

# What makes dependency on homecare bearable?

## A phenomenological study

### **Abstract**

Becoming dependent on homecare in old age is a radical life change that requires complex adaptation. The purpose of this study was to explore the existential dimension of being dependent on homecare with a particular focus on what makes dependency bearable. Fifteen older people living in Denmark or Norway were interviewed using a phenomenological approach. The material was analysed employing Max van Manen's meaning-giving approach coined "Phenomenology of practice". During the analysis, four themes emerged: pure acceptance of an inevitable situation, acting independently as much as possible, negotiating to receive good care, and gratitude towards caring caregivers. The results point to a need for respectful and individualised homecare levelling out the subordinate position in which dependency on homecare tends to place older people.

Keywords: Care dependency, homecare, interviews, phenomenology

Since the late 1980s, the concept of "successful ageing" has played a significant role in research and in the public discourse defining the characteristics of good life in old age (Bülow & Söderqvist 2014). The basic principles of this model are that independency, activeness, productivity and consumption should continue long into retirement (Bülow & Söderqvist 2014). Thus, at first sight, the idea of successful ageing is indisputably positive, but, on closer inspection, the fact that most people experience some measure of deterioration during the process of ageing seems to be ignored. Furthermore, research shows that older people in

general fear becoming dependent on care regardless of their state of weakness (Fjordside & Morville 2016). Even in late life, being dependent on assistance from other people is feared more than pain (Seale & Addington-Hall 1994). This fear of being dependent on others was further substantiated in a synthesis of qualitative studies (Abad-Copa et al. 2012). Here, the authors found that “dependency” was defined with regard to “subordination”, “biographical disruption”, “life dissatisfaction”, “feeling or carrying a burden” and “the establishment of a relationship of care based on accommodation, resignation and resistance” (Abad-Copa et al. 2012). Furthermore, losing control over bodily functions may generate feelings of guilt and embarrassment (Eriksson & Andershed 2008), and the experience of being dependent often equals a “move forward in a life that hurts” (Strandberg et al. 2003, p. 77). Hence, dependency on care requires complex adaptation, a process during which the dependent person gradually needs to develop a new self-image integrating dependency as part of a “new normal” (Abad-Corpa et al. 2012, Piredda et al. 2015). Being dependent on care in old age thus means that one needs to accept receiving help from caregivers in various intimate situations such as bathing, dressing, going to the toilet, etc.

### **Dependency in homecare**

In Europe, “ageing in place” has been a political healthcare strategy for the past two decades (WHO 2002). Thus, people are supposed to remain as long as possible in their own homes and receive the care they need there. In the Nordic countries homecare nursing consists of services being offered to all citizens in need, regardless of income, family situation and network, and paid for primarily by public funds, though private providers also exist. Homecare services conduct tasks that are usually the responsibility of family members in

many other countries. However, receiving homecare has several drawbacks: Care visits are rarely planned to fit into the life rhythm of the person living with dependency wherefore the visits may threaten his or her personal autonomy (Cotterell 2008, Ellefsen 2002, Fjordside & Morville 2016; Witsø, Vit & Ytterhus 2012). Moreover, older people receiving homecare find that they have minimal or no influence on decisions concerning the allocation and overall planning of the care they receive. Important decisions involving their life are made at an organisational level beyond care receivers' sphere of influence (Fjordside & Morville 2016, authors). Dependency on homecare also tends to affect the care relation negatively; the more dependent a person is, the lower his or her level of self-determination is (Møller & Norlyk 2017).

Consequently, becoming dependent on care brings a radical change in a person's life as it alters one's being in the world. In other words, dependency on care encompasses an existential dimension by introducing an existential struggle. As stressed by Hörberg et al, (2019), it is important to acknowledge the need to integrate medical, biological and existential aspects within caring practices because these dimensions are equally important and intertwined. However, this existential struggle risks being neglected in our treatment of older people due to the value attributed to independency and the priority given to self-reliance in the Western world.

