

ARTICLE

The experience of dependence on homecare among people ageing at home

Bente Martinsen^{1*} , Annelise Norlyk¹ and Astrid Gramstad²

¹Department of Public Health, Research Unit for Nursing and Healthcare, Aarhus University, Aarhus, Denmark and ²Centre for Care Research North, UiT The Arctic University of Norway, Tromsø, Norway

*Corresponding author. Email: bm@ph.au.dk

(Accepted 31 January 2022; first published online 9 March 2022)

Abstract

Being dependent on homecare potentially threatens a person's integrity and autonomy, particularly when people are dependent on help to manage basic bodily functions that involve intimacy and nudity, making the person vulnerable despite being in his or her own home. As the population continues to age and live longer, more people are expected to be dependent on homecare. The aim of this study was to investigate the phenomenon of dependence on homecare among people ageing at home. Individual in-depth interviews were used to explore 15 Danish and Norwegian homecare receivers' experiences of dependence on homecare. Interview records were transcribed and analysed in a hermeneutical phenomenological process described by van Manen. First and foremost, the experience of dependence on homecare is a question of adaption. The older people in this study struggled to get used to their deteriorating body and at the same time they continuously had to negotiate to get care in accordance with their values. Being dependent on care could be experienced as being reduced to a task or a problem to be solved though the participants had a significant need for undivided mental attention. The presence of homecare staff in the participants' homes could entail a change where the participants experienced that they lost control over the surroundings. According to the voices of the older people in this study, future homecare should be accommodated in an organisational set-up that gives priority to stability and continuity in the relation between the homecare receiver and the homecare staff. Also it is significant that homecare staff do not have a task-oriented approach to their job and are sensitive to the values of the homecare receivers.

Keywords: Homecare; dependence on care; older people; phenomenology; interview

Introduction

Independence is highly valued and derives from a basic human desire for autonomy defined as a set of actions including self-governance, liberty, privacy, individual choice and the freedom to follow one's own will. The notion of autonomy was coined by the German philosopher Immanuel Kant (1724–1804), who stated

© The Author(s), 2022. Published by Cambridge University Press. This is an Open Access article, distributed under the terms of the Creative Commons Attribution licence (<http://creativecommons.org/licenses/by/4.0/>), which permits unrestricted re-use, distribution and reproduction, provided the original article is properly cited.

that humans are self-legislative and determined to follow ethical laws and principles they find reasonable (Henriksen and Vetlesen, 1997). Often autonomy is described as a human right, a right that does not relate to a person's actual ability to carry out concrete actions. The notion of autonomy *a priori* applies to a person's functional status irrespective of health and other life conditions. However, many people are unable to meet their own needs and require practical support from other humans for a shorter or longer time. For instance, ageing often generates a need for assistance to perform activities of daily living and this need may be permanent. Thus, the progressive ageing of the population suggests that dependence on care may become more common.

In Denmark and Norway, as well as in the other Nordic countries, homecare is for the most part funded and delivered by the state. The trend in health-care policy in the Nordic countries is to facilitate active ageing, ageing in place and to avoid institutionalisation for as long as possible (Torjesen *et al.*, 2016; Ervik, 2019). To strive for sustainability in the care sector, government also encourages family care takers, volunteers and older adults to co-produce the services (Norwegian Ministry of Health and Care Services, 2017–2018).

Current research mainly defines dependence in terms of a person's ability to function unaided (Secker, 2003), but the term may also refer to a person's ability to decide on her or his own (Leece and Peace, 2010). Thus, high levels of dependence may coalesce with the experience of feeling independent if independence is seen as subjectively self-assessed life experiences (Secker, 2003; Martinsen and Dreyer, 2012). A concept analysis defines care dependence as 'a subjective, secondary need for support in the domain of care to compensate a self-care deficit' (Boggatz *et al.*, 2007: 568). Functional limitations are a necessary antecedent of care dependence, and having unmet needs is a possible consequence hereof (Boggatz *et al.*, 2007). The level of care dependence varies between individuals; so does the quality of the relationship between the person needing assistance and the person providing help. However, common for all dependence relations is that getting assistance with basic bodily functions means that another human is close to one's body. This kind of help may be experienced as threatening for personal integrity (Vetlesen, 2001) and may induce embarrassment (De Sao José *et al.*, 2016).

People who are dependent on assistance from others to manage basic bodily functions may either be living in institutions or in their own homes. Studies show that being dependent on homecare workers may be experienced as a curtailment of one's personal autonomy (Ellefsen, 2002; Cotterell, 2008; De Sao José *et al.*, 2016). For patients, being part of a larger group of fellow patients, it may also be necessary to accept that one's care needs are subject to capacity and resource constraints (Martinsen *et al.*, 2018). Thus, care visits may be planned to suit the caregiver's working schedule rather than the patient's needs and are rarely negotiable. Accordingly, how homecare is organised significantly affects older people's experience of independence (Witsø *et al.*, 2012; Fjordside and Morville, 2016; Møller and Norlyk, 2017). Receiving homecare may be perceived as a constraint and a burden in daily life (Ellefsen, 2002; Ahlstrom, 2006; Cotterell, 2008). One study stresses that dependence on care tends to create an asymmetrical relation between the involved parties; and the more dependent a person is, the lower is the level of self-

