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Andersen, Helle Elisabeth; Hoeck, Bente; Nielsen, Dorthe Susanne; Ryg, Jesper; Delmar, Charlotte

Published in:
International Journal of Older People Nursing

DOI:
10.1111/opn.12335

Publication date:
2020

Document version:
Accepted manuscript

Citation for published version (APA):

Go to publication entry in University of Southern Denmark's Research Portal

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Download date: 14. Sep. 2023
Caring Responsibility from the Perspectives of Older Persons whose Adult Children are their Caregivers

Parental views on child caring responsibility

Authors:

Helle Elisabeth ANDERSEN¹,² MSc, RN, PhD student
1) Department of Public Health, Nursing, Aarhus University, Denmark
2) Health Sciences Research Centre, UCL, Denmark
Corresponding author E-mail: hean@ucl.dk
Telephone: 0045-24964192

Bente HOECK³ PhD, RN, Postdoc
3) Department of Public Health, University of Southern Denmark
E-mail: bhoeck@health.sdu.dk

Dorthe Susanne NIELSEN⁴,⁵,⁶ PhD, RN, Professor
4) Department of Clinical Research, University of Southern Denmark
5) Migrant Health Clinic, Odense University Hospital, Odense, Denmark
6) Department of Geriatric Medicine, Odense University Hospital, Denmark
E-mail: dnielsen@health.sdu.dk

Jesper RYG⁴,⁶ PhD, MD, Associate Professor
4) Department of Clinical Research, University of Southern Denmark

This is the author manuscript accepted for publication and has undergone full peer review but has not been through the copyediting, typesetting, pagination and proofreading process, which may lead to differences between this version and the Version of Record. Please cite this article as doi: 10.1111/OPN.12335

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Author contributions

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ACKNOWLEDGEMENTS

We kindly thank the participants for sharing their experiences and also extend our gratitude to the staff at the Department of Geriatric Medicine, Odense University Hospital for helping with recruitment.

CONFLICTS OF INTEREST

The authors declare no conflicts of interest.
FUNDING STATEMENT

This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.
Aim: To describe lifeworld insights into the phenomenon of caring responsibility from the perspectives of persons aged 80+ years living alone with chronic illness, physical frailty and dependency on adult children.

Design: A phenomenological inquiry inspired by Reflective Lifeworld Research.

Method: Semi-structured lifeworld interviews with eleven persons aged 80+ years were conducted following their discharge. The interviews lasted 35-83 minutes, were audio-recorded, transcribed verbatim. Both interviews and the analysis followed the epistemological and methodological principles of Reflective Lifeworld Research.

Findings: We identified the essential meaning “It means everything” and four constituents illuminating different aspects inherent in the complex phenomenon of caring responsibility; “A life-constraining transition”, “Trusting the children to fill the gaps and be the glue”, “Tacit responsibility, agreement and acceptance” and “Depending on the children and knowing they are burdened by you”.

Conclusions: Caring responsibility is based on a trusting relationship and tacit agreements indicating an understanding of interdependence and acceptance of dependence on adult children.
However, a paradox appears when older persons express a deep-rooted perception of autonomy and independence as they have difficulties with their growing dependency and feelings of being burdensome. Older persons try to balance the continuum of autonomy, their existential self-image and actual capability. The practical part of caring responsibility seems to dominate and strongly affect the parent-child relationship because the child needs to take care of practical issues related to healthcare management and instrumental activities of daily living, leaving less time for meaningful togetherness.

**Keywords**

Older ill persons, frailty, adult children as caregivers, caring responsibility, own home, independence/dependence, phenomenology, interviews

**SUMMARY STATEMENT OF IMPLICATIONS FOR PRACTICE**

What does this research add to existing knowledge in gerontology?

- Our research contributes to gerontological nursing literature on family care giving a rare voice to older persons 80+ years with high care needs.

- Our inquiry provides lifeworld insights into what it means to have adult children who show caring responsibility towards their older parent, who lives alone with illness and frailty.

- Caring responsibility is experienced as a condition of life based on a trusting relationship and tacit agreements where older persons try to balance their existential self-image and actual capability in terms of independence/dependence.

What are the implications of this new knowledge for nursing care with older people?

- Our findings can help gerontological nurses, nursing students and other professionals understand how older persons aged 80+ years living alone with illness and frailty experience dependency on their adult children in this vulnerable situation.

- The older persons do not mind handing over some responsibility to their children provided they are informed along the way; in fact, they experience this as a relief.

- Older persons want their adult children to be involved and acknowledged when planning care and treatment because they manage complex issues on behalf of their parent and often seem to serve as the “glue” that makes it possible for the parent to remain in his/her own home.
How could the findings be used to influence policy or practice or research or education?

- Our findings are important to take into consideration in nursing practice and education when understanding family care for older persons living in a vulnerable situation with illness and frailty regardless if the context is a hospital or home care.
- At a policy level, our study shows how adult children are filling gaps left by the healthcare systems and play an important role in policies helping older persons stay in their own home.
- Older persons do not want to be experienced as a burden by their children. This insight is important when planning future care interventions for older persons and their families.

1 INTRODUCTION

Worldwide, populations are ageing and the number of older persons aged 65 years or more is projected to double to 1.5 billion in 2050 United Nations (2019) leading to issues of great concerns regarding quality of care and rising healthcare costs.

