

# **Making user participation work – on ethical dilemmas of long-term care work practice in context**

*Karen Christensen and Mariya Bikova*

## **Abstract**

User participation has become one of the central concepts of long-term care policies in many European countries including Norway. While an increasing body of literature discusses user participation in long-term care, ethical aspects related to practising user participation are less discussed. The aim of this paper is to give insight into ethical dilemmas for health and care staff within different care service settings of the long-term care sector context of Norway. The discussion is based on ethnographic data collected in 2015-16 in two different Norwegian municipalities. Theoretically, the discussion is inspired by bringing together theories about user participation with theories about care ethics, and using the concept ‘microethics’ to approach the problematics of everyday care service practice. The findings include three contextual ethical dilemmas. One is related to the limited time for user participation in home-based nursing services. Another is related to the arduous involvement of relatives of nursing home residents whose own participation are limited by weakness such as dementia. And a third is related to the pressure of governing user participation for residents in grouped homes through behaviour therapy forcing residents to learn how to live normal lives. Overall, the article is a contribution to the discussion about contextual microethics of long-term care services for older and younger users.

## **Introduction**

The aim of this paper is to contribute to bringing the discussion about user participation closer to the discussion of care ethics by discussing ethical dilemmas related to long-term care work.

While an ethic of care has been discussed early, starting in the 1980s (e.g. by Gilligan, 1982; Noddings, 1984, and in the Nordic countries by e.g. Wærness, 1984, and Eliasson, 1987), a renewed discussion of this started in the beginning of the 2000s, with the work by Joan Orme (2002). She raised the need for a discussion about ethics and social work practice and argued against dichotomising care and justice. A body of literature has followed her upstart and is now further developing links between ethics and care (see Koggel & Orme, 2011). This renewed discussion contains several sub discussions, of which two are relevant here. One is about digging deeper into social work practice, using the lens of care ethics to understand more of social work practice (Featherstone & Gupta, 2019; Banks, 2016; Ward & Barnes,

2016; Lloyd, 2006). Utilising a care ethics based relational ontology they are criticizing individualised welfare models inspired by neo-liberal thinking and within this context, they use the care ethics as a language to enter a renewed understanding of social work practice. Banks (2016), for example, conceptualises this through her concept ‘ethics work’, suggesting that this is basically about professional’s efforts to continuously developing themselves as better practitioners towards the people they are supposed to help. A particular useful conceptualization from this body of literature for our discussion is the distinction between ‘ethical trespass’/’ethical dilemma’ and ‘moral distress’ (Featherstone & Gupta, 2019), a concept first developed by Weinberg (2009). The distinction separates the emotional and individual challenge (distress) in concrete care situations from the wider conflict of interests that the situation is mirroring. This is relevant here, because it provides an analytical tool for analysing ethical dilemmas further. The other sub discussion (see e.g. Rummery, 2011; and Lloyd, 2010) is closer in topic to the aim of this paper, because it somehow discusses user participation. However, it only discusses this in what we could call an extreme version. This is through personalisation welfare schemes, which aim at empowering users by giving them cash to employ their own care workers; a scheme mostly used by disabled people. This is, social politically, based on ideas about empowering users through giving them more choice and control over their services. Many European countries have used these schemes within the last decade, but with many variations (Ungerson & Yeandle, 2007). Rummery (2011), for example, uses a comparative analysis, to point out, how important the national welfare context is – very relevant here too – for the potentials of developing choice and control not only for the users, but also the care workers. She uses the fourfold care ethic aspects by Tronto (caring about, caring of, caregiving, care receiving) (Tronto, 1994; see also Fisher & Tronto, 1991) to point out, that the personalisation scheme primarily secure caregiving and care receiving. However, it fails to include the ‘caring about’ and ‘caring of’ aspects, as suggested by the care ethics (see more below), while she suggests that there is an option of combining empowerment of older and disabled people *and* an ethics of care. This is through more comprehensive welfare states, which means that Nordic countries play a central role as forerunners. While this is an important discussion, and important here in the sense that it points at the option of strengthening user participation without basing it on an independence logic, we find that it undermines the discussion about user participation in non-extreme variants. Included in this is also the variations of daily care work supposed to involve the users as active participants. While there is a growing literature into the discussion about user participation in public care services (see e.g. Askheim, Christensen, Fluge and Guldvik,

2018), the ethical discussion is largely missing. Summarized, the user participation literature is largely missing the discussion about care ethics, while the care ethics discussion is on the other hand largely missing the discussion about users as participating actors. Simultaneously, ‘there is a need for more empirically grounded studies’ on ethics and social work, as pointed out by Featherstone & Gupta (2019: 2). We intend to contribute to these gaps by presenting an empirically based ethically critical discussion about user participation in long-term care within the Nordic country, Norway.

As the context for such a discussion is crucial, cf. also Rummery (2011), we will start presenting the long-term care context in more detail, here also clarifying the concept ‘user participation’. We will then outline the theoretical framework combining classical care ethics with user participation theories. Following this, we will present our methods and empirical material, then provide an analysis of different dilemmas in three long-term care settings, and finally present a concluding discussion.

### **Contextual background – international and local developments in the long-term care sector**

In many countries all over the world, an increasing attention is currently paid to long-term care services for older and disabled people, but with older people as the majority group in most countries (see Christensen & Pilling 2018). The attention is due to ageing populations that pose considerable demographic challenge. The concept and phenomenon of ‘user participation’ is one response to this challenge. It implies giving users of welfare services different kinds of influence on the services they receive (Askheim, Christensen, Fluge and Guldvik, 2018). Internationally, user participation builds on three pillars – the human rights perspective, the ideology of aging-in-place and the policy framework of active ageing. These three perspectives are informing also our discussion of ethical dilemmas in the long-term care sector in Norway. The human rights perspective is grounded in international human rights law (UN, 1966) and includes the right to health, social security and housing. This right extends to all people, including older people. Recently, the human rights perspective in the long-term care sector has been strengthened through the UN Convention on the Rights of Persons with Disabilities (2006). The convention is specifically oriented towards persons with disabilities, but it contributes to strengthening, more generally, the human rights perspective in the long-term care sector (see Meld.St.45, 2012-2013: 10).