determination (Møller and Norlyk, 2017). Contrary to this finding, Martinsen and Dreyer (2012) found that people living with a high degree of functional impairment who are employers for their helpers and live in their own homes may experience co-operation with their helpers as liberating if the helpers have genuine knowledge of the dependent person and strong practical skills. Hereby, helpers compensate for the dependent person's functional impairment to such a degree that it becomes possible to live a life similar to that of a self-reliant person. Furthermore, not everyone responds to dependence on homecare in the same way. For some, being dependent on others' help is very emotional, while others have a more rational approach. Hence, the quality of the relationship between the person getting help and the helper is crucial for the experience of getting help (Roe *et al.*, 2001; Martinsen *et al.*, 2009). Still, being dependent on care presupposes some level of gradual adjustment to the situation (Abad-Copa *et al.*, 2012; De Sao José *et al.*, 2016) and may be seen as part of a personal development (Pierrad *et al.*, 2015) involving a major shift in life, where older people may experience insecurity and uncertainty about their present and future situation (De Sao José *et al.*, 2016).

The above studies demonstrate that being dependent on care is multi-faceted and that being dependent on homecare potentially threatens a person's integrity and autonomy, particularly when people are dependent on help to manage basic bodily functions that involve intimacy and nudity, making the person vulnerable despite being in his or her own home. Consequently, in-depth insights into people's experiences of dependence within the context of homecare are needed. Hence, the aim of this study was to investigate the phenomenon of dependence on homecare among people ageing at home.

To broaden the perspective on dependence, we included participants from Norway and Denmark, which are both Nordic countries. Denmark has a population of approximately 5.8 million and Norway has a population of approximately 5.5 million. Denmark and Norway build on the same welfare model whose policies give priority to access, treatment and public health. Each element is tackled differently at a national or local level, but the overall structure and operation are similar (Einhorn, 2021).

Methodology

Phenomenology is a philosophical tradition that encompasses a wide range of qualitative methodological approaches aiming at capturing the essential meanings attributed to the lived experience of a given phenomenon. Subjective experiences are considered as means of both data collection and analysis. This study was designed as a hermeneutic phenomenological study, informed by the methodology of van Manen (2014), which is a recognised phenomenological approach. Hermeneutic phenomenological research is the study of the lifeworld, that is, the lived experience as immediately experienced and the meaning attributed to it. When using a phenomenological approach, it is key that the researcher stays open to the phenomenon under investigation for as long as possible. Thus, data gathering and analysis based on a theoretical framework is not consistent with the method. Since human experiences are nuanced, findings in phenomenological studies may also be nuanced, ambiguous and antagonistic.

Method

Individual in-depth interviews were used to explore peoples' experiences of dependence on homecare.

Recruitment

We recruited participants via public homecare services in Denmark and Norway. Leaders of the homecare services in four municipalities were invited to recruit persons receiving their services who were over the age of 65 and dependent on care, able to give informed consent, and able and willing to participate in an in-depth interview. Fifteen individuals, nine from Denmark and six from Norway, consented to participate and were interviewed in their homes. In the sampling process, we aimed to get variation in age, marital status and latest employment (Table 1) to achieve enough experiential material to create a reflective phenomenological text (van Manen, 2014).

Interviews

The semi-structured interviews were conducted to elicit rich descriptions of experiences of being dependent on homecare. BM conducted the Danish interviews and AG conducted the interviews in Norway. Both asked questions such as 'Could you please describe what you experience as significant when getting help from the homecare staff?' and 'How do you experience the co-operation with the homecare staff?' described in a common interview guide; and both encouraged participants to narrate freely on their experiences of dependence on care. The interviews lasted between 30 and 120 minutes. All interviews were audio recorded and transcribed verbatim. AG transcribed the Norwegian interviews and a professional transcriber transcribed the Danish interviews.

Ethical considerations

Ethical considerations followed the basic principles for research given in the Helsinki Declaration (World Medical Association, 2015). The Danish part of the study was approved by the Danish Data Protection Agency and the Norwegian part of the study was approved by the Norwegian Social Science Data Service. The participants received verbal and written information about the purpose of the study. Further, their right to withdraw and the confidentiality of the data given were outlined. Acknowledging that the older people might feel under pressure, the interviewers introduced themselves as respectively nurse (BM) and occupational therapist (AG) and stressed that there were no right and wrong answers to the questions. After the interviews, the interviewers assured that the participants were comfortable and urged them to call if they needed to have a follow-up talk.