While most people manage the changes accompanying ageing well and continue to experience good health into late old age (WHO, 2018), many will live with multimorbidity, decreasing functional capacity, risk of frailty and dependency on formal (paid) and informal (unpaid) care occurring markedly after the age of 80 (WHO, 2015, Tanderup et al., 2018).
Research suggests that most people prefer to remain in their own homes as they age (Wiles et al., 2012). Home is for many a sense of place that provides a degree of security, comfort, familiarity, continuity and unreflective ease (Todres et al., 2009, Board and McCormack, 2018). However, a combination of frailty and living alone in old age is a particularly vulnerable situation (Kharicha et al., 2007) with higher risks of unplanned hospitalization (Pimouguet et al., 2017), loneliness (Taube et al., 2016) and reduced ability to manage daily living (Ebrahimi et al., 2013), especially following hospitalization (Andreasen et al., 2015). Older persons with high care needs have been described as ‘invisible’ and lacking a loud collective voice (Katz et al., 2013). In this vulnerable situation, adult children are generally expected to assume caring responsibility for their older parent. These expectations may arise from the older parent, adult children and/or social norms (Stuifbergen and Deklen, 2011).

Although considerable empirical and theoretical attention has been paid to this issue from the adult children’s perspective (Bookman and Harrington, 2007), rather less attention has been paid to older persons’ voices on adult children’s caring responsibility (Cahill et al., 2009, Dale et al., 2011). Therefore, the ambition of this phenomenological inquiry is to show how it is for older persons to be cared for by adult children.

2 BACKGROUND

2.1 Vulnerability and frailty

An interview study with older persons focusing on the meaning of vulnerability showed that with ageing came a deeper sense of vulnerability involving physical, mental and social losses that made life more limited and uncertain, thus vulnerability as frailness could be seen in the meaning of “becoming an old person” (Sarvimäki and Stenbock-Hult, 2016). However, recent studies (Pan et al., 2019, Nicholson et al., 2017) reported that older persons perceive the label ‘frail’ negatively and often reject the term when used about themselves. Nevertheless, frailty is a commonly used term in the geriatric field and in the present inquiry, we recruited older persons who were chronically ill, had just been hospitalized and were dependent on home care, home nursing and informal care from adult children. At the time of their participation, they were in a vulnerable situation and embraced by the definition of physical frailty proposed by Morley et al. (2013): “A medical syndrome with multiple causes and contributors that is characterised by diminished strength, diminished endurance, and reduced physiologic function that increases vulnerability for developing increased dependency and/or death.”
2.2 Home care and home nursing

The older persons in our inquiry needed help with one or more activities of daily living (ADL), e.g., personal hygiene, dressing or getting outside; and with instrumental activities of daily living (IADL), e.g., cooking and cleaning. In Denmark, where this inquiry is conducted, home care falls in two categories: practical help (e.g., cleaning) and personal care (e.g., bathing). Home care and home nursing services are provided by the municipalities. Home care nurses provide treatment and care for temporarily or chronically ill or dying patients, thus enabling people to stay in their home for as long as possible. The municipalities provide these services free of charge as all health and social services in Denmark are financed by general taxes (Ministry of Health, 2017). However, like many other countries, the Danish healthcare and social services\textsuperscript{1} are challenged by scarce resources reducing e.g. practical help to a minimum. The prevalence of informal caregivers in Denmark is high compared with other European countries (Verbakel et al., 2017).

2.3 Family care

In this vulnerable situation with illness and frailty, older persons often receive informal care provided by family, friends and neighbors (Verbakel et al., 2017), especially adult children become caregivers if the parent lives alone (Stuifbergen and Delden, 2011). The motives behind Family or intergenerational care is widely studied and often from a caregiver perspective.

Based on interviews with adult children and older parents in the context of dementia Bowers (1987) introduced a typology of informal caregiving as anticipatory, preventive, supervisory, instrumental and protective. Bower’s theory was later extended by Nolan et al. (1995) with three categories; preservative caregiving, re-constructive caregiving, and reciprocal caregiving. These categorizations are more or less recognizable in other research that focuses on informal caregivers as a homogeneous group within e.g. a hospital setting (Lindhardt et al., 2006, Uhrenfeldt et al., 2018), within home care (Søvde et al., 2019, Lewinter, 2003, Jarling et al., 2019, Andersen et al., 2020) or nursing homes (Ekström et al., 2019).

Motivations of family care have been described in terms of solidarity and norms of filial obligation (Bengtson and Roberts, 1991), as ambivalence (Luescher and Pillemer, 1998, Lendon, 2017), and as altruism and reciprocity (Silverstein et al., 2012, Klimaviciute et al., 2017). In line

\textsuperscript{1} Healthcare and social services are referred to as healthcare systems in this article.
with the theory of ambivalence, informal caregiving is often associated with caregiver burden (Adelman et al., 2014, Ringer et al., 2017, Bastawrous, 2013) and cooping (Del-Pino-Casado et al., 2011). In a recent review on caregiving for aging parents, Luichies et al. (2019) highlighted how adult children have to deal with a wide range of contradicting and conflicting norms and values.