The second pillar of user participation is the ideology and policy of aging-in-place that builds on the idea that people prefer to stay in their local communities as long as possible and that long-term care services should therefore be given higher priority than institutional care. In Norway, this policy has been on the political agenda since the 1980s and has received a renewed strength in the mid-2000s (Christensen, 2005).

The third pillar is active ageing. It has roots in WHO's report 'Active ageing: a policy framework' (2002) that defines active ageing as 'the process of optimizing opportunities for health, participation and security to enhance quality of life as people age' (WHO, 2002). Active ageing is currently discussed in terms of 'person-centred care', where the need for care 'rather than the structure of the service' (WHO, 2015: 135) is important. Active aging is also seen as part of an 'integrated system of long-term care', in which the national government is still responsible for the public long-term care system, but involves also unpaid workforce in the provision of care. Of particular relevance here is, that this both includes users' own resources as well as their relatives' resources. Involvement of these other resources is an important trend in the sector that, according to WHO, for example, enables older people's self-expression and ability to make choices (WHO, 2015:135).

### *Local development*

In Norway, the long-term care sector has undergone substantial changes since its comprehensive expansion in post-war time. Long-term care services in Norway comprise traditional home-based services in terms of home help and home nursing services (with an alternative organisation of user controlled personal assistance, used by a minority of users), institutional services in terms of mainly nursing home places, sheltered housing, and other types of services such as e.g. safety alarm and meals on wheels. Local municipalities have played a major role in the development of public services for older and vulnerable people. During the 19<sup>th</sup> century, when the first initiatives towards developing these services started, Norwegian municipalities – supported financially by the state – cooperated with voluntary organisations in local communities particularly around institutions for older people (Christensen & Wærness, 2018). Later, this municipal role was legally anchored, starting with the Social Care Act of 1964 that required the municipalities to support people who could not take care of themselves; in practice comprising those without family network and resources.

However, legally anchored was also the early separation of social care and health care, as seen in giving the county municipalities – an administrative level between the state and the

municipality – the responsibility for nursing homes. With the service expansion in the 1970s, the number of nursing home places increased, while places in old people's homes were less prioritised (Borgan, 2012). This development continued until the so-called nursing home reform in 1988 transferred the responsibility for nursing homes to the municipalities. The ideology of living-at-home-as-long-as-possible has had further impact on municipalities' priority of home-based services over places in institutions. From a peak around 50 000 in the late 1980s, places in institutions were reduced to 40 000 in the beginning of the 2000s (Borgan, 2012: 28). Measured in staff's work years, the shift towards home-based care domination took place around 2003 (Brevik, 2010: 240).

Home-based services also separated social care from health/medical care, by separating home help (support with household tasks like cleaning and laundering), from home nursing tasks (e.g. body care, wound care and giving medicine). During the 1980s and 1990s home help services dominated the picture (Borgan, 2012: 16). However, since the beginning of 2000, mixed home help and home nursing services – but carried out separately in users' homes – have been increasing, a development that has continued until today (Mørk, Beyrer, Haugstveit, Sundby and Karlsen, 2017: 23). This trend may be seen as a medicalisation of the home-based care services and is quite similar with the process going on in institutions (Christensen & Wærness, 2018). It mirrors the fact that users of long-term care services are now more vulnerable; they are more dependent on help.

The developments in institutional services and home-based services, and the relationship between them are even more visible in the third type of housing we discuss in this article – the sheltered housing that lies 'in between' home-based care and institutional care. One important difference is that while residents of nursing homes are paying for diet and accommodation (with a room allocated), residents of sheltered housing are paying a rent (income based) and the home is then at their own disposal (Otnes, 2015: 50). Whether they receive home-based services depends on their needs and the way the municipality assesses these needs.

Sheltered housing includes also grouped homes for persons with intellectual disabilities and persons with mental health problems. Because of residents' needs, in the grouped homes, services are available 24/7. Sheltered housing has increased substantially since the 1980s. Over the last decades and especially between 1991 and 2009, a push factor for this development has been several political reforms and national plans. These have given municipalities the responsibility for more user groups, including persons with intellectual disabilities, people with mental health problems and people with drug addictions. Today,

sheltered housing living places are at a similar level in numbers as those living in institutions (Mørk et al. 2018: 15). This development has contributed to the fact that an increasing number of services are directed at younger people, below 67. Over the years, this has raised issues about age as a new factor of inequality in these services (Gautun, Skevik & Hermansen, 2012).

Due to the overall trend in the sector of limiting the service allocation and applying the principle of lowest effective care level (Øygdard, 2018), a differentiated set of services has developed that 'distribute' users in specific ways. The users of home-based services are now mainly frail older people, who receive home nursing. The services they receive are highly/strictly time-regulated and predefined as illustrated by Førland et al. (2017). Some of these users are living in sheltered housing ('service apartment/home') and this can then contribute to making the period living 'at home' longer, if possible avoiding a place in an institution.

When no longer able to live at home, frail older people are allocated place at a nursing home, now typically viewed as 'the last station' in long-term care. Therefore, today, vulnerable old people, 80 percent with dementia (Meld.St. 29, 2012-2013: 36), primarily occupy them.

In this situation of limited service allocation, sheltered housing is a way of maintaining the new distance between home-based services and institutional services. Although more 67+ people are living here than those below 67, this domination is much weaker than in institutional care (Mørk et al., 2018: 15). Sheltered housing, therefore, very much represents a (preventive) care setting, with the aim of avoiding 'real' institutional life.

Summarised, and important for our discussion of ethical dilemmas in the long-term care context, are the main and different current care settings developed historically, as we have illustrated above. By care setting, we mean the specific combination of the type of housing in which a specific type of care services is carried out for a specific group of users. In this sense, one typological care setting is the home-based care with a strong focus on nursing services allocated to older people who are able to live at home. Institutional care in a nursing home with health care services carried out in an institution is another typological care setting. A third is about sheltered housing, an in-between housing type pushing more clearly the residents' participation in their everyday life, and where the care services are therefore more about assisting 'normal lives'. 'Translated' to implications for user participation this means,

that there is an expectation, but a low one, in participation in home-based services, a very low expectation for those in nursing homes, and a high expectation for those in sheltered housing.

