strength or courage to become involved and ask about the matters that caused them to worry? Patients' families are entitled to be treated in a caring manner, and the daughter also

had a responsibility to ask for information. Like the daughter, some patients' families may feel that they are in a flux, wavering between hope and resignation, grief and loss, loneliness and social contact. This makes me wonder: In my role as supervisor and educator, has my teaching clearly conveyed the families' 'tacit' suffering? I ask myself of the daughter: Why didn't you say anything – were you afraid?

I also wonder if home death could have been a good alternative for your mother, was it not possible? This puzzles me, and I cannot reconcile this with the person I know. I think that if someone should be allowed to die at home, or alternatively to spend as much time as possible at home, it is exactly in such situations as yours. I am confident that you in particular, with your skills and networks, would have been able to ensure this. I ask myself what stopped you. I wonder whether ideas formed in retrospect manifest feelings of guilt. Perhaps my own story is having an effect here. I am thinking of my father, who at the age of 75 was allowed to die at home in the sitting room with his loved ones around him. I have frequently felt grateful that this was possible. As the daughter, you describe situations where I feel that there were 'flaws' in the way you were treated. On the other hand, I think that something happened to you that caused you to be disciplined into silence and disempowerment. This is an issue that I would like to reflect on with you. How can new knowledge be derived from your narrative, knowledge that can help ensure that patients' families are treated with respect and dignity?

Response to the daughter's narrative from co-researcher no. 2

In the narrative I see a daughter's strong bond with her mother, and a daughter who does everything in her power to alleviate her mother's suffering. The daughter's voice is especially important, since she knows her mother extremely well. Two of the three siblings have long-standing experience as nurses, but despite this they are not invited into a collaboration on their mother's well-being. The siblings' efforts are undertaken in parallel with those of the nursing personnel, and there are no formal points of contact where the mother's situation is jointly discussed. The family members perceive themselves as witnessing their mother's final journey, but outside any collaboration with the primary healthcare personnel.

This is about geriatric care in Norway in the twentieth century, as seen through the daughter's eyes. The daughter sits arm in arm with her two siblings 'on the sidelines', as a tight-knit family, competent and filled with love for the mother who is now engaged in one of life's final battles. Is it the responsibility of the patient's family to take the initiative for collaboration on their parents' situation? In palliative care, nobody sits on the fence waiting for the family to declare what they need. The family are invariably involved in palliative care. This is just as natural as alleviating the patient's pain. The ideals of good palliative practices are not followed – perhaps because nobody wants to mention that their mother is dying?

What interests me is what is happening to my brave, fearless, articulate and strong colleague and the mother's daughter. The daughter did not want to be a nuisance. And when the personnel were unable to answer the daughters' questions, they stopped asking because they felt embarrassed on the personnel's behalf. What lies behind not wanting to be a nuisance? Does the experience from working life as a nurse and a university employee play a role? Is it possible that the grief is draining the siblings of their

energy, leaving them without the strength required to oppose decisions with which they disagree? Why did they accept being excluded? It is surprising that my colleague (the daughter) made no requests for collaboration with the healthcare personnel, so that they could jointly establish a good plan for her mother's welfare. Why didn't she make her voice heard?

Patients' families are also socialised into a role that involves being sensitive to the personnel's expectations and what is deemed acceptable. They feel their way forward when it comes to what is their responsibility. I read about a daughter who along with her siblings did everything in their power to help their mother, but still feel guilty. Is it because they feel they could have done even more? That 'everything' was not enough? Because they believe that their mother is not doing as well as she ought to? Because they sense that their mother is not being regarded as the person she still is? Because the nursing care fails to reach the nursing ideal? Because they could not find the courage to protest when the healthcare service 'took charge' of their mother? The daughter and her siblings were prepared to comply with their mother's wish to go home to die. The willingness and competency were present, but the mother and her children all yielded to the personnel's assessment that the institution was the best place for her. If willingness and competency are insufficient, what is it that is needed? What would have happened if the mother's children had stood their ground on the decision to take care of her at home? The healthcare personnel's advice was well-intentioned, but they did not know their mother and were unaware of the siblings' capacity to care for her. The decisions were not rooted in the mother's and the siblings' wishes. Will they ever be?