In comparison, the literature on what it means for older persons to receive family care, especially from adult children is limited. Crist (2005) reported that older persons generally incorporated family care comfortably into their lives while viewing themselves as autonomous; for them, the acceptability of receiving family care was tied closely to positive relationships between them and their caregivers. This is further supported by Dale et al. (2011), who found that the majority of home-living persons 75+ years receiving home nursing and family care were not bothered about receiving family care, especially those who had a partner and were co-residing. However, these older persons were less confident that their family could extend the care in case of increasing needs in the future.

Lindvall et al. (2016) described how older persons with multimorbidity feel gratitude toward family caregivers for their support with everyday life and for representing their interest in contact with healthcare professionals. In contrast research by Barken (2017) revealed that older persons try to reconcile tensions between care needs and concerns about burdening others. Furthermore, Cahill et al. (2009), Stuifbergen et al. (2010), and Lewinter (2003) showed that older persons have ambivalent feelings about receiving informal care from their children, since they do not want to burden them with their care needs.

3 Aim
The aim of this inquiry was to describe lifeworld insights into the phenomenon of caring responsibility, from the perspectives of persons aged 80+ years living alone with chronic illness, physical frailty, and dependency on adult children.

4 APPROACH & METHOD
To gain insights into the phenomenon of caring responsibility, our inquiry is inspired by Reflective Lifeworld Research (RLR) (Dahlberg et al., 2008, Dahlberg and Dahlberg, 2019a). RLR draws on phenomenology and hermeneutic philosophies from Husserl, Heidegger, Gadamer, and Merleau-Ponty with the lifeworld theory as the starting point. The lifeworld is the world we take for granted in daily life (Zahavi, 2019). Lifeworld-based research thus aims to describe the lived, pre-
theoretical world of experience through a continuous search for meaning (Dahlberg and Dahlberg, 2019b). In this inquiry, the ambition of the lifeworld-based approach is to show how it is for the older persons to be cared for by adult children.

As researchers, we have to problematize and reflect on the lifeworld’s taken-for-granted-assumptions and practice openness to let the phenomenon show itself more fully. In RLR, this slow process of understanding is called “bridling” and implies ongoing openness, reflexivity and flexibility throughout the entire research process, including such as planning the inquiry as well as both the data generation and analysis. The idea is to let new meanings arise that otherwise might have been clouded by established meanings of the phenomenon and the researchers’ preunderstandings (Dahlberg et al., 2008). Importantly, the findings in RLR are always contextual and infinite and thus never to be understood as universal. They are always on their way (Dahlberg et al., 2008, Dahlberg, 2019).

4.1 Participants
Eleven (five female and six male) older persons aged 81-98 years (mean 88 years) were selected at a department of geriatric medicine. Patients admitted to this department have acute illness in addition to their chronic illnesses, loss of independence and polypharmacy. To ensure that participants had experience with caring responsibility, we used a purposeful sampling strategy (Holloway and Galvin, 2017) with the following inclusion criteria: 1) older persons with chronic illness, 2) aged 80+ years, 3) living alone, 4) not diagnosed with dementia, and 5) having at least one adult child living nearby taking care of his/her parent. We ensured variation regarding sex, age, medical conditions and former occupation to allow a diversity of perspectives to illuminate the phenomenon (Dahlberg et al., 2008).

Before approaching participants, the first author discussed with the nurse responsible for the older person whether he/she met the inclusion criteria and was well enough to be invited to participate. Participant characteristics are presented in Table 1.

Table 1 Participant characteristics

4.2 Interviews
From January to September 2018, the first author conducted eleven semi-structured lifeworld interviews in Danish approximately two to three weeks post-discharge; nine in the participants’
homes; two in a short-time rehabilitation home. The interviews lasted 35-83 minutes, were audio-recorded and transcribed verbatim. Quotes were translated into English by the first author. We used an interview guide (Table 2) with suggested questions and prompts to maintain focus on the phenomenon leaving room for an open and reflective dialogue (Dahlberg et al., 2008, Brinkmann and Kvale, 2015).

Table 2 Interview guide

4.3 Ethical considerations
The study was approved by the Danish Data Protection Agency (reference number 2015-57-0066) and conducted in accordance with the ethical guidelines for nursing research in the Nordic countries (Northern Nurses' Federation, 2003) and the European Union’s General Data Protection Regulation (GDPR) (Regulation (EU) 2016/679). We informed the participants about their rights concerning the processing of their personal information, and secured confidentiality and anonymity during the entire research process.

Assuming the older persons were in stressful and vulnerable situations during the recruitment process, the first author introduced herself as a nurse and researcher and carefully informed participants about the purpose of the research, allowing time for reflection and questions. Furthermore, the older persons were given written information about the inquiry, specifying their option to withdraw from further participation without any consequences for care and treatment. They had time to discuss participation with their children before giving written consent.

4.4 Data analysis
In the analysis, the methodological principles of RLR imply a movement between whole-parts-whole to identify the meaning structure of the phenomenon and its further constituents, including the meaning variations (Dahlberg, 2006). The circular process involved the following phases: 1) Transcripts were read several times to obtain an understanding of the whole. 2) Significant pieces of text, called meaning units, were highlighted and initial thoughts and revelation in relation to the phenomenon were written down. 3) Meaning units that appeared to be related to one another were gathered into clusters. 4) The clusters were related to each other in order to find a pattern that described the meaning structure of the phenomenon, including a description of essential meanings.
followed by descriptions of meaning that further constitute the phenomenon. Phase 1 and 2 was
carried out by the first author, phase 3 and 4 was reflected upon with all co-authors.