### **Theoretical framework**

The theories framing our discussion in this article have two roots: one relates to the ethics of care. Another relates to the discussion about user participation. We intend to bring these two discussions together, first theoretically here, then empirically through the analysis. In particular, we find the concept of ‘ethically important moments’ helpful in doing this.

#### *Care ethics encountering user participation*

The feministic inspired care ethics are based on two central classical work that have laid the groundwork for much of the discussions later developing further this ethical area, and we see the classical thoughts as highly relevant today. One is the work by Carol Gilligan (1982) claiming that there is a ‘different voice’ to moral reasoning, which is different from the justice perspective on moral (but not necessarily related to a female voice as often misunderstood). The other is the work by Nel Noddings (1984), who introduced the important difference between ‘caring about’ and ‘caring for’ others, where the first is involving an emotional part in caring about the other, while the latter relates to the support and help provided, the practical assistance. Several feminists developed these thoughts further (e.g. Tronto, 1994; Kittay, 1999). Tronto, for example (as briefly mentioned earlier), developed the fourfold aspects that a care ethic depends on, adding care giving (competence) and care receiving (response), and she pointed at this, importantly here, as moral aspects of care. However, particularly important here, are the Nordic developments. For example, Wærness (1984, 2009), inspired by Gilligan and Noddings, was a leading figure in bringing into the international discussion the concept ‘rationality of caring’, a concept developed from empirical work in social care (paid) work in the public sector. She made it clear that this rationality represents a ‘different voice’ in society by combining (traditional) rationality with emotional feelings. The actor is in this sense a ‘sentient actor’, as presented early by Hochschild (1975). Important for the discussion here is the strong emphasis on the concept of care as developed within a relational perspective, understanding the practice of care as a process of *caring* involving a continuous receiving and giving part, and taking place within organisational conditions as well as historical time and context. Another Nordic scientist paid attention to the growing Nordic welfare state context by discussing the potential dilemma here for on one hand to carry out

paternalistic social care services, and on the other hand to risk reaching the sins of omission (Eliasson, 1987), where the carer passively lets anything happen without any intervention. This represents an important discussion about the context-based power distribution in the relationship, principally asymmetric (Wærness, 1984), because the user is receiving care services from the welfare state. A rationality of caring, as is empirically shown then implies using the available ‘power’ in the care giver position to meet the individual needs of the user, also suggested to call ‘other-orientation’ (Christensen, 1998). In this sense, the discussion about involving the user in terms of making her/his needs and wishes central – within certain and changing conditions – is of no new date (although it is not a discussion about participation of the users). It has been central to the ethics of care ever since its introduction in the 1970s/1980s.

Around the same time as the feministic care ethics was introduced, but from another angle, the first formal expression of user/patient participation was introduced in the British welfare sector, when Community Health Councils were set up in order to give patients access to influencing NHS (Barnes and Cottrell, 2012: xv). However, when the concept of user participation was introduced into the European social welfare sector, during the 1990s and 2000s, it started to change its democratic and rights-based orientation. It became more individualised, more consumer-oriented (Askheim, Christensen, Fluge, & Guldvik, 2017), stressing for example particularly in the UK context individual choice and control in regards to long-term care services (Christensen & Pilling, 2014). Important is that the idea of user participation, shaped by the policy changes in Europe, takes a very different direction when compared to what is involved in the ethics of care. The ethics of care, through its relational and process-oriented perspective, sees dependency as inherent in the human condition. Kittay (2002), for example, refers to ‘inevitable dependencies’. The social policy idea about user participation, shaped by ideas about e.g. active aging, on the other hand, rather increasingly makes the idea of independency an ideal (WHO, 2002), then translated into different national contexts. In the Norwegian context, and in particular since the 2010s (Christensen and Pilling, 2019) this international context makes a co-production discourse relevant. In everyday health and social care practice, this means different things. It means an increasing stress on making the users active participants in their healthcare services; it also means that health and care workers increasingly are dependent on conditions giving room for ‘care-full deliberation’ (Ward and Barnes, 2016), where there is time and flexibility to realise the user’s participation. The Norwegian long-term care sector development, as described above, in general has



reduced this room for care-full deliberation – and one could add the ‘caring about’ dimension, ‘other-orientation’ and even broader, rationality of caring – but in different ways, depending also on the expectation of user participation. When a healthcare worker approaches this situation with an ethic of care and encounters barriers for realising it, ethical dilemmas, of different type, appear, starting with the personal emotional feeling of moral distress (Weinberg, 2009). The concept of ‘microethic’ provides the theoretical understanding of such dilemmas and how we were able to find such dilemmas in an everyday health and social care context in Norway through our research.

### *Microethics in social research*

In order to understand dilemmas in everyday life in the municipal health and care sector we deploy the concept of ‘microethics’ (Komesaroff, 1995) as a sensitizing concept. The concept comes from the literature on ethics in clinical (medical) practice and was originally proposed by Komesaroff (1995) to address what he saw as a disjuncture between ‘big issue’ bioethics and everyday ethics in clinical practice (Guiellimin and Gillman 2004: 265). Bioethics, especially in its mainstream form, where it arises out of analytic moral philosophy, provides philosophical tools for analysis of the fundamental ethical issues in now classic debates such as reproductive technologies, cloning, euthanasia etc. These debates are usually conducted in general rather than in particular terms and may readily be interpreted as recommendations for public policy rather than as a guide to individual ethical reflection or action.

Hence, bioethics has been critiqued for either ignoring or being unable to deal with ethical questions at the local and individual level. For Komesaroff, however, ‘medical ethics is not just about the dramatic questions that are discussed widely in the popular media or in philosophical texts. Ethics is what happens in everyday interactions between every doctor and every patient’ (1995: 68). Within social work practice we see a parallel in the concept ‘ethics work’ (Banks, 2016), as this also stresses everyday ethics. By introducing the term microethics, Komesaroff (1995) attempted to capture the everyday ethical issues that arises in clinical practice - the establishment of trust between the doctor and the patient, the taking of sexual history, the dealing of past fears etc. Even though none of these issues represent a ‘dilemma’ in the classic sense of the word, with the concept of microethics at hand, Komesaroff was able to validate these as important ethical matters worthy of clinician’s attention and provide a language for reflecting on them. The distinction suggested within social work between ‘ethical trespass’/’ethical dilemma’ and ‘moral distress’ (Featherstone & Gupta, 2019; Weinberg, 2009) can here function as a further development of this language.