Analysis

van Manen developed his meaning-giving approach 'phenomenology of practice' based on the thoughts from the Utrecht School (van Manen, 2014). This approach

Table 1. Participant characteristics

Participant number	Age	Gender	Marital status	Latest employment	Nationality and mother tongue	Depend on assistance in the following activities
1	86	Male	Married	Teacher (art)	Danish	Bathing, dressing, going to the bathroom, care of catheter
2	73	Male	Married	Local politician	Danish	Bathing, dressing
3	67	Male	Widower	Truck driver	Danish	Bathing, dressing, going to the bathroom
4	82	Male	Widower	Farmer assistant	Danish	Bathing
5	75	Male	Widower	Manager	Danish	Bathing, dressing, changing diapers, going to the bathroom, care of catheter
6	79	Female	Widower	Housewife	Danish	Hair wash, (now and then) bathing
7	90	Female	Widower	Assisting wife	Danish	Bathing
8	65	Female	Divorcee	Home carer	Danish	Bathing, putting on compression stockings
9	75	Female	Divorcee	Saleswoman	Danish	Bathing, dressing, changing diapers, going to the bathroom
10	69	Male	Single	Researcher	Norwegian	Bathing, dressing, changing diapers, care of catheter, eating, drinking
11	84	Female	Widower	Nurse assistant	Norwegian	Dressing
12	72	Female	Co-habitant	Nurse	Norwegian	Bathing, dressing, going to the bathroom
13	68	Male	Widower	Head of public relations	Norwegian	Bathing, dressing, going to the bathroom
14	68	Male	Divorcee	Consultant	Norwegian	Bathing, dressing, going to the bathroom, eating, drinking
15	82	Male	Married	Economical adviser	Norwegian	Bathing, dressing

advocates using both description and interpretation during the research process to gain insight into various aspects of the phenomenon, but also stresses openness as crucial to the entire research process. Hence, use of a theoretical framework is not consistent with van Manen's phenomenological approach (van Manen, 2014). Having mutual research interests in ageing at home and coming from different professional backgrounds, it was both challenging and necessary for the authors to strive for an open attitude towards the phenomenon, attempting to make preconceptions explicit and challenge them. The analysis followed the steps in thematic analysis as suggested by van Manen (2014). The research question: what is the experience of being dependent on homecare?, was pivotal throughout the analysis process. Danish and Norwegian are quite similar and in the holistic reading approach, all transcripts were read several times by BM and AG to get a picture of the material as a whole. In the next selective reading approach, BM and AG analysed in depth the interviews they had performed themselves in their respective mother tongue to facilitate the process of grasping the meanings. In the detailed reading approach, we tried to 'identify and capture thematic expressions of the phenomenological meaning' (van Manen, 2014: 320) by discussing, writing and re-writing evolving themes. BM and AG agreed on the final themes during a three-day intensive analysis workshop. During the writing process, the transcripts were reread to ensure that the themes were relevant and valid. Hereafter, all three authors discussed and agreed on the themes presented in the results and jointly prepared the rest of manuscript. In line with other qualitative methods, quotes are included in the findings where they serve to deepen rather than verify the meaning of the analytical text (Kvale and Brinkmann, 2014).

Results

The analysis revealed five themes describing aspects of experiences of being dependent on homecare when ageing at home.

Struggling to get used to the deteriorating body

First and foremost, the experience of dependence on care is a question of adaption. The participants describe that it was an awkward or a transcendent experience to get help in the beginning when their functional impairment made assistance unavoidable. One gradually adapts to the situation of having to rely on help from other people, but some care activities are easier to accept than others. It may be particularly difficult to get used to getting help with personal hygiene, going to the lavatory and other situations implying nudity. Even after many years with dependence on help from professional carers, some situations may be nearly unbearable and generate a feeling of impotence:

If I've had an accident and my trousers get really dirty ... I just cannot get used to that. It is so degrading. I cannot go to the bathroom and take off my pants and clean them and put them in the washing machine and everything; that is the worst. Sometimes, I wait for half an hour or an hour before I call them [the carers].

It does not help at all, but I delay it because I am so embarrassed. I never get used to that. (Participant 13)

Living with age-related changes does not mean that the participants pay no attention to their appearance. However, dependence on care leaves them with no choice but to disclose their naked body and be touched, sometimes by young strangers. This may be very uncomfortable, and the participants have limited or no influence on who is sent to help them. Situations with nudity and intimacy are dreaded, especially if the carer has another gender than the one preferred by the participant:

One thing is to stand there completely naked, right? And then to have a young man to help me with the diaper. That was really uncomfortable. (Participant 9)

Being a deteriorating body also entails a certain awareness where the participants compare their own level of dependence to that of others. Confrontation with people who are weaker seems to evoke fear of getting in a similar situation where the need for help increases. Therefore, it may be a challenge to receive rehabilitation in a training facility if it is part of a nursing home inhabited by ill residents:

Well, the nursing home is not the worst thing about it, but ... well there is so much dementia. So much absence of the mind. And I don't want to be ... be forced to be around mentally reduced people; really, that does not suit me at all. There you are, this is honest speech. (Participant 10)

Another consequence of the bodily awareness and the fear of getting more dependent is that patients try to handle as many of their personal activities as possible though this may be difficult. For example, one woman had severe difficulties putting on her underwear, but because of her incontinence, she had to change clothes several times during the day. To avoid calling for additional help, she developed a complicated and energy-consuming technique of rolling into the clothes when lying on her bed. A man also emphasised the importance of training and rehabilitation to avoid further deterioration:

I will not receive help until it is inevitable. I put faith in the exercise I get from the physiotherapist, because it is working for me, and I talk with my doctor to have more physiotherapy sessions. (Participant 15)

Overall, the experience of dependence involves a balance between acceptance of having a deteriorating body and fighting the deterioration as much as possible with whatever is left of one's capacity. Being dependent on homecare is not the same as being totally indifferent to one's appearance and just resign.