Discussion

In the discussion, we explore the opportunities of patients' families to speak their mind about their expectations for involvement in healthcare services. At first, we clarify the article's clinical context and discuss how recent reforms in the healthcare sector have influenced the ability of personnel to maintain dignity for frail old people and ensure collaboration with patients' families. We then discuss whether the central government and community services decentralisation of responsibility also entails consequences for patients' families. Conflicting pressures on the personnel and the increased responsibility of the family gives grounds for concern that the families and the personnel are directing their anger at each other, rather than holding representatives of the system to account.

The narrative's clinical context

The narrative's clinical context is the collaboration between the primary and the specialist healthcare services on shared goals for patients who are users of healthcare services at both service levels. When based on a person's need instead of illness, palliative care should include the frail elderly (Östlund, Brown, and Johnston 2012). The palliative nursing care that the mother received in the specialist healthcare service was not followed up by generalist palliative care in the primary healthcare service. The lack of coordination between these service levels had serious repercussions for the mother's situation, and the narrative shows her vulnerability in the transitions between the hospital and the nursing home. The objective of the most recent healthcare reform in Norway (the Coordination

Reform) was to ensure coordinated palliative care and treatment, which is particularly important for the provision of health care for frail older people (Hauser 2009; NOU 2017:16, 2017). Researchers have therefore pointed to the importance of arenas where healthcare personnel can discuss challenges related to the admission and discharge of older patients (Storm et al. 2014a; Storm et al. 2014b). No such venue had been established in the municipality in question. The daughter had the impression that even though the specialist healthcare service gave her and her siblings hope that their mother still had a life worth living, the primary healthcare service gave up on her. Seen from the daughter's perspective, it was not overtreatment on the part of the specialist healthcare service that compromised her mother's dignity, but rather the sins of omission in the primary health care. The daughter's encounter with the primary healthcare service was stirring and emotionally charged. She felt that her mother was in a transition of an existential nature, in which she changed from being regarded as living by the specialist healthcare service to being regarded as dying in the primary healthcare service. One may wonder why the daughter did not demand to be involved in these processes. According to Jenhaug (2018), the welfare state expects patients' families to take more responsibility for their frail, older relatives (Jenhaug 2018). Norwegian authorities have given the daughter the right to co-determine her mother's nursing care in partnership with the personnel (Christensen and Fluge 2016).

Conflicting pressures on the personnel

Good collaboration between patients' families and personnel develops within specific sociocultural, political and personal contexts. In light of the assumption that user involvement is associated with a general spread of market-based solutions in the design of public welfare services (Egilson, Dybbroe, and Olsen 2018), we question the way in which political systems in fact support user involvement and partnership with the patients' families. Do the personnel have the latitude of action to empower patients' families and enter into collaborative relationships with them? Or, are the authorities' eloquent words about co-determination and partnership no more than rhetoric and an abdication of responsibility?

Experiential knowledge indicates that the mother is a typical representative of the patients in primary health care: the patients are multimorbid and chronically ill, and need generalist palliative care. While the complexity of the daily work in primary health care has increased, productivity and efficiency have become increasingly important premises for the work performed by healthcare personnel both in Norway and abroad (Kendall and Reid 2017; Larsen and Esmark 2013). The imbalance between the endorsement of welfare policy goals on the one hand and the means required to achieve them on the other is well documented (Vike 2002; Westin 2010). Well aware of the capacity shortfall in primary health care, the daughter felt it was futile to demand ideals that are non-existent in established practice. For the professionals, such high-reaching welfare goals mean that they feel exposed to conflicting pressures between scarce resources, increased efficiency and the provision of appropriate care (Engen, Rømer, and Jørgensen 2019; Nydal et al. 2016).

These conflicting pressures on the personnel are reflected in the prevailing concept of knowledge in NPM as well as in concepts of care. Dignity in palliative care is based on humanist values, in which a holistic understanding of human life and an understanding

of the human as part of a 'family' serves as the basis and guideline for the provision of care (NOU 2017:16, 2017, 177). The daughter was concerned about the personnel's ability to understand her mother's unique situation. She worried about her mother's dignity when none of her family were present.