This distinction offers an analytical tool to understand, why there is not always at first hand a direct dilemma – between two options – but rather an emotional situation of stress, that can then be interpreted (by the social researcher) as a conflict of interests or a contradiction between different care work approaches.

As the traditional starting point for discussions of research ethics has been the ethical principles formulated by biomedical research, social scientists have, since the 1960s', started exploring ethics in qualitative social research and focused particularly on how externally generated principles of research ethics have been applied to qualitative social research. As part of this discussion, Guillemin and Gillman (2004: 262) distinguish between two different dimensions of social research ethics – procedural ethics and 'ethics in practice'. Procedural ethics, as implied by its name, concerns the procedures around obtaining approval from a relevant ethics committee to undertake research that involves humans. 'Ethics in practice', on the other hand, concerns the everyday ethical issues that arise in doing research and that are not usually addressed in research ethics committee applications. Some researchers do not necessarily regard such issues as ethical in the sense that they may not be seen as 'dilemmas' or may not appear to be of great consequence. If dilemma is to be seen as referring to a situation in which there is a stark choice between different options with equally compelling ethical advantages and disadvantages, some of the issues pertained by 'ethics in practice' are certainly not dilemmas. For some researches, these issues may seem unimportant because of having an 'everyday' sort of quality. Guillemin and Gillam (2004), however, see these issues as 'ethically important moments' and claim that much is missed by not taking into consideration these moments. In these 'ethically important moments', the approach taken or the decision made may have important ethical ramifications, but the researcher does not necessarily feel being on the horn of the dilemma.

## **Methods and data**

Our discussion of typological dilemmas in the long-term care sector in Norway is based on ethnographic data collected in 2015-2016 as part of a larger study of user participation among different user groups in Norway.<sup>1</sup> We analyze ethnographic data from participant observation and focus group interviews with health care professionals in home-based care, nursing homes and sheltered housing. The data is collected in two Norwegian municipalities that differ in terms of size, geography (a rural and urban municipality) and in terms of whether or not the

municipalities practice a purchaser/provider model in the long-term care sector. The researcher who collected the data carried out four weeks of fieldwork in each of the two municipalities conducting interviews with employees, user representatives and leaders in home-based care, institutional care and sheltered housing. The overall purpose of the fieldwork was to observe and map the everyday life of different service users and employees working with them, and to explore the opportunities and limitations for ‘user participation’ in everyday situations. Another objective was to explore how ‘user participation’ is perceived by employers and service users.

Deploying participant observation as a way of exploring how people participating in a social setting interact and influence each other implies ‘a deep investigation of social life and life experience’ (Øye, Bjelland & Skorpen, 2007: 2299) as well as ‘[...] getting to know about, and being involved in events and participants’ lives to learn about their social life and cultural ideas. Only by being involved, can the researcher gain knowledge about daily life matters in different social settings’ (Øye, Bjelland & Skorpen, 2007: 2303). However, this way of exploring the social life requires researcher’s greater involvement with the research participants and may potentially pose ethical challenges to the researcher (Fangen, 2011).

In the course of the fieldwork, the researcher faces a number of unexpected and challenging situations. In qualitative research and particularly when doing participant observation, the researcher has to handle these situations at the moment they occur (Fangen & Sællerberg 2014; Hastrup, 2009; Guillemin & Gillam, 2004). Based on our reading of the empirical material we identified three typological ethical dilemmas related to service users’ opportunities for ‘user participation’ that the researcher observes and has to relate to.

Our method for developing these ethical dilemmas is inspired by Komesaroff’s (1995) concept ‘microethics’ and by the researcher’s experiences of so-called ‘ethically important moments’ (Guillemin and Gillam, 2004). Guillemin and Gillman refer to ethically important moments as ‘the difficult, often subtle, and usually unpredictable situations that arise in the practice of doing research’ (2004: 262). In these moments, the researcher is co-experiencing – together with involved healthcare workers – an ethical difficult situation in care work. It is first at foremost the healthcare worker who is faced with and has to respond to the dilemma. However, the researcher experiences the dilemma as well, as she is not only witnessing the ‘ethically important moments’, but is also drawn into these by the health care workers and the relatives of the care users who share their concerns and opinions with the researcher. Hastrup (1988) has called this to become a ‘third person’, expressing thereby the deep involvement

one can feel as an ethnographer, when suddenly becoming part of emotionally challenging situations in the field.

Even though in some cases it might be relatively clear how the researcher should respond when faced with an ethical difficult situation related to the field of study, responding is an ethically important moment that also implies the possibility for the researcher to ‘go native’, i.e. identify herself with and engage emotionally so much with the study participants that she loses the focus of research (Fangen, 2011; Hastrup, 2009).

The selection of cases of dilemmas presented in this paper is based on the idea of pointing out typological challenges related to different social care settings and their different development. The three empirical cases presented below are based on excerpts from a research diary written by the researcher<sup>ii</sup> who collected the data.