During this process, we were especially aware of practicing openness, reflexivity and flexibility
(briding), and holding back our theoretical, professional and personal knowledge about the
phenomenon to gain new insights. The analysis showed that the eleven participants’ lifeworld
experiences adequately represented the meaning structure of the phenomenon. An example of the
analytic process is presented in Table 3.

Table 3 Example of the analytic process

5 FINDINGS

Following RLR, we first present the essential meaning of the phenomenon of caring responsibility
as “It means everything”. The phenomenon is further described by four intertwined constituents,
which open up for more contextual nuances and individual meanings from the participants.

5.1 It means everything

The meaning of the phenomenon of caring responsibility is characterised by a strong and trusting
relationship, and appreciated by the parents as evidence of connection and care. It is a condition of
life. Metaphorically, the children gradually become the “glue” that keeps things together, ensuring
that the parents receive the right care. As such, the adult children’s care “means everything” to
them, even when the children express concern and occasionally try to overprotect and control their
parents.

Caring responsibility is characterized by tacit agreements and acceptance where caring
responsibility is automatically assumed and tailored to the parents’ increasing frailty and care needs,
while the parents still strive for active participation in everyday life, trying to balance their
existential self-image and actual capability. It is a process wherein the parents struggle both
passively and actively to maintain integrity while adapting to various kinds of loss and growing
dependency, at the same time as they are cooperating with the adult children caring for them.

5.2 A life-constraining transition

Caring responsibility assumed by adult children is foregrounded by the older persons’ current
situation, which is experienced as a life-constraining transition characterised by loss and
dependency. Their everyday life is affected at several intertwined levels: literally because of physical and social loss; existentially because of the consequences of these circumstances, leading to life-constraining experiences that cause feelings of loneliness, isolation, emptiness and sadness.

Physically, the older persons experience loss due to aged-related changes and illness accompanied by frailty. These circumstances constrain their possibility to keep up and participate in enjoyable things in life. It is difficult to be unable to perform basic taken-for-granted self-care such as bathing, dressing, cooking and going out. Socially, Liz for example has always been an outgoing person engaged in gymnastics and swimming until the age of 89 years when physical weakness stopped her from being active.

“I am just sitting here, trapped in my home and dependent on others. Family and friends come to visit me, but it is not the same.” (Liz)

The feeling of being trapped in one’s home, being unable to fulfil social needs, is followed by existential feelings of loneliness and isolation. Maria explains how she used to participate in the Wednesday cafe in the vicarage, but she cannot go there by herself anymore so now she mainly stays in her apartment. Existential loneliness is enhanced by the loss of a lifelong partner, causing feelings of emptiness and sadness. Not having a partner to share things with is difficult.

“After my husband’s death, life is empty and sad, and now I am dealing with a lot of illness.” (Anne)

Coming to terms with the transition from independence to dependency is described as terrible and demanding. The older persons try to establish a balance between their existential self-image and their actual performance. This demanding transition forces them to recognize and accept their growing need for help. However, despite dependency, they strive for active participation in everyday life instead of just giving up and being passive.

“Sometimes I try to hang up the laundry, but it takes a long time, and my daughter does not like me doing it due to my dizziness. It is terrible and demanding to be dependent on others. I try to do whatever I can.” (Liz)

The older persons express a basic instinct of wanting to do things on their own. Being more or less independent is a deep-rooted self-image. Acknowledging the growing need for help and living with constraints is therefore experienced as a very difficult transition, which shapes the experiences of being cared for by adult children.
5.3 Trusting the children to fill the gaps and be the “glue”

In this life-constraining transition, the older person becomes dependent on informal care from the children. This is experienced as a gradual process with the parents showing confidence that the children will help and support in areas where they can no longer manage on their own. Making the children manage complex issues is experienced as a relief, even if it means leaving a huge responsibility to the children. The children gradually become a kind of “glue” keeping things together and ensuring that the parent receives the right care and treatment. Even though the parent receives home care and home nursing, the children are filling the gaps, including those missed by the healthcare systems, like ensuring sufficient nutrition.

Maintaining an overview and navigating the healthcare system is also a challenge. Therefore, the parents appreciate when the children participate in medical appointments and decisions related to e.g. hospital discharge and home care. For the parents, this reduces some uncertainty regarding their current health and life situation.

“The help from my daughter means everything. Without her, I could not stay in my own home.” (Adam)

This essential statement “it means everything” is inherent in all interviews, showing just how important the children’s caring responsibility is perceived by the parent. The parents can remain in their own home because the children complement home care in IADL such as shopping, cooking, doing laundry and gardening. Such practical support is often straightforward. Another area where the parent shows great trust is that of administrative matters.

“I have asked my son to manage my electronic post and finances. He tells me what to do and what not to, and it doesn’t bother me. I trust him. He takes care of everything and informs me. I could not manage without him.” (Ben)

Handling the mail (especially from the healthcare and social systems) and finances is a matter of trust and may be closely related to family history and the close bond between parent and children. The parent relies upon the children and does not express doubts about leaving the responsibility to them when being informed along the way.