Losing control over the surroundings

Experiences of dependence on care mean that one is losing control over one's surroundings. Carers can change the home environment to suit their work and facilitate care situations, *e.g.* by installing a hospital bed in the living room. Assistive technology such as rails and ramps may be installed to facilitate everyday life.

These practical adjustments delay having to move to a nursing home but may also compromise the aesthetics of the home.

The participants also lose control of their close surroundings in a more concrete way. Restrictions in mobility and capacity mean that there are places at home and outside that are getting harder or impossible to reach, and that some tasks are difficult to perform: 'Now I cannot even let the cat in' (Participant 1).

Although the space one controls is shrinking, it may be a struggle to maintain a structure of the days and uphold influence over one's surroundings:

Every morning, I go out to do some shopping to keep myself busy. Because once you start sitting at home, one day you do not bother [to get out], then two, then three, and suddenly you do not bother at all. So, I keep myself busy, I just have to get out. (Participant 5)

When dependence limits a person's possibilities to move or act independently and maintain control, one's everyday life and surroundings become severely restricted, life starts to lack meaning:

When I was young, every day was a new day, but it is not like that anymore. Today is a continuation of yesterday. A new day means that there is some variation, but I cannot live up to that now. (Participant 3)

Control over the social environment is restricted, partly because getting out is more complicated, but also because visiting and going out implies getting help from others and involves presenting oneself as dependent:

I do not get out much. I used to be a party person, but now my wife goes to parties and I stay at home. I am not suited to go to parties with a wheelchair, I feel like I am in the way. (Participant 1)

Being dependent on care and ageing at home is associated with gradual and sudden loss of some or all autonomy and control over the physical and social surroundings one used to possess.

Being in continuous negotiations to get care in accordance with one's values

Experiences of dependence on care forces one to deliberate one's own values and make priorities when faced with the withering of resources and capabilities. Dependence on care is associated with work to negotiate an acceptable image and establish a balance between past and present life and self-concept:

It is very important for me to be nice and clean. I tell them [the carers], if they see a spot or stain on me, they must tell me. [My clothes] should be clean and whole. I shall not look like a tramp. (Participant 4)

Maintaining an impeccable style may support a previous self-concept, which is at stake when experiencing declining functioning. Thus, for the participants, 'good care' is care supporting their values and habits:

Sometimes I need to tell them: I am the one in need of care, and you are here to help me. You must be considerate of me ... Other times, I ask them to reconsider what they would have needed if they were in my position, to think about what it is like for me. (Participant 12)

Dependence on care involves being in forced togetherness with carers one might not have chosen oneself and who do not necessarily share one's experience of dependence of care. From a sensing perspective, being on the receiver's end of care, 'care' is experienced as layers of powerlessness, vulnerability and uncomfatableness. The carers may not have the same views of good care as the patient. For example, being dependent on help to get dressed is associated with vulnerability, shyness and discomfort for the receiver. When the carer decides that this activity should take place in the living room instead of the bathroom or the bedroom to save time or because it is more practical for the carer, the participants' values and perspectives are being ignored or devalued and rejected:

I would rather be sitting on my bed. But the carer who bathed me this morning, she does not want that. You know, I would have to stand out there, fluttering with my arms up to get out of my shirt and trousers. I would have to lift my legs and stuff ... I get nervous when I have to stand there, fluttering on my two legs. What if I fall? Will she grab me? (Participant 9)

The process of negotiating needs and values of care with the carer is further complicated by the myriad of carers often involved in participants' everyday lives. The participants must start again with new negotiations with each person involved in their care. Negotiating a common ground with a myriad of carers in accordance with one's values is a continuous, exhaustive adaptation process:

Why do they [the managers of the homecare services] send different people down here? ... Why don't they send those [carers] who know that to do and with whom I can communicate? They should not be sending a newly employed substitute even if I am able to tell them what to do. 'Now, you take the transfer belt and do like this. I have to be lying like this, the belt like that, no higher than to the shoulders' and so on and so forth. 'You need to use that ointment with this or that. It is over there in the white box. Just take it out. I need to wear a diaper, like this, and so on.' (Participant 5)

Instructing shifting carers and thereby being responsible for the quality of one's own care may be frustrating.