### **The home nursing example – older people in their homes**

*We – Charlie, a health care worker, originally from Pakistan, in his 40s; Veronika, assistant, from Lithuania, in her 20s, and me – are driving in a car from the home nursing base to a housing estate comprising 60 apartments. Guddny, 67 years old, is living in one of these apartments. Guddny is the first care user we are visiting today. She is highly dependent on nursing. She has had multiple sclerosis since she was 16 years old, and has now started developing dementia. Guddny is bed-ridden until the first home nursing visit in the morning and is usually nursed, washed and dressed, and then moved into a special electric wheel chair with the help of lift. At the day of my visit to her apartment, her wheel chair is not working and Charlie and Veronika have to take her to a manual wheel chair without a headrest or leg rest. Guddny is protesting and trying to explain what has happened with the wheel chair, but her voice is too weak and does not reach Charlie and Veronika. The electric wheel chair is broken, so the problem is not an empty battery as Charlie firstly assumes. What Charlie does not know is that this chair has a long problem-history.*

*Because Veronika is new in this job and is rather inexperienced, she refrains from taking part in decisions related to problems such as the wheel chair. Charlie has no other choice but taking charge over the situation and is clearly irritated about this. He does not communicate well with Veronika. Moreover, Charlie has a water leakage in this own home and has to*

*contact several craftsperson. He is stressed. Charlie shares with me that, often, he does not know enough about the patients, their diagnoses or medical needs.*

*Charlie gets even more stressed because the wheel chair situation will cause delay in the rest of his work day. He tries to reach the technical aids centre by telephone, but they cannot promise to help, because many other patients need help. It is Friday and the service centre is closed during weekends. Charlie is frustrated, but he decides to leave Gudny in the manual wheel chair. He sees that she is sitting uncomfortable, but announces – with a low voice – to Gudny, himself and me that he will try to figure this out.*

*While Charlie tries to be funny, friendly and attentive towards his other patients, he is still stressed and tries to hide this from me and the patients. It's not even lunch time yet and Charlie has already visited seven patients after Gudny. In between other work tasks, Charlie calls the home nursing base, to give them information about the wheel chair, but they say they cannot do more than contacting the technical aids centre again. When arriving at lunch, Charlie discusses the case with his leader. At this point, Charlie has tried to get help from many people, and he even presents the problem at the lunch mid-day meeting report. However, the response he gets is that it is dangerous to call the patients' homes for a service-home, because this gives the patients a reason to ask for full service. This response results in a fit of laughter in the group.*

*The lunch is over and we are back in the car and back to the apartments. Time has now passed one o'clock, and the shift has to finish at three o'clock. We are visiting patient number nine – the task now mainly is about serving a ready dinner meal from their fridge or from the central kitchen. When we arrive at the third patient after lunch, Charlie's alarm starts. Charlie calls the office and it turns out that it is Gudny who released the alarm. Quickly, we leave the current patient and go back to Gudny. Veronika comes running too. In the apartment is now Gudny's sister, telling us that she cannot understand that we just left Gudny the whole day, in this chair from which she is falling down. She could have felt on the floor and hit herself. Charlie gets more stressed and announces that we, first and foremost, need to move her to her bed. Gudny is in pain and expresses fear. Charlie and Veronika move Gudny to her bed, it is heavy work. Time is now two o'clock. Being in bed, Gudny says that she cannot stay in bed the whole weekend, and she gets support from her sister, who suggests that Gudny should borrow another chair. Gudny's sister shares that they have tried to get a new chair for Gudny for some time now, but that they have not succeeded to get one yet. Charlie calls the technical centre again and they promise they will do whatever they can to help, but*

*there are many other people who need help. He informs Gudny and her sister about this, and tells that he has to leave in order to finish his work for other patients, but promises to come back and see if the problem is solved. In the moment when Charlie is outside the room, Gudny's sister shares with me how shocked she is about the situation with Gudny and that she could not even imagine what Gudny's life would be without the support of her family.*

**What is the ethically important moment and dilemma about?** The ethically important moment comes to the front of the working day when Gudny, by telling Charlie and Veronica that she is unwilling to spend the whole weekend in the manual wheel chair, shows participation in her own situation and makes claim for an immediate change. As all work in the long-care sector should be pervaded with user participation, Charlie enters an emotional difficult situation, the moments Gudny starts to express, that the manual wheel chair is very uncomfortable to sit in, in particular if this is going to be for the whole weekend. This comes on top of a difficult care work situation, with Veronika as an unexperienced care worker, and with a water problem at home that has to be solved in between working; additionally, there is a researcher observing the situation. Charlie experiences 'moral distress' because his highest moral in this situation, caring about Gudny's situation, should actually make him able to stay with her, until the electric wheel chair was there. However, there is a long list of patients, he is supposed to visit, and he feels a duty to do this too. This is his working day duty: to support all the patients on this list. The ethical dilemma that this situation brings forward is whether to stay with one patient – fulfilling the caring duty – or leave and thereby fulfil duties for all patients. Is the requirement so important that he should stay? He chooses to leave, but is then suddenly taken back to the situation when Gudny, encouraged by her sister, releases the alarm she is provided with. This makes the ethical dilemma strong and challenging, as the patient's voice has now been strengthened by the voice of her sister. The situation is suddenly transformed into a dilemma of 'public' art also due to the presence of the researcher, who is involved in the situation. Sharing her frustration with the researcher, Gudny's sister tries to ally with the researcher and contributes to draw the researcher into the ethical important moment.

The ethical dilemma is due to a care-setting context, in which no time is included for unforeseen situations. The dilemma is also due to sometimes-uncoordinated functions of the care sector, which in everyday life can be crucial.

## **The nursing home example – old people and their relatives**

*A middle-aged married couple in their 60's has asked for a meeting with the nursing home doctor to discuss the situation of the woman's mother who is living at the nursing home. The woman's mother, Jenny, has dementia in an advanced stage and has been living at the nursing home for more than three years. Jenny is mostly staying at her own apartment comprising of dining and sleeping room in one, a small entrance and a bathroom. Due to her dementia, Jenny is difficult to make a contact with, sometimes she is not eating and her condition has utterly deteriorated during the last months.*

*The couple has an issue they want to discuss with the nursing home personal. They plan a longer stay outside Norway and will be staying at another continent for six months. The couple owns an apartment there and have travelled to that place many times during the last years, as they are now both retired. After some small talk they present the aim of the meeting – they wonder whether the nursing home doctor (the nurse is never asked the same question) thinks that Jenny, taken in consideration her worsened condition, is going to die while the couple is away. The couple wants the doctor to estimate how long the woman's mother is going to live based on his medical expertise. They want to know his professional opinion, because they are not sure if travelling abroad for such a long period is the right thing to do. On the other hand, Jenny's health condition has been poor but stable for many years now and the couple does not want to put their own life on hold while waiting for Jenny to die. It is Jenny's daughter who is doing most of the talking, while her husband holds her hand. Jenny's daughter speaks fast and frantically, she blushes and wipes away the tears in her eyes.*