None of the interviewed parents received assistance with intimate ADL areas such as personal hygiene and toileting from their children. There seems to be an unspoken agreement on the part of both sides that to maintain the parent’s dignity, these areas are best handled by home care.
5.4 Tacit responsibility, agreement and acceptance

The caring responsibility assumed by the children does not generally seem to be discussed explicitly. It is tacitly agreed upon. There seems to be a mutual understanding, an implicit willingness and acceptance from both parts of the parent’s growing need for help and support.

“The help from my children means everything. I helped them earlier in life, looked after their children. It is just natural. They do not say that they assume responsibility for me, but I think they do.” (Liz)

However, since the parent also wants to be active and participate in everyday life, the help offered is sometimes renegotiated or even rejected. This may potentially lead to conflicts, since the children may try to convince their parent about the need for letting the child take control, like the daughter who scolds her dizzy mother because she hangs up the laundry by herself. This kind of interference and overprotectiveness can be annoying and stressful for the parent. As a strategy to avoid conflict and manage their ambivalent feelings about children’s attempts to obtain control, most parents do not correct their children but accept their ideas and interference, often by responding with silence and/or passivity. This strategy is justified by the appreciation of the children’s concern as a sign of love and care.

“My sons have scolded me again because I think I can do it all, which I cannot. It cannot always be, as I would wish…However, I do not correct them or complain. I have a good relationship with the boys.” (Max)

Nevertheless, some level of family conflict cannot always be avoided, since not all siblings take or are assigned responsibility; often, one or two children become the main caregivers through tacit agreement. This is not surprising for the parent, but it may create some tension between siblings.

“One of my three children has to take responsibility, but it also means that the distance between my son and oldest daughter has increased slightly because of some kind of jealousy. However, I do not think that my oldest daughter is the right one to handle things.” (Ben)

By a kind of tacit agreement and acceptance, the son has become the main caregiver responsible for his father because he is the most suitable person for the tasks at hand. Most parents seem tacitly to rely mostly on the children having the resources to take on responsibility as the main caregiver. These resources can either be time, knowledge or just the fact that they live nearby or have the closest relationship with their parent.
5.5 Depending on the children and knowing they are burdened by you

The social and emotional support and the bond with the children mean a lot. However, the most important thing is not what the children do; equally important is the motive behind their support, namely that they show care and responsibility as a sign of love and connection. The emotional connection provides a sense of meaning and belonging. For the parents, it is important to simply spend time together, having a chat or a nice meal. However, togetherness is often backgrounded because the children have to take care of practical issues when they visit.

“They (the children) help with everything but this was not my plan. Of course, I am happy and grateful for what they do for me, but I would rather be able to do it myself. That is also why I keep telling them to speak up if things get too burdensome. They may just visit. We can have coffee and a chat without them having to ‘work’ for me. This should not be the reason for their visit.” (Helen)

The parents rely on their children; however, receiving help and support also gives rise to thoughts about being a burden since the parents understand that the children have their own busy lives. Therefore, although the parents experience that the children assume caring responsibility, they may also try to resist being at the receiving end. Nevertheless, they depend on their children, which is a dilemma. Some older persons express this as a critique of the healthcare system claiming that it often fails to deliver the expected services and thereby increases the burden on the children. Especially one older person is very angry at the Danish welfare system because a representative from the municipality told him to ask his children, friends, or neighbours for help:

“What kind of nonsense to say. My children have theirs and the neighbours have theirs. I know that they will help me if I am in need, but they cannot help in everyday life; you cannot expect that in the long run.” (Jim)

The support from the welfare system has an important influence on the parent’s feelings of being burdensome. The parent strives to maintain some balance in the relationship by giving gifts or money to the children and emphasizes that the children should tell when helping gets too burdensome. However, the children make no complaints to the parent.

6 COMPREHENSIVE UNDERSTANDING AND DISCUSSION

The older persons studied were in a vulnerable situation resulting in literal and existential constraints. Literally, they found it difficult to adapt to physical and social loss but did not give up. They strived for active participation, balancing their existential self-image and their actual
capability to perform ADL/IADL. Other studies report similar findings, showing how older persons with frailty demonstrated creativity in creating new daily routines as they experienced loss (Birkeland and Natvig, 2009, Nicholson et al., 2013, Skilbeck et al., 2018).

Existential constraints were closely intertwined with living alone and with physical and social loss causing feelings of emptiness, sadness, isolation and loneliness despite informal care from the children. These existential life-constraining phenomena have been described elsewhere from both theoretical (Delmar, 2013, Delmar, 2018, Delmar, 2006) and empirical perspectives (Delmar et al., 2006, Delmar et al., 2009), showing the importance of paying more attention to patients’ life courage. Our inquiry reveals that children cannot replace the parent’s experience with these life-constraining phenomena. However, by assuming caring responsibility, they nevertheless appear to have a profound influence on the parent’s general well-being. This finding echoes recent research revealing that meaningful togetherness can push a life-constraining phenomenon like existential loneliness to the background (Sjoberg et al., 2019).

Our findings show that caring responsibility is experienced as a condition of life and based on a trusting relationship between older parents and their adult children. There are an implicit willingness and tacit acceptance from both sides. The parents experience relief by handing over some responsibility to the children. They rely on those children who are best at taking this responsibility, which is consistent with research by Pillemer and Suitor (2014). Tacit acceptance is congruent with findings from Crist (2005), showing that older persons perceived a trade-off between accepting help from family caregivers and maintaining autonomy.