Needing undivided mental attention

Dependence on help means that the participants have to rely on acts performed by other people on their behalf. Optimally, these actions are the result of fine-tuned co-operation between the care recipient and the carer. However, whether the carer acts alone or on behalf of the participant, full attention to the task and the care recipient is crucial. Co-operation is hampered, for instance, when carers lack sufficient language competencies. Communicating one's needs and giving instructions is experienced as crucial to get good care and continuity in the care. However,

a large proportion of the carers were non-fluent in the native language of the people for whom they provided care:

I think that is what irritates me the most, that they do not listen, and that they do not understand. But I also get frustrated with the system that employs people that do not speak the language sufficiently. (Participant 14)

Another issue that adds burden to experiencing dependence on care is when carers lack practical competencies and knowledge. Lack of competence generates a sense of uncertainty as the participants have to keep an eye on the carers and cannot surrender themselves to the care. Instead of being constantly on guard, some of the participants assume responsibility for their carers' training so that they gradually become more competent, though it still puzzles some participants why incompetent carers are employed at all:

Care assistants coming straight off the street, right? There are no quality requirements, and he could do nothing, no hygiene, no nothing. (Participant 14)

Another element of presence is carers' use of mobile phones and headphones. It is not easy to co-operate with somebody who is looking at the phone while working and such behaviour hampers dialogue. Firstly, a carer's lack of presence impedes the quality of care, as one woman said:

They send someone over who is not yet educated, or very young, who just stands there looking at the phone, and it was not job related. I get so shocked over this behaviour. They are helping me with my diaper with one hand, their phone in the other. That is not good enough, and my diaper is not going to stay on. They are not present at all. (Participant 9)

Secondly, some participants thought that carers' lack of presence sent the message that the care work was not worthy of their attention:

A man came here one morning for my routine. He washed me and should fix the external catheter, and I thought he was so unfocused. So I asked him: are you more busy thinking about what you'll have for dinner today than to be here? Yes, he answered. You wouldn't believe it until you've heard it. (Participant 14)

Dependence on care may also be associated with a limited social life, which is another explanation for older people's strong wish for carers to be present. Visits from carers may be the only or one of the few contacts that older people living in their homes have.

Being reduced to a task that has to be completed

Being dependent on care may be experienced as being reduced to a task or a problem to be solved. Carers often focus strictly on the help the older people are entitled to receive and have no time for a cup of coffee or other similar social activities. Moreover, a high staff turnover does not facilitate a personal relationship between

the carer and the participant but reinforces elderly persons' experience of being a task rather than a person. Often the carers are very busy trying to get their work done in a rush so that they can move on to the next client. Their busyness can affect people who tend not to demand anything or very little when they sense that their carers are pressed for time. In some situations, carers are so impatient that they cannot wait for a given activity to end and therefore take over. One woman told:

I am under pressure the whole time; it is tough. I was at dinner at the day centre, and I eat slowly. Suddenly [a carer] took my plate and started to feed me without asking me. I could not stand it. Tears rolled down my cheeks. (Participant 8)

Being a task also means that the participants' days are often structured around the homecare visits. Often they simply have to adapt to get the help they need, and therefore they arrange their sleep, meals, visits, *etc.* so that they fit with the carers' schedules. Thus, when the schedules are modified, this may be perceived as very frustrating because changes bring the participants into situations where they are under time pressure even though they may have been waiting to get help for hours. One man said:

I wish that I could get up earlier, so I could be able to leave [to get to town or to appointments] at 10 o'clock or half past 9, without nagging them about it. (Participant 15)

Changes of life rhythm may also be needed due to the planning of the carers' visit rounds. For instance, the participants may have to accept getting help to go to bed much earlier or later than they were used to in their former life. Also, they may be disturbed in the middle of a favourite activity on a daily basis:

It is really annoying sometimes, when there is a good movie on the television or something. But it is of no use, I think to myself that I have to watch it another time. I cannot say 'please come back in an hour'. (Participant 13)

Receiving care in a private home means that fellow care recipients are not directly visible, even if the participants are very much aware that that they are part of a large group of care recipients for whom a certain carer is responsible. The carer's behaviour is one of the few clues to fellow care recipients' conditions; another is carers' telephone contact with other recipients. If fellow care recipients are unwell, this generates an extra pressure on the carers that is immediately felt:

They walk in without taking time to say hallo. They just start to work and are so stressed, and it affects their mood. (Participant 6)

So, the care the participants receive is indirectly affected by other care recipients' conditions.

Discussion of the results and methodological considerations

Our findings show that a major challenge associated with the experience of being dependent on homecare was the perceived loss of control over significant aspects of one's life. For instance, the people dependent on homecare were not allowed to decide which carers should help them although they needed care in the most intimate situations and felt shy about exposing their deteriorating bodies. Nor could they decide how and when they were assisted; instead, they had to negotiate if they wanted influence over their own situation. Furthermore, the participants experienced difficulties in setting boundaries, insisting on the carers' presence and considerations for their wishes. This dependence seemed to relegate the older people to a subordinated position. This finding is in line with the findings of Møller and Norlyk (2017), who found that dependence on homecare tends to create an asymmetric relation between the involved parties, and the more dependent a person is, the lesser becomes the scope for self-determination. In opposition to this, it has previously been shown (Secker, 2003; Martinsen and Dreyer, 2012) that it should be possible to combine high levels of dependence with the experience of perceived independence if this independence is seen as subjectively self-assessed life experience. However, in our study, the participants did not assess themselves as independent. On the contrary, they experienced that their limited physical faculty and subsequent dependence generated experiences of restriction and powerlessness. Dependence on homecare was not assessed as being in an independent situation at all. Nor was dependence experienced as a compensation for a self-care deficit as described by Boggatz *et al.* (2007) and Martinsen and Dreyer (2012). Rather, it was perceived as a process of continuous adaption to the shifting carers, the growing physical limitations and the organisational conditions of homecare. Loss of autonomy was evident in this study where the participants not only experienced a physical loss of control over their surroundings but also lost control over their total social situation. This is in line with other studies in this area (Ellefsen, 2002; Cotterell, 2008). Other studies (Fersch, 2015; Meldgaard and Kamp, 2016) have described how homecare services can be developed to foster agency and dignity among homecare recipients; however, in our study such initiatives were absent.