Despite the severe challenges related to dependency on care in old age, only little is known about this existential dimension. Dependency was described as being and carrying a burden (Abad-Corpa et al. 2012), but little is known about the existential dimension carried by older people. In short: How do older people who become dependent on home care make this burden bearable?

## **Purpose**

The purpose of this study was to explore the existential dimension of being dependent on homecare in general and what makes dependency bearable in particular. This paper forms part of a larger study aiming to explore the experience of dependency among people ageing at home.

## **Methods**

### Participants and settings

Individual in-depth interviews with older adults receiving home care were conducted. The participants were recruited via public homecare services in Denmark and Norway. Leaders of homecare services sent out invitations for participation in the study to home care recipients who were more than 65 years of age, capable of giving informed consent and able to participate in an in-depth interview. Nine men and six women consented to participate by contacting the first- or the last author and were interviewed by either the first or the last author. Interviews were held in the participant's home. Table 1 lists selected patient characteristics.

Please insert Table 1 about here

### Interviews

A semi-structured interview guide was developed to elicit rich experiential descriptions of what it is like to be dependent on homecare and what is needed to make the situation bearable.

The guide included questions such as “Please describe what it is like to receive help with...?” and “What do you experience as significant when receiving help from the homecare staff?”. Furthermore, the interviewers also encouraged participants to narrate their experiences freely. The duration of the interviews was 30-120 minutes. Interviews were audio recorded and transcribed verbatim.

#### Methodological approach and data analysis

The analysis was guided by Max van Manen’s meaning-giving approach coined “Phenomenology of practice”. This approach advocates gaining insight through the use of descriptions as well as interpretation in the course of the research process. The approach stresses openness towards what the material may reveal as crucial to the phenomenon under investigation. The aim of exploring the existential dimension of being dependent on care guided the analysis process, and special attention was paid to what makes dependency bearable. The analysis followed the steps suggested by van Manen (2014). In the holistic reading approach, all transcripts were read several times by the first and last author to build a comprehensive overall understanding of the material. Next, in the selective reading approach, the first and last author analysed in depth the interviews which they had conducted in their respective mother tongue. All segments of the interviews related to making dependency on care bearable were identified and extracted for further scrutiny. In the detailed reading approach, all authors strived to “identify and capture thematic expression of the phenomenological meaning” (van Manen 2014: 320) by discussing, writing and re-writing evolving themes.

#### Ethical considerations

This study was conducted in accordance with the Helsinki declaration (World Medical Association, 2015). The participants received verbal and written information about the study and were also informed about the confidentiality of the data and their right to withdraw from the study. The Danish part of the study was approved by the Danish Data Protection Agency [ID no.: 2016-051-000001-1073]. The Norwegian part of the study was approved by the Norwegian Social Science Data Service [ID no.: 61085].

## **Results**

The material revealed various existential dimensions that make dependency on homecare bearable, ranging from accepting the situation to engaging in a constant struggle to receive appropriate help. During the analysis, we identified four themes describing diverse aspects of making the burden bearable: pure acceptance of an inevitable situation, acting independently as much as possible, gratitude towards caring carers, and struggling to receive good care. Below, we elaborate on each of these themes.

### **Pure acceptance of an inevitable situation**

A deliberate decision

When dependency on care was inevitable, accepting the situation without mourning the loss of independency and previous abilities was an important aspect to making dependency bearable. Acceptance was associated with focusing on other elements of everyday life, not allowing dependency on care to occupy one's mind. Receiving homecare was, indeed, necessary to uphold one's everyday life, and imagining being in a situation where one could not receive the help needed was intimidating:

*I just decided to consider it a necessity (...). It does not need to be a problem (8)*

The older people were very much aware of their aged bodies. In situations with undressing and nudity, it would occasionally be particularly challenging to stick to their deliberate choice of accepting dependency. At times, they needed to remind themselves that no alternative existed and that they had decided to accept their situation. Humour would be used deliberately to make situations bearable in which dependency caused awkward situations. The material showed that humour was linked to surplus energy.