*The medical doctor – a man in his thirties, wearing civil clothing, and with a long experience as a nursing home doctor, has been listening quietly for the most of the conversation. When he finally starts speaking, he tells the couple that he is just a human being and that only God can tell when our days are over. The couple seems confused by his answer and wonder if he jokes or not; they smile carefully and look at each other. But they seem also relieved, probably because the doctor has finally started speaking. It is clear that the doctor is not joking. He observes their insecurity and continues therefore with a careful voice. The doctor says that, on a general level, and taken into consideration Jenny's diagnosis, poor condition and old age, it would not be unlikely that she may die within a short period, regardless of whether they are travelling or not. The doctor says that he cannot give the couple a guarantee that Jenny is still alive when they come back from their trip and that the decision of whether to travel or not is up to them to make.*

*It turns out, however, that the tickets are already bought and that the conversation with the doctor, therefore, is not the turning point for their decision. The couple has also talked to their adult children, who have assured them that they will handle the situation should their grandmother die. During the conversation, and after having received more information, the doctor supports the couple's decision more and more. He says that given Jenny's condition she might not be mentally able to notice whether they or somebody else is present at her deathbed. Having received this information, the couple seems even more relieved and look at me as if they want me to confirm that I have heard what the doctor has just said. What in the beginning of the conversation looked like insecurities have now developed into a common agreement that it is important to live one's life and that Jenny would have supported their decision to travel had she been able to express her opinion. Practicalities in case of Jenny's death are discussed and arranged.*

*During the whole conversation, a nurse is present too, but she, just like me, remains silent and leaves the estimation of Jenny's medical condition to the doctor even though the doctor does not really know the patient. The doctor knows Jenny's medical history only through her medical journal, while the nurse is Jenny primary contact, which means that she has provided daily healthcare for Jenny, knows her medical history very well and has had a regular contact with Jenny's relatives. The nurse is in her 60s and has a long career in eldercare. However, at no point she is asked about anything. After the couple has left, she shares with me that the decision they have taken is wrong. She is clearly upset, but rather than speaking about Jenny, she speaks about the decreasing presence and insufficient care that people are showing for their sick and old family members.*

**What is the ethical important moment and dilemma about?** The ethical important moment has a point of departure in an end-of-life situation for a resident at a nursing home, having no influence on whether her daughter will be with her when she is dying or not. She has no say in this decision, which is discussed instead by her daughter and son-in-law with the nursing home's doctor. Moral distress is then experienced by the doctor, but in a much weaker version than is the case for the nurse, as this is a medical case for him, and a case about a patient she knows good and cares about, for her. The moral distress is also deeper for the nurse because her highest moral about older people when dying is that they should have the family around; they should participate in the last moments before death. The ethical dilemma here is twofold. One part is about whether (close) relatives should be expected to take care of their family member 'till the end', or they should have their free will to act as they want to. Another part is



about whether to discuss, in a public setting, an important matter without the main person present.

The ethical dilemma here is due to a long-term care sector context, where public care increasingly reduces the duties of family care, where ties between generations are loosening, and where the sector has made the nursing home ‘the last station’ without recognising older people’s user participation towards their end-of-life situation.

### **Grouped homes – the case of persons with intellectual disabilities**

*Henrik is 45 years old and a qualified nurse assistant. He has been working in the grouped home for many years. Ingeborg, a woman in her late 50s, is one of the residents of the house. For most of her life, Ingeborg has been living in institutions. With the introduction of a reform that decentralized the services for persons with intellectual disabilities, Ingeborg moved from a central institution to a grouped home. Ingeborg is working in a sheltered job where she produces wood logs from processed newspapers. Her condition lies between intellectual disability and psychiatry in addition to having some signs of dementia. Her family history is marked by broken relationships and an unstable childhood. Her apartment is tidy and she proudly shows it to guests. Ingeborg has a large collection of things, a lot of things and the personal in the grouped home sees this as a problem. Ingeborg loves shopping and uses all her money to buy things. However, the personal is divided in their view of how big this problem is. Henrik is one of those who think the personal is too involved in what the residents are doing; they should decide themselves. For Ingeborg, however, a behaviour-regulation-programme is developed. The ‘brain’ behind the specific programme for Ingeborg is developed in particular by three of the female employees who are playing a dominant role in the culture of this grouped home, not because they have leader positions, but simply because they have been working in the grouped home for a very long time.*

*Today, Henrik is going to carry out the conversation – called daily living training – where Ingeborg gets points depending on tasks she has carried out in her own home. When having gathered enough points, she is receiving a certain amount of money, and she can then use it for shopping. It often takes a long time for Ingeborg to earn enough points for buying something she would like to buy. Tasks may involve folding up cloth, starting a dishwasher and taking out the clean dishes, or dusting her home. The personal then uses a key code for*

*converting the points into money. Thereby, they can decide when Ingeborg gets access to her own money.*

*Although Henrik has been working in the grouped home for quite some time, he has not achieved any dominant position and rarely voices his opinion when discussions are taking place. When Henrik is carrying out the conversation with Ingeborg, he is forced to take on the role related to the dominating culture in this grouped home, a culture he is not part of and that he dislikes. Henrik has a book in which the tasks Ingeborg has carried out during week (and earlier) are written down and Ingeborg has a box with notes showing her amount of points. It is also a rule that Ingeborg always has to quit a piece of clothing every time she is going to buy a new one. Ingeborg has found some pieces she can quit, but the new thing she wants to buy – a set of bedclothes – is not achievable with the points she has earned so far. Sometimes she hides things she has bought behind bushes in the garden. When the personal finds out about this behaviour, they punish her by taking back some of the points she has earned through household chores. Henrik tells me that such punishment makes Ingeborg very sad and that she sometimes cries when treated badly by the personal. Henrik suspects that Ingeborg has been abused at the institutions she has been living earlier and is therefore afraid of adults just like abused children are.*

**What is the ethical important moment and the dilemma about?** The ethically important moment is about personal taking control over money that belongs to a resident living in a grouped home. Although the money is hers, the personal are using them to give her daily-living-training and thereby govern her use of her own money. The moral distress that Henrik experiences is that he has to carry out the ‘training’ as expected by the dominant culture of the house even though personally disagreeing with this care culture and the programme. He thereby works against his own will and his highest moral in this situation, which is to care about this resident by following her own will and taking account of her experiences from the past, rather than forcing her to control her money, as is expected of a person living a normal life. The ethical dilemma is about the development of a care culture, a specific way of approaching social work, that has to be carried out by all employees and towards all users involved, independent of professionals’ different ‘ethics work’ approaches.