Another important finding is that dependence on homecare may generate an experience of being reduced to a task that has to be accomplished, of receiving deficient care and being affected by the carers' busyness, wherefore older people keep their wishes to themselves and accept the care they get. It is well known that people who receive homecare want to be recognised as individuals, to be paid interest to, to be talked and listened to, and to discuss their daily lives in the context of a human-to-human relationship (Holmberg *et al.*, 2012). We here for the first time show how feelings of powerlessness, vulnerability and uncomfortableness are intertwined and reinforce one another among people receiving homecare. We also demonstrate that growing accustomed to dependence on homecare is exceedingly difficult, notably when the carers' approach is task oriented. Reducing the care to fulfilling tasks leads to unnecessary suffering (Eriksson, 2006). According to Dāvøy and Martinsen (2014), treating patients like objects without taking their wishes into consideration is shameless and undresses the patients. Imprudent actions feed on both parties' life energy and is tantamount to abuse of trust that

is given with life. Building care on imprudent actions equates with a state of lawlessness where the boundaries of privacy are transgressed and unacceptable situations generated. To act imprudent is devastating because this approach hinders growth and development (Dåvøy and Martinsen, 2014). Consequently, when older people in this study experienced that they were reduced to a task, they were unintendedly brought into a locked position.

This task-oriented approach in homecare reflects the rationale pertinent in the management of Danish and Norwegian homecare that every task has to be minutely organised and time-scheduled to optimise cost-efficient homecare. This way of organising homecare thus reflects several aspects of Taylor's ([1911] 1998) theory of scientific management developed with the production industry in mind (Morgan, 2006). However, today scientific management has transferred from mass production into service companies and the public sector (Miller, 2012). In a hospital context, Norlyk *et al.* (2017) describe this approach to care as 'McNursing' because it favours standardisation and does not include the perspective of the individual patient. Our findings add to these findings by showing how this pervasive rationalisation in a homecare context represents an inherent danger of oppressing the older person's individual needs and wishes and has depersonalising consequences – particularly when older people are dependent on homecare. However, receiving homecare is not *per se* negative or positive. Rather, it is primarily the attitudes and the behaviour of the carers that determine whether the care is experienced as positive or negative (Pirreda, 2015; De Sao José *et al.*, 2016).

Terms of employment where carers are employed by the very people who are dependent on care may change the power structure in relations because in these situations care is found to be individualised and liberating (Martinsen and Dreyer, 2012). This model may be beneficial because the care recipient may partly control the care received and the conditions under which care is provided. Private homecare providers have been an option in addition to public homecare in Denmark and Norway in the past years. Private homecare provision has been introduced in response to a growing demand for standardisation and task orientation in public homecare (Hjelmar and Rostgaard, 2019). Also a political reform in Denmark in 2003 ensured that municipalities must give care recipients the choice of engaging a private homecare provider. In Norway, the municipalities decide for themselves whether or not they want to collaborate with private homecare providers. However, frail users with bodily care needs still tend to prefer public homecare (Hjelmar and Rostgaard, 2019). This development has to be considered in light of the political idea of 'ageing in place' (World Health Organization, 2002). Indeed, continuation of this strategy requires a continued effort to ensure sustainable, high-quality homecare. For policy makers, the present results are significant in one major respect: dependency should not be accommodated in an organisational set-up that involves a high flow of carers who have a task-oriented approach to their job.

Methodological considerations

A strength in our study is that the participants belong to a group of older people who are rarely given voice. Rigour was achieved by incorporating the classic notions of credibility, dependability, transferability and conformability described by Lincoln

and Guba (1985). To accede to these criteria in a way that is consistent with phenomenology, we approached the study with an attitude of balancing our existing knowledge derived from former research and clinical work with an open and wondering mind (van Manen, 2014). To truly identify the phenomenon of dependence on homecare when ageing at home, we continuously questioned our pre-assumptions to hinder self-confirmation to sneak behind our back during the interviews and the analysis.

As sampling within a phenomenological study is focused on gathering in-depth knowledge and variations of experiences of the phenomenon rather than demographics and a large study sample (Giorgi, 1997; van Manen, 2014), we included 15 older people who varied in nationality, age, civil status and functional conditions. Thus, the sample was limited in accordance with phenomenological recommendations (Norlyk and Harder, 2010; van Manen, 2014). The participants' descriptions were sufficient to achieve enough examples to truly describe the phenomenon. To attain confirmability, the authors jointly worked back and forth in the material in a transparent process of analysis to agree on five themes that were beyond the taken-for-granted understanding of everyday life (van Manen, 2014).