*I think you need a sense of humour. I mean that you try to make things funny. And I think it is nice if we can have an easy tone when they come to visit, joke a bit and then it all works out fine. (...) So, if I notice any mistakes and funny situations, I write it down and give it to the care workers. Some funny little verses (13).*

However, not all older people were capable of dealing with their involuntary situation of dependence by employing humour.

Slowly sliding into the role

Accepting the inevitable situation was not necessarily a deliberate decision. In some cases, becoming accustomed to care dependency was a gradual process. For some, it was surprising

that dependency was bearable, because, when self-reliant, they had thought that dependency on care would be unbearable.

*I never thought that I was even close to needing help with anything. I just thought that this is getting very difficult now. Difficult to get dressed, difficult getting to the toilet in time. (...) But when I ended up in the wheelchair, I got care services quite quickly, and then it was all right, I just had to (14).*

However, being in a situation in which dependency on care was inevitable changed one's perspective, which made the change bearable. Knowing that dependency was irreversible and realising that the only development one could expect was a growing need for help made it necessary to deal with the situation to carry on living. Dealing with the situation occasionally involved avoiding thinking about it and at other times required settling into resignation.

*I never think about it. Right now, I think my life is ok (1).*

Dependency on homecare could be difficult to bear when it was experienced as a precursor to living in a nursing home, which the participants spontaneously stated that they preferred to avoid. Some had experiences from temporary admissions to nursing homes during which they had received comprehensive rehabilitation and found the perspective of needing to live in a nursing home threatening:



*Regardless of how frail I become, moving to a nursing is the last thing in the world I want to do. I just don't want that, no way. Three months was more than enough (5).*

Dependency on care per se generated thoughts about what might be the 'next level' in a potential development of dependency, and the participants expressed an intense desire to freeze their degree of care at the current level. To make the situation bearable, they tried to keep negative thoughts at bay, though they were aware that end of life was near. This was described as a frustrating, but natural situation.

In all, making the best of the situation by accepting, getting used to and getting along with their new everyday life was a prominent aspect in making dependency on care bearable.

### **Acting independently as much as possible**

Another aspect of making dependency on homecare bearable was to do as much as possible independently. Hereby, it would be possible to slow down the process of deterioration and postpone the point at which more care would become necessary. However, acting independently would occasionally call for alternative ways of tackling everyday activities:

*It may sound a bit odd; but getting dressed is among the toughest things to do. A t-shirt, for example, it can be extremely [bothering]. You see, some mornings I*

*tumble around trying to put on a buttoned one. That's just completely out of the question (3).*

In situations in which the participants were unable to obtain the care they wanted or had no say as to the time it was provided, they occasionally opted to use informal helpers, e.g., spouses. For some participants, this served as a flexible solution allowing them to sustain their former life rhythm or ensuring that they would receive services that the professionals were unable to provide due to statutory limitations. Also, decreasing one's needs could make dependency on homecare bearable if it was difficult to obtain the desired care; e.g., instead of taking a daily shower in some cases, the older people would change their routine to washing by the sink.

### **Negotiating to receive good care**

Negotiating and collaborating with care personnel and their managers to receive the amount and quality of the care wanted was another aspect of making care dependency bearable. Specifically, some of the participants engaged in what may be termed "silent rebellion" against the received care in order to achieve the care they wanted. This approach was founded on the assumption that complaints and making demands would potentially improve the care they were receiving. Furthermore, dialogue with caregivers and leaders served as a possible means to level out the subordinated role in which dependency on care had placed the older people. Calling the leaders of the homecare or arguing with caregivers during their visits generated a feeling that they were taking action to influence their situation and maintain some level of self-determination despite their dependency:

*Well, occasionally I have made quite a bit of noise in the home care service (...), and I have met with their manager to explain calmly and quietly, properly and decently, how I perceived the care (5).*

At times, it would be difficult to negotiate one's wishes face-to-face with caregivers if one feared that discussions would interfere with a good relationship or even result in a conflict reinforcing the older person's subordinate role. Conflicts with caregivers did not contribute to making dependency bearable. Rather, they would potentially relegate the older person to an even lower level of power *vis-à-vis* the caregiver. However, drawing on one's experiences as a recipient of care and on knowledge of one's own situation and needs could also be a powerful resource in achieving good care:

*I am quite clear (to the carers) about how I want things; that I am the one who needs help; and that they are here to help me. And I've worked as a nurse for so long, so I know this. So, not to complain, but you must learn, and you should be considerate to me (12).*

Overall, this theme describes the dependent persons' active efforts to achieve good care from their carers, and the theme captures how this work made dependency on care bearable.

### **Gratitude towards caring carers**

Dependency on homecare would be easier to bear if the older people experienced that their caregivers were eager to meet their wishes. In some cases, the caregivers bent the rules and went out of their way to ease the older person's life:

*She went out to do my shopping, and she's not allowed to on Sundays. But even so, she did my shopping (3).*

Occasionally, the caregivers adjusted the care to the individual person and situation, thereby shifting care from a duty-bound activity to playful collaboration:

*I like for those young carers to come over so that we can hold hands and go to toilet dancing. Well, dancing may not be the word, but things work better (...) that way (9).*

Experiencing caregivers who were committed and willing to do something extra was very much appreciated by the older people ageing at home. The participants repeatedly referred to situations in which they had experienced healthcare professionals who made them feel special and in good hands. These situations made their dependency on homecare more bearable.

*I had one assistant who was here all the time. All the time, almost every day, not one time did she fail to ask if my shoelaces were tied right. On both legs. She asked me every time. I thought that was very good. Because you know, when you tie someone's shoes, you don't know how tight they should be. (...)*

*Of course, I don't mind that people tie my shoes without asking me, it's not such a big deal, but it was... she was a caring person (13).*

So, the caregivers' attitude and actions played a profound role in making the dependency bearable for the older people in this study.

## **Discussion**

Our findings revealed that participants adapted to their dependency on care in a range of ways to make it more bearable. Being dependent was a new way of being in the world that made them respond by employing one or more elements on a continuum of adaptive strategies ranging from making a deliberate decision about accepting dependency as a way of being to continuously insisting on receiving as good a care as possible. Making dependency on care bearable was a process that would occasionally change over time, starting with resistance and slowly shifting towards acceptance. Seen from a self-reliance perspective, it may be unbearable to be dependent on care; however, when dependency becomes inevitable, people tend to adapt as there are no alternatives (Bakken 2014). Similarly, Abad-Corpa et al. 2012 and Piredda et al. 2015 stressed that dependency on homecare demands complex adaptation integrating dependency as part of a new self-image.

Our findings highlighted that dependency on care forced the older people into a relationship characterised by inequality where one part was performing a job function, whereas the other part was trying to continue life in the face of new and more severe circumstances. Our findings showed that these two different agendas may collide and that the participants

experienced that good care was contingent on both the caregivers' willingness to provide such care and the care recipient's own active efforts. Thus, the character of the caring relationship became essential in making dependency bearable.

Furthermore, our findings showed that dependency on care tended to generate an experience of being in a subordinate position, which is supported by Adap-Corpa et al. (2015). Overall "dependency work", understood as "the task of attending to dependents" (Kittay 1999, p. 30) and, more broadly, to mitigate the moral tensions of dependency relationships (Weele et al. 2021) consist of practices aiming at making dependency on care more bearable (Weele et al. 2021). Even if caregivers are unaware of this, dependency work is a task that in which they are habitually engaged. Though they may try to mitigate dependency on care through agentive, equalising and affirmative goods, this will not solve the fundamental problem inherent in dependency relationships. On the contrary, a risk exists that these well-intentioned approaches may tighten the dependency relationship further (Weele et al. 2021). This has been termed "the paradox of dependency work" (Weele et al. 2021, p. 7), which means that dependency on care cannot be undone. Instead, the relationship may be optimized to the extent possible.