Elderly people who receive nursing care are vulnerable and dependent, and we want to emphasise the importance of dignity. Östlund, Brown, and Johnston (2012) identified several care actions within the Dignity Model. Examples include: listening to the patient and taking them seriously, and encouraging the family members' presence. The relatives have unique knowledge of the older person, and it is therefore important for staff to actively incorporate them into the care for the proper planning of the person's remaining life (Bökberg, Behm, and Ahlström 2019).

The conditions of the care sector are a result of multiple factors over which the employees have no control, including market forces, cost-cutting and understaffing. In the wake of NPM, the pressure is growing for evidence-based practices that pull the rug from under this value base. The critics of this evidence-based mindset claim that giving priority to research-based guidelines, manuals and standardised treatment programmes has given rise to a concept of knowledge that shifts the focus away from the life perspectives of patients and their family (Hoel 2018; Martinsen 2018; Midtbø and Hauge 2010). The knowledge base becomes oriented towards outcomes with a focus on cost-effectiveness, thus fostering a more instrumental approach (Martinsen 2018). The traditional, value-oriented knowledge base of nursing is under pressure (Vetlesen 2010).

The authorities' abdication of responsibility and conflicting pressures on the family

Jenhaug (2018) notes how a diminishing emphasis on the responsibilities of the welfare state has become a common feature of contemporary social development. The responsibility for performing activities is delegated to healthcare personnel, while their real influence over the wider framework is being reduced. Vike (2002) highlights how nurses constitute 'the conscience of power' by tacitly compensating for framework and conditions that inhibit the provision of care. Political and economic governance systems affect the personnel in the form an inundation of responsibilities, in parallel with a weakening of their authority. The personnel feel that they are unable to do their work in the way they should. As a result, they feel a sense of resignation and disempowerment (Thomassen 2013; Vike 2002). In this picture, user involvement may give rise to a conflict-ridden relationship between the personnel and the patient's family. While the responsibility for 'poor execution of professional duties' is unfairly shifted onto the personnel, the families are encouraged by the authorities and the Ombudsmen to more frequently call attention to situations that are deemed reprehensible. In this manner, society decentralises the consequences of resource shortages and ambitious welfare policy goals to the patients' families. According to Ekeland and Heggen (2007), the authorities' empowerment of the personnel and patient's families represents an abdication of responsibility by society. The patient's family expects the personnel to comply with their feedback, and may also put demands on personnel that they have no authority to meet. It is fully understandable that tensions arise when families who are empowered to speak

their mind meet personnel that have less and less time to engage in involvement because of system routines, procedures and practices.

Vike (2002) shifts this critical perspective on power from the healthcare personnel to the structures that establish the premises for performing care work. Juritzen and Heggen (2006), on the other hand, are critical of a perspective in which the personnel and the patient's family are seen as disempowered victims of determining structures of power. They claim that the strong emphasis on the collective aspects of disempowerment may help engender a harmonised understanding that a common fate is common consolation. The authors claim that thematising disempowerment may thus act as a hindrance to an exploration of how power is exercised, experienced and discussed in the area of care. Moreover, a deadlocked sense of disempowerment cannot foster any change or improvement. In the narrative, we can see a silent, but not paralysed or disempowered daughter. She is the one who upholds the rational ideas of care and the mother's dignity. Along with other close family she implements practical measures. She turns up at mealtimes, because she knows that these situations are challenging for both her mother and the personnel, she establishes her own documentation system, acts as an intermediary between the outpatient clinic and the nursing home ward etc. This mobilisation of initiatives can be understood as a form of resistance or countervailing power to what she sees as inadequate nursing care. The daughter was far from being paralysed. Her efforts, however, were directly aimed at taking care of her mother and not directed towards the system from which her mother received services.

Conclusion

Reforms in the healthcare sector in recent years have entailed major consequences for the personnel's ability to uphold the patients' life-world perspective. Patients' families experience this, but have only limited opportunities to come into a position where they can engage in collaboration on service design for their loved ones. The increasing requirements for efficiency and cost-cutting thus also entail consequences for patients' families. This legitimises an increased focus on where the real responsibility should be placed. Conflicting pressures on the personnel and the increasing responsibility of patients' families give reason to fear that the families and the personnel will direct their anger at each other, rather than holding representatives of the system to account.

A decentralisation of responsibility also entails consequences for patients' families. If the authorities are serious about their prioritisation of involvement and partnerships in which patients' families also play an important role, the preconditions need to be improved.

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