Interpreted within the theory of relational autonomy (Mackenzie and Stoljar, 2000), the parents in our inquiry do not abdicate their autonomy when asking their trusted children to manage complex issues and engage in decision-making. According to this theory, we are socially embedded and our identities are formed within the context of social relationships (Mackenzie and Stoljar, 2000). Hence, we all fundamentally exist in relation to others, in interdependence. When interpreted from this standpoint, being autonomous is not perceived to be in opposition to valuing the children’s input or engaging them in important decisions. This is opposite to the traditional and individualistic understanding of autonomy concerning patients’ independence (Walter and Ross, 2014) and the promotion of own choice and responsibility (Delmar et al., 2011). These two perspectives on autonomy are interesting because they both seem to be at play in our inquiry. When the older persons describe difficulties in coming to terms with increasing dependency and express feelings of not wanting to be a burden, they express a deep-rooted perception of autonomy as independence.
Our findings show that they strive for active participation in everyday activities to maintain their integrity. Furthermore, feelings of being a burden are foregrounded because of disappointment with the support offered by the Danish welfare system, which forces older persons to become dependent on their children. Nevertheless, they also describe caring responsibility as a condition of life, indicating an understanding of interdependence and thus a tacit acceptance of being dependent on their children. They seem to be struggling to balance this continuum of autonomy in relation to dependence/independence.

Our findings further echo earlier research (Lewinter, 2003, Cahill et al., 2009, Stuifbergen et al., 2010) showing that older persons were hesitant to make demands on family members because they were busy and had families on their own. However, the older persons in our inquiry were not in a position where they had a choice since they could not manage without informal care from their children, and they did not mind handing over some responsibility to their children, provided they were informed along the way. In fact, they experienced this as a relief. Roe et al. (2001) interpreted this kind of acceptance as ‘positive acceptance’, which appeared when older persons were losing some of their independence but were able to retain control through choice and involvement in decision-making. However, our findings also show that tacit acceptance is a means to avoid conflict when discrepancies appear between the parent’s self-image and the children’s concerns and interference.

The practical part of caring responsibility seems to dominate and affect the parent-child relationship considerably. The child needs to take care of practical issues related to healthcare management and IADL, leaving less time for meaningful togetherness, although older parents are reported to be more interested in emotional support and contact (van Der Pas et al., 2005). The relationship is also stressed by healthcare systems not delivering the expected service, primarily regarding IADL but also in ADL areas like ensuring sufficient nutrition. As a way to ease feelings of being burdensome and keep some balance in the relationship, some older persons reciprocate by giving (financial) gifts to their children, as also reported by Tomini et al. (2016), Roe et al. (2001) and (Nolan et al., 1995).

6.1 Methodological considerations
The strength of our inquiry is that we give a rare voice to a vulnerable group of older persons and their perceptions of the phenomenon of caring responsibility. To increase credibility, dependability, transferability and confirmability (Lincoln and Guba, 1985) of the findings, different considerations
were taken into account. We used clear inclusion criteria. In reflective lifeworld research, a diversity of perspectives is important to illuminate the phenomenon (Dahlberg et al., 2008). Therefore, we sought variation regarding sex, age, medical conditions and former occupation and provided information about the context, which enhance the transferability of the findings.

To achieve credibility, confirmability and dependability, we approached the phenomenon in an open ‘bridled’ way during the whole process of inquiry. During prolonged engagement (Lincoln and Guba, 1985) with the phenomenon, reflexivity and flexibility was an on-going process (Dahlberg et al., 2008). We questioned our preunderstandings as healthcare professionals and having (had) older parents ourselves in order to find something new, not already existing in our pre-understandings (Nyström and Dahlberg, 2001). The eleven interviews appeared to be sufficient to achieve a meaning structure of the phenomenon. Otherwise, due to the flexibility in reflective lifeworld research, more data would have been included. To achieve confirmability, all authors were engaged in a transparent analysis process to achieve agreement. Findings were discussed and redefined, and a dense description of the research process established dependability.

Some limitations should be considered. The older persons all seemed to have good relationships with the children, who were the main caregivers. However, this may not be the case in other families. The participants lacked ethnic and racial diversity, and we did not include even more vulnerable groups of older persons, namely those without relatives and those diagnosed with dementia.

7 CONCLUSIONS
Caring responsibility is foregrounded by the older persons’ experience of a physically, socially and existentially life-constraining situation. Their children cannot remedy this situation, but by assuming a caring responsibility they appear to have a profound influence on their parent’s general well-being and make it possible for the parents to remain in their own home.

Older persons experience caring responsibility as a condition of life rooted in a trusting relationship and tacit agreements, indicating a mutual understanding of interdependence and acceptance of their dependence on their children. However, a paradox appears when the older persons express a deep-rooted perception of autonomy as independence, facing difficulties of increasing dependency and feelings of being burdensome. Older persons try to find their feet in this continuum of autonomy, spanning from their existential self-image as independent at one end to their actual capability in terms of being dependent at the other end.
Older persons need to be handing over some responsibility to their children. Due to them being included in such decisions, they experience this as a relief. The practical part of caring responsibility seems to dominate and affect the parent-child relationship extensively because the children need to take care of practical issues related to healthcare management and IADL, thus leaving less time for meaningful togetherness.

**IMPLICATIONS FOR PRACTICE**

- Supporting older persons in vulnerable situations with illness and frailty while still living in their own home requires acknowledgement of adult children as informal caregivers and their influence on the parent’s care and well-being.
- Involving adult children in decision-making is appreciated by older persons and experienced as a relief.
- This insight is important when striving to understand the lifeworld struggles of these older persons in gerontological nursing. Within this context, nurses and other professionals should explore and be sensitive to older person’s expectations relating to their children when planning care and treatment.

**ACKNOWLEDGMENTS**

We kindly thank the participants for sharing their experiences and also extend our gratitude to the staff at the Department of Geriatric Medicine, Odense University Hospital for helping with the recruitment.

**CONFLICTS OF INTEREST**

The authors declare no conflicts of interest.

**AUTHOR CONTRIBUTIONS**

Study design (HA, BH, DN, CD), data collection (HA), analysis (HA, BH, DN, CD, JR) and manuscript preparation (HA, BH, DN, CD, JR)

**ORCID**

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T. K., MCCARTER, R. J., GUTIERREZ ROBLEDO, L. M., ROCKWOOD, K., VON HAEHLING, S.,


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**Table 1** Participant characteristics

<table>
<thead>
<tr>
<th>Participant pseudonym</th>
<th>Age/sex</th>
<th>Adult children</th>
<th>Former occupation</th>
<th>Medical conditions</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Ben</td>
<td>86/M</td>
<td>One son &amp; two daughters</td>
<td>Sales business</td>
<td>Heart disease and prostate cancer</td>
</tr>
<tr>
<td>2. Maria</td>
<td>83/F</td>
<td>One daughter &amp; one son abroad</td>
<td>Laundry business</td>
<td>Severe rheumatoid arthritis and osteoporosis</td>
</tr>
<tr>
<td>3. Liz</td>
<td>92/F</td>
<td>One daughter &amp; one son</td>
<td>Cook</td>
<td>Dizziness and balance problems</td>
</tr>
<tr>
<td>4. Max</td>
<td>93/M</td>
<td>Two sons</td>
<td>Insurance business</td>
<td>Chronic obstructive pulmonary disease (COPD) and prostate problems</td>
</tr>
<tr>
<td>5. Mary</td>
<td>93/F</td>
<td>One daughter &amp; one son</td>
<td>Cleaning business</td>
<td>Osteoporosis, fall problems and gastric ulcer</td>
</tr>
<tr>
<td>6. Helen</td>
<td>88/F</td>
<td>One son and three daughters</td>
<td>Sales business</td>
<td>Heart and fall problems, osteoporosis and urinary problems</td>
</tr>
<tr>
<td>7. Jim</td>
<td>86/M</td>
<td>Two sons</td>
<td>Bus driver</td>
<td>COPD and prostate problems</td>
</tr>
<tr>
<td></td>
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<td>---</td>
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</tr>
<tr>
<td>8. Eve</td>
<td>87/F</td>
<td>Three daughters</td>
<td>Cashier</td>
<td>Diabetes, rheumatoid arthritis and fall problems</td>
</tr>
<tr>
<td>9. Adam</td>
<td>98/M</td>
<td>One daughter</td>
<td>Truck driver</td>
<td>Heart and circulation problems</td>
</tr>
<tr>
<td>10. Anne</td>
<td>83/F</td>
<td>Two sons</td>
<td>Sales business</td>
<td>Diabetes and cancer</td>
</tr>
<tr>
<td>11. John</td>
<td>81/M</td>
<td>One daughter &amp; one son abroad</td>
<td>Engineer</td>
<td>Stroke, fall problems and alcohol abuse</td>
</tr>
</tbody>
</table>

Abbreviations: M=Male, F=Female
Table 2 Interview guide

<table>
<thead>
<tr>
<th>Suggested questions/interview areas</th>
<th>Prompts</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Introduction – initial briefing</strong></td>
<td>Can you elaborate on that…</td>
</tr>
<tr>
<td>- Acknowledgments for time and participation</td>
<td>Can you tell more about it…</td>
</tr>
<tr>
<td>- Information about aim of research project</td>
<td>How do you experience…</td>
</tr>
<tr>
<td><strong>Interview</strong></td>
<td>What do you mean by…</td>
</tr>
<tr>
<td>- Could you please tell about yourself and your family background?</td>
<td>What happened…</td>
</tr>
<tr>
<td>- Can you describe how you experience getting older?</td>
<td>What did you think/feel…</td>
</tr>
<tr>
<td>- How have you been since your discharge from hospital?</td>
<td>What does it mean to you…</td>
</tr>
<tr>
<td>- How do you experience managing daily activities?</td>
<td></td>
</tr>
<tr>
<td>- Can you describe how you experience a typical day?</td>
<td></td>
</tr>
<tr>
<td>- You receive home care and home nursing, could you please elaborate</td>
<td></td>
</tr>
<tr>
<td>on your experiences with the assistance you get?</td>
<td></td>
</tr>
<tr>
<td>- What does it mean to you to receive home care and home nursing?</td>
<td></td>
</tr>
<tr>
<td>- Can you describe what kind of assistance you receive from your</td>
<td></td>
</tr>
<tr>
<td>children and how often?</td>
<td></td>
</tr>
<tr>
<td>- How do you experience getting help and support from your children?</td>
<td></td>
</tr>
<tr>
<td>- What does it mean to you to receive assistance from your children?</td>
<td></td>
</tr>
<tr>
<td>- How would you describe your relationship with your children?</td>
<td></td>
</tr>
<tr>
<td>Debriefing</td>
<td></td>
</tr>
<tr>
<td>-----------------------------------------------</td>
<td></td>
</tr>
<tr>
<td>- Is there anything further you would like to tell?</td>
<td></td>
</tr>
<tr>
<td>- Closing words and summarizing</td>
<td></td>
</tr>
</tbody>
</table>
**Table 3** Example of the analytic process