In our study, some participants contributed to a good relationship by attempting to behave as they believed the carers expected them to. Some also employed humour to make their dependency bearable. A strong and collaborative relationship between the carer and the older person was identified as imperative in making dependency bearable. It was much appreciated when carers went out of their way to make the participants comfortable or happy. However,

our findings also demonstrated that in some caring relationships, participants hesitated to express their wishes, which may impede the development of a genuine relationship where good care may be provided (Strandberg et al. 2003). In principle, the dependent person has the possibility to verbalise precisely how he or she would like the care to be provided; however, in reality, dependent peoples' tendency to state demands to their carers is closely related to their personality, their current situation and their relationship with the caregiver (Martinsen et. al. 2008). From an existential viewpoint, care is provided in a tiny, shared space occupied by the caregiver and the care recipient, and in this space, the caregiver is responsible for using his or her power to assist and underpin the dependent person's being. More specifically, the caregiver needs to respect and uphold the care recipient's boundaries. Even so, a caring relationship often requires that the caregiver crosses these to conduct activities that would be unacceptable beyond a caring context (Brunstad 2014). To take an example, caring often requires assistance in intimate situations. This duality may be considered as creating "ethical border situations" in which it is *always* up to the caregiver to decide how to proceed (Brunstad 2014). Of note, the findings of the present study showed that the participants were determined to receive as good care as possible and were aware that dependency on homecare had changed their life conditions. None of our findings suggest that the older people expected caregivers to hold the primary responsibility for the course of their care. Instead, they sought in various ways to adapt to the situation, thereby making it bearable.

Explored from an existential viewpoint, becoming dependent on homecare was a life-changing process for the older people in this study. While they were still self-reliant, some imagined that dependency would be unbearable. However, when dependency eventually did become inevitable, the older people attempted to limit their dependency by acting

independently as much as possible to delay further functional decline and to stop dependency from increasing. Furthermore, in situations where they had no choice, the older people tended to adapt either through a slowly developing acceptance or by making an immediate and conscious decision to do so. Additionally, a carer relationship characterised by respect and willingness to make an extra effort played a significant role in making dependency bearable. Nevertheless, dependency on homecare implied that the receivers were placed in a subordinate position where they were assigned to a care and to conditions that they could either accept or try to influence. This is in accordance with the findings of Candela et al. (2020) who identified a similar experience among people living with advanced cancer admitted in hospital: Dependency was experienced as upsetting and life changing and impacted quality of life, but the participants slowly adapted to the situation where they had to rely on other people.

This study adds to the theoretical understanding on dependency on care. Rather than view the person as a passive recipient of care, our results demonstrate that dependency on care involves active and deliberate work on the part of the patient. Care givers should foster a collaborative approach to aid in making dependency on care bearable.

### **Strengths and limitations**

The study was conducted in two Nordic countries sharing the same view on dependency on care as generally unwanted. This view is common in the Western world but may be different in countries which pay less tribute to autonomy. Thus, it may not be possible to generalize the results outside the Western world.



Inclusion of participants from two nationalities contributed with variation that contributed to the validity of the results. Phenomenological research is concerned with gathering in-depth knowledge and variations of experiences to examine the phenomenon in all its aspects. The participants included in this study varied not only in nationalities, but also in age, civil status and disability. This The first and second author has a professional background in nursing whereas the last author is an occupational therapist. The multiprofessional composition of the research team contributed to challenge preconceptions based on professional background and experience.

### **Declaration of Conflicting Interests**

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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