This ethical dilemma is due to the relative autonomy of how to carry out social work in local care settings – and particular in sheltered housing (in terms of grouped homes), where a small group of users are meeting a small group of employees, developing their own care culture in

everyday life. The ethical dilemma is also due to the expectation of drawing residents of sheltered housing closer to ‘normal’ life.

### **Concluding discussion**

While the literature mostly has separated the discussion about care ethics from the discussion about user participation, we have demonstrated a connection. Theoretically, we have done this, in particular by utilising the concept of microethics. This can be viewed as a broader concept for different kinds of ethics work, including here the area of social work, putting on the agenda the emotional difficult situations of every day social work, and including also the feministic care ethics discussion. Although feministic care ethics, originally starting with the ‘other voice’ thinking of Gilligan (1982), did not speak about user’s participation, the key issue of the other voice is the requirement of placing the person receiving care centre stage above other – economic and bureaucratic – priorities (e.g. Christensen, 1998; Eliasson, 1987; Wærness, 1984), but without missing the perspective of those carrying out the work (e.g. Rummery, 2011; Tronto, 1994). The idea of ethically important moments has given us an approach as social qualitative researchers to ‘find’ moral distress in everyday care; stress that can be interpreted into wider ethical dilemmas, to do with history and context for, here, long-term care work in Norway. As we have chosen to explore and develop the ethical dilemmas within different topological care-settings, we find that they are representing key ethical dilemmas in current long-term care in Norway. In this sense, they are also – when one leaves the specific settings – representing more general ethical dilemmas in social work practice today, where the context increasingly limits the potentials of combining user participation with care ethics in everyday life.

### **References**

- Askheim, Ole Petter, Christensen, Karen, Fluge, Synnøve & Guldvik, Ingrid (2017): User participation in the Norwegian welfare context: an analysis of policy discourses, *Journal of Social Policy*, 46(3), pp.635-644.
- Banks, Sara (2016): Everyday ethics in professional life: social work as ethics work, *Ethics and Social Welfare*, 10(1), pp. 35-52.

- Barnes, Marian (2005): The same old process? Older people, participation and deliberation, *Ageing & Society*, 25, pp.245-259.
- Barnes, Marian and Cotterell, Phil (2012): From margin to mainstream, in Barnes, Marian and Cotterell, Phil (eds.) *Critical Perspectives on User Involvement*, Bristol: The Policy Press, pp. vv-xxvi
- Borgan, Jens-Kristian (2012): Pleie- og omsorgsstatistikk 1962-2010 [Health- and care statistics1962-2010], SSB report 10/2012, Oslo-Kongsvinger: Statistics Norway. Available at: [https://www.ssb.no/a/publikasjoner/pdf/rapp\\_201210/rapp\\_201210.pdf](https://www.ssb.no/a/publikasjoner/pdf/rapp_201210/rapp_201210.pdf)
- Brevik, Ivar (2010): De nye hjemmetjenestene – langt mer enn eldreomsorg [The new home-based services – much more than elderly care], NIBR report 2/2010, Oslo: Norsk institutt for by- og regionforskning (NIBR). Available at: <https://evalueringsportalen.no/evaluering/de-nye-hjemmetjenestene-langt-mer-enn-eldreomsorg-utvikling-og-status-i-yngres-bruk-av-hjemmebaserte-tjenester-1989-2007/2010-2.pdf/@@inline>
- Christensen, Karen (1998): Andre-orientering og omsorgsarbejde [Other-orientation and care work], *Tidsskrift for velferdsforskning*, 2, pp. 82-97.
- Christensen, Karen & Wærness, Kari (2018): Long-term care services in Norway: a historical sociological perspective, in Christensen, Karen and Pilling, Doria (eds.) *The Routledge Handbook of Social Care Work Around the World*, London and New York; Routledge, pp.15-28.
- Fangen, Katrine (2011): *Deltakende observasjon*, Bergen: Fagbokforlaget Vigmostad og Bjerke AS. Fangen, Katrine & Sellerberg, Ann-Mari (ed)(2014). *Mange ulike metoder*, Oslo: Gyldendal Akademisk.
- Featherstone, Brid & Gupta, Anna (2019): Social workers' reflections on ethics in relation to adoption in the UK: Everywhere but nowhere?, *British Journal of Social Work*, 0, pp. 1-17
- Fisher, Berenice & Tronto, Joan (1991): Toward a feminist theory of care, in Dean, H. (ed.) *The Ethics of Welfare: Human Rights, Dependency and Responsibility*, Bristol: Policy Press, pp. 29-49. Available at: [https://books.google.dk/books?hl=no&lr=&id=Wj0ZKVMa5-wC&oi=fnd&pg=PA35&dq=towards+a+feminist+theory+of+care&ots=U7auD44FA1&sig=dS9ZqjTN7HlvBw1rMwoXBkEyLDo&redir\\_esc=y#v=onepage&q=towards%20a%20feminist%20theory%20of%20care&f=false](https://books.google.dk/books?hl=no&lr=&id=Wj0ZKVMa5-wC&oi=fnd&pg=PA35&dq=towards+a+feminist+theory+of+care&ots=U7auD44FA1&sig=dS9ZqjTN7HlvBw1rMwoXBkEyLDo&redir_esc=y#v=onepage&q=towards%20a%20feminist%20theory%20of%20care&f=false)