<table>
<thead>
<tr>
<th>Related meaning units</th>
<th>Temporary clusters</th>
<th>Constituent</th>
<th>Essential meaning</th>
</tr>
</thead>
<tbody>
<tr>
<td>The last five years have been sad due to illness. (Ben)</td>
<td>Sad because of illness.</td>
<td>A life-constraining transition</td>
<td>Caring responsibility as a condition in life. “It means everything.”</td>
</tr>
<tr>
<td>Everything takes a longer time, and I get tired so easily. (Maria)</td>
<td>Tiredness.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>After my husband’s death, life is empty and sad, and now I am dealing with a lot of illness. (Anne)</td>
<td>Life is sad and empty because of loss and illness.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sometimes I feel lonely. (Eve)</td>
<td>Loneliness.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I am just sitting here, trapped in my home and dependent on others. (Liz)</td>
<td>Isolation.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I recognize, I am old and may not be able to manage on my own. (Max)</td>
<td>Difficult to manage without help.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sometimes I try to hang up the laundry, but it takes a long time, and my daughter does not like me doing it due to my dizziness. It is terrible and demanding to be dependent on</td>
<td>Striving for participation in everyday life activities.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Others. I try to do whatever I can. (Liz)</td>
<td>Terrible and demanding to be dependent. Doing whatever she can.</td>
<td>Leaving responsibility to the children. Trusting the children to fill the gaps and be the ‘glue’</td>
<td></td>
</tr>
<tr>
<td>------------------------------------------</td>
<td>-------------------------------------------------</td>
<td>-------------------------------------------------</td>
<td></td>
</tr>
<tr>
<td>It means everything that my sons make sure that home care and everything is on track. I cannot handle it all myself. (Max)</td>
<td>My son takes care of everything; I could not manage without him. (Ben)</td>
<td>My son participates in my visits to the doctor and the hospital. He takes care of all sorts of things. It is great. (Mary)</td>
<td></td>
</tr>
<tr>
<td>My daughter always does the shopping and often makes dinner. For a long time, she made oatmeal for me in the morning, so I could recover after my hospitalization. (Liz)</td>
<td>Trusting children to take care of everything. The parent cannot manage without this support. Children accompany and take care of healthcare management.</td>
<td>Supporting instrumental activities of daily living, ensuring sufficient nutrition.</td>
<td></td>
</tr>
</tbody>
</table>

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| My daughter takes care of everything with money and what needs to be paid and informs me about, which is good. (Maria) | Administrative matters and trust. | Being informed is good. |
| The help from my daughter means everything. Without her, I could not stay in my home. (Adam) | Support from the child means everything. Could not remain in own home without this support. |
| The help from my children means everything. I helped them earlier in life, looked after their children. It is just natural. They do not say that they assume responsibility for me, but I think they do. (Liz) | Helping is natural. Responsibility not verbalized. |
| “My sons have scolded me again because I think I can do it all, which I cannot. It cannot always be, as I would wish. The boys take care of my interests. They are strong and sometimes quite rough with the | Tacit responsibility, agreement and acceptance |
| | Interference and overprotectiveness. | Accepting and recognizing help from children. |
| Healthcare system. However, I do not correct them or complain. I have a good relationship with the boys.” (Max) | Potential conflicts. Not correcting the children. Good relationship. |
| “One of my three children has to take responsibility, but it also means that the distance between my son and oldest daughter has increased slightly because of some kind of jealousy. However, I do not think that my oldest daughter is the right one to handle things.” (Ben) | Family tensions and tacit agreements and acceptance of whom of the children become the primary caregiver. |
| My daughter should not use all her time on helping me. (Liz) | Children should not use their entire time helping. Children help with everything. Would prefer to be able to manage on her own. Things must not get too burdensome. |
| They (the children) help with everything, but this was not my plan. Of course, I am happy and grateful for what they do for me, but I would rather be able to do it myself. That is also, why I keep telling them to speak up if things get too | Depending on the children and knowing they are burdened by you |
burdensome. They may just visit. We can have coffee and a chat without them having to ‘work’ for me. This should not be the reason for their visit. (Helen)

When I was talking to a representative from the municipality about getting more home care, she told me to ask my children, friends or neighbours for help. What kind of nonsense to say. My children have theirs and the neighbours have theirs. I know that they will help me if I am in need, but they cannot help in everyday life, you cannot expect that in the end. (Jim)

The children clean my house and take care of my garden. I appreciate their help. Sometimes I give them money as a way to show my gratitude. (Anne)

| Just having a coffee and a