A limitation of the study is that we were unable to obtain data on the carers' educational background. Some carers may have been nurse assistants, others social and health assistants, and yet others may have had no care-related education and training at all. Further, the Danish participants were recruited by one homecare nurse, which might have influenced the selection of the Danish participants. However, we had no reason to believe that the homecare nurse had any interest in biasing our findings. It may have been beneficial to include some observations to enhance the understanding of the experience of being dependent on homecare.

Conclusion

Dependence on homecare was experienced as a process of adaptation where the older people had to get used to disclosing their deteriorating bodies to shifting carers with whom they also had to negotiate the wishes they had for the care. Despite detailed negotiations, the older people could experience that their care was reduced to a task that had to be fulfilled in the shortest time possible. Lack of knowledge, engagement and language skills among carers occasionally made the older people experience themselves as invaluable and not worthy of the carers' attention. Gradually, the space the older people were able to control was shrinking, and their surroundings were invaded by care remedies. The structure of the day was affected by the homecare visits and their functional impairments prevented them from unfolding their lives. A greater understanding of homecare recipients' experiences of dependence is crucial to improve the quality of the care.

Acknowledgements. We appreciate the older people who contributed to this study.

Author contributions. BM and AG designed the study and conducted the interviews. BM and AG did the initial data analysis, and all authors discussed the results and contributed to the final manuscript.

Conflicts of interests. The authors declare no conflicts of interest.

Ethical standards. Ethical considerations followed the basic principles for research given in the Helsinki Declaration. The Danish part of the study was approved by the Danish Data Protection Agency (ID number 2016-051-000001-1073) and the Norwegian part of the study was approved by the Norwegian Social Science Data Service (ID number 61085).

References

- Abad-Corpa E, Gonzalez-Gil T, Martínez-Hernández A, De la Cuesta-Benjumea C, Monistrol-Ruano O and Mahtani-Chugani V** (2012) Caring to achieve the maximum independence possible: a synthesis of qualitative evidence on older adults' adaptation to dependence. *Journal of Clinical Nursing* **21**, 3153–3169.
- Ahlstrom G** (2006) Personal assistance for patients living with a severe neurological disorder. *Journal of Neuroscience Nursing* **38**, 183–193.
- Boggatz T, Dijkstra A, Lohrmann C and Dassen T** (2007) The meaning of care dependency as shared by care givers and care recipients: a concept analysis. *Journal of Advanced Nursing* **60**, 561–569.
- Cotterell P** (2008) Striving for independence: experiences and needs of service users with life limiting conditions. *Journal of Advanced Nursing* **62**, 665–673.
- Davøy G and Martinsen K** (2014) Skam på godt og ondt [Shame for good and bad]. In Alsvåg H, Føland O and Jacobsen FF (eds). *Rom for omsorg? [Space for Care?]*. Bergen, Norway: Fakkbokforlaget, pp. 93–109.
- De Sao José J, Barros R, Samitca S and Teixeira A** (2016) Older persons' experiences and perspectives of receiving social care: a systematic review of the qualitative literature. *Health and Social Care in the Community* **24**, 1–11.
- Einhorn SE** (2021) *Healthcare in the Nordics*. Available at <https://nordics.info/show/artikel/healthcare-in-the-nordic-region/>.
- Ellefsen B** (2002) Dependency as disadvantage – patients' experiences. *Scandinavian Journal of Caring Sciences* **16**, 157–164.
- Eriksson K** (2006) *The Suffering Human Being*. Chicago, IL: Nordic Studies Press.
- Ervik R** (2019) Policy responses to aging: care services for the elderly in Norway. In Jing TK, Kuhnle S, Pan Y and Chen S (eds), *Aging Welfare and Social Policy: China and the Nordic Countries in Comparative Perspective*. Cham, Switzerland: Springer International Publishing, pp. 105–124.
- Fersch B** (2015) Expectations towards home care re-ablement in Danish municipalities. *International Journal of Sociology and Social Policy* **35**, 26–140.
- Fjordside S and Morville A** (2016) Factors influencing older people's experiences of participation in autonomous decisions concerning their daily care in their own homes: a review of the literature. *International Journal of Older People Nursing* **11**, 284–297.
- Giorgi A** (1997) The theory, practice, and evaluation of the phenomenological method as a qualitative research procedure. *Journal of Phenomenological Psychology* **28**, 235–260.
- Henriksen J and Vetlesen AJ** (1997) *Naerhed og distance. grundlag, vaerdier og etiske teorier i arbejdet med mennesker [Closeness and Distance, the Foundation, the Values and the Ethical Theories in the Care]*. Oslo: Ad Notam Gyldendal.
- Hjelmar U and Rostgaard T** (2019) Supplemental home care and topping-up: a shift from service universalism towards a new and privatised public service model? *International Journal of Social Welfare* **29**, 118–128.
- Holmberg M, Valmari G and Lundgren SM** (2012) Patients' experiences of homecare nursing: Balancing the duality between obtaining care and to maintain dignity and self-determination. *Scandinavian Journal of Caring Science* **26**, 705–712. doi: 10.1111/j.1471-6712.2012.00983.x.
- Kvale S and Brinkmann S** (2014) *Interview. Det kvalitative forskningsinterview som håndværk [Interviewing as a Craft]*. Copenhagen: Hans Reitzels Forlag.
- Leece J and Peace S** (2010) Developing new understandings of independence and autonomy in the personalised relationship. *British Journal of Social Work* **40**, 1847–1865.
- Lincoln YS and Guba EG** (1985) *Naturalistic Inquiry*. USA: Sage.
- Martinsen B and Dreyer P** (2012) Dependence on care experienced by people living with Duchenne muscular dystrophy and spinal cord injury. *Journal of Neuroscience Nursing* **44**, 82–90.
- Martinsen B, Harder I and Biering-Soerensen F** (2009) Sensitive cooperation: a basis for assisted feeding. *Journal of Clinical Nursing* **18**, 708–715.