- Førland, Oddvar, Fagertun, Anette, Hansen, Roar, & Kverndokk, Snorre (2017). *Normtider til besvær. Evaluering av normtider for hjemmetjenestene i Bergen Kommune*, Report(4) FRISCH HVL, Bergen: Senter for Omsorgsforskning.
- Gilligan, Carol (1982): *In a Different Voice: Psychological Theory and Women's Development*, Cambridge, MA: Harvard University Press.
- OECD (1994): *New Orientations for Social Policy Studies 12*, Paris: Organisation for Economic Co-operation and Development.
- Eliasson, Rosmari (1987): *Forskningsetik og perspektivval*, FoU-rapport 7A, Stockholm: Forsknings- og utvecklingsbyrå.
- Gautun, Heidi, Skevik, Anne & Hermansen, Åsmund (2012): *Hvordan fordele omsorg? Utfordringer med å prioritere mellom elder og yngre brukere* [How to distribute services? Challenges of priority between older and younger users], Fafo-report 62/2012, Oslo: Fafo.
- Noddings, Nel (1984): *Caring: A Feminine Approach to Ethics and Moral Education*, Berkeley: University of California Press.
- Hastrup, Kirsten (1988): Den tredje person: køn og tid i det islandske landskab [The third person: gender and time in the Islandic landscape], in Kirsten Hastrup and Kirsten Ramløv (eds.) *Feltarbejde, oplevelse og metode i etnografien* [Fieldwork, experience and method in ethnography], København: Akademisk forlag, pp.
- Hastrup, Kirsten (ed.)(2009): *Mellem Mennesker*, København: Hans Reitzels forlag.
- Hochschild, Arlie R. (1975): The sociology of feeling and emotion: selected possibilities, in Marcia Millman and Rosabeth M. Kanter (eds.) *Another Voice*, New York: Anchor Books, pp. 280-307.
- Koggel, Christine & Orme, Joan (2011): Care ethics: new theories and applications – Part II, *Ethics and Social Welfare*, 5(2), pp. 107-109.
- Lloyd, Liz (2010): The individual in social care: the ethics of care and the 'personalisation agenda' in services for older people in England, *Ethics and Social Welfare*, 4(2), pp. 188-200.
- Lloyd, Liz (2006): A caring profession? The ethics of care and social work with older people, *British Journal of Social Work*, 36, pp.1171-1185.
- Meld.St. 29 (2012-2013): *Melding til Stortinget: Morgendagens omsorg* [Report to the Storting: Tomorrow's care], Oslo: Helse- og omsorgsdepartementet.

Meld.St. 45 (2012-2013), *Melding til Stortinget: Frihet og likeverd – om mennesker med utviklingshemming* [Report to the Storting: Freedom and equality – about persons with intellectual disabilities], Oslo: Barne-, likestillings- og inkluderingsdepartementet

Mørk, Eiliv, Beyrer, Svetlana, Haugstveit, Fatima Valdes, Sundby, Brith & Karlsen, Håkon Torfinn (2018): *Kommunale helse- og omsorgstjenester 2017. Statistikk om tjenester og tjenestemottagere* [Municipal health- and care services 2017. Statistics about services and service recipients]. Report 26/2018. Oslo-Kongsvinger: Statistics Norway.

Orme, Joan (2002): Social work: gender, care and justice, *British Journal of Social Work*, 32, pp. 799-814.

Otnes, Berit (2015): Utviklingen i pleie- og omsorgstjenestene 1994-2013, *Tidsskrift for omsorgsforskning*, 2015, 1(1), pp.48-61. Rummery, Kirstein (2011): A comparative analysis of personalisation: balancing an ethic of care with user empowerment, *Ethics and Social Welfare*, 5(2), pp.138-152.

Tronto, Joan (1994): *Moral Boundaries: A Political Argument for an Ethic of Care*, New York: Routledge.

Ungerson, Clare & Yeandle, Sue (eds.)(2007): *Cash for care in developed welfare states*, Basingstoke: Palgrave Macmillan.

United Nations (2006): UN Convention on the Rights of Persons with Disabilities.

United Nations (1966): International Covenant on Economic, Social and Cultural Rights. New York: United Nations. Available at:

<http://www.ohchr.org/Documents/ProfessionalInterest/cescr.pdf>

Ward, Lizzie & Barnes, Marian (2016): Transforming practice with older people through an ethic of care, *British Journal of Social Work*, 46, pp.906-922.

Weinberg, Merlinda (2009): Moral distress, *Canadian Social Work Review*, 26(2), pp. 139-151.

WHO (2002): *Active aging: a policy framework*. WHO/NMH/NPH/02.8

[https://www.who.int/ageing/publications/active\\_ageing/en/](https://www.who.int/ageing/publications/active_ageing/en/)

WHO (2015): *World report on ageing and health*. Available at:

[https://apps.who.int/iris/bitstream/handle/10665/186463/9789240694811\\_eng.pdf;jsessionid=06DD6E5E41DB38EE17E24E5311281DB9?sequence=1](https://apps.who.int/iris/bitstream/handle/10665/186463/9789240694811_eng.pdf;jsessionid=06DD6E5E41DB38EE17E24E5311281DB9?sequence=1)

Wærness, Kari (1984): 'The rationality of caring', in *Economic and Industrial Democracy*, 5(2), pp.185-212.

Øye, Christine; Bjelland, Anne Karen & Skorpen, Aina (2007): Doing participant observations in a psychiatric hospital – Research ethics resumed, *Social Science & Medicine* 65, pp. 2296-2306

Øydgard, Guro (2018): Individuelle behovsvurderinger eller standardiserte tjenestetilbud? En institusjonell etnografi om kommunale saksbehandlers oversettelse fra behov til vedtak. [... An institutional ethnography on local government administrators' transition from requirements to decisions.], *Tidsskrift for omsorgsforskning* 4(1): 27-39. DOI: 10.18261/ISSN.2387-5984-2018-01-04

---

<sup>i</sup> The larger project is entitled 'Making user participation work – from policy to practice', and funded by The Research Council of Norway, and the Healthcare (HELSEOMSORG) programme. This project is a cooperation between Innland Norway Applied Sciences in Lillehammer and the University of Bergen.

<sup>ii</sup> We thank the researcher, who carried out this work.