- Martinsen B, Mortensen F and Norlyk A** (2018) Nordic homecare nursing from the perspective of home-care nurses – a meta-ethnography. *British Journal of Community Nursing* **23**, 597–604.
- Meldgaard AH and Kamp A** (2016) From carers to trainers: professional identity and body work in rehabilitative eldercare. *Gender, Work and Organisation* **2**, 63–76.
- Miller K** (2012) *Organizational Communication: Approaches and Processes*, 6th Edn. Boston, MA: Wadsworth.
- Møller AF and Norlyk A** (2017) Ældre patienters oplevelse af selvbestemmelse, når de modtager sygepleje i eget hjem – en fænomenologisk-hermeneutisk undersøgelse [Older patients' experience of self-determination when they receive home care nursing – a phenomenological hermeneutic study]. *Klinisk Sygepleje* **31**, 252–277.
- Morgan G** (2006) *Images of Organization*, 4th Edn. London: Sage.
- Norlyk A and Harder I** (2010) What makes a phenomenological study phenomenological: an analysis of peer-reviewed empirical nursing studies. *Qualitative Health Research* **20**, 420–431.
- Norlyk A, Haahr A, Dreyer P and Martinsen B** (2017) Lost in transformation? Reviving ethics of care in hospital cultures of evidence-based healthcare. *Nursing Inquiry* **24**, e12187.
- Norwegian Ministry of Health and Care Services** (2017–2018) *Report No. 15 to the Storting. A Full Life – All Your Life. A Quality Reform for Older Persons*. Oslo: Norwegian Ministry of Health and Care Services.
- Piredda M, Matarese M, Mastroianni C, D'Angelo D, Hammer MJ and De Marinis MG** (2015) Adult patients' experiences of nursing care dependence. *Journal of Nursing Scholarship* **47**, 397–406.
- Roe B, Whattam M, Young H and Dimond M** (2001) Elders' perceptions of formal and informal care: aspects of getting and receiving help for their activities of daily living. *Journal of Clinical Nursing* **10**, 398–405.
- Secker J** (2003) Promoting independence: but promoting what and how? *Ageing & Society* **23**, 375–391.
- Taylor FW** ([1911] 1998) *The Principles of Scientific Management*. Mineola, NY: Dover Publications.
- Torjesen DO, Kvåle G and Kiland C** (2016) The quest for promoting integrated care in the Scandinavian countries – recent reforms, possibilities and problems. In Lounsbury M, Pinheiro R, Ramirez FO, Geschwind L and Vrangbaek K (eds), *Towards a Comparative Institutionalism: Forms, Dynamics and Logics Across the Organizational Fields of Health Care and Higher Education*. Bingley, UK: Emerald Group Publishing, pp. 195–213.
- van Manen M** (2014) *Phenomenology of Practice: Meaning-giving Methods in Phenomenological Research and Writing*. Walnut Creek, CA: Left Coast Press.
- Vetlesen A** (2001) Omsorg -Mellem afhængighed og autonomi [Care – between dependence and autonomy]. In Ruyter K and Vetlesen A (eds), *Omsorgens tvetydighed: Egenart, historie og praksis [The Ambiguity of Care: It's Distinctive Character, History, and Practice]*. Oslo: Gyldendal Akademisk, pp. 27–42.
- Witso AE, Vik K and Ytterhus B** (2012) Participation in older home care recipients: a value-based process. *Activities, Adaption & Ageing* **36**, 297–316.
- World Health Organization** (2002) *Active Ageing: A Policy Framework*. Available at https://www.who.int/ageing/publications/active_ageing/en/.
- World Medical Association** (2015) *Declaration of Helsinki – Ethical Principles for Medical Research Involving Human Subjects*. Available at <https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/>.

Cite this article: Martinsen B, Norlyk A, Gramstad A (2024). The experience of dependence on homecare among people ageing at home. *Ageing & Society* **44**, 282–297. <https://doi.org/10.1017/S0144686X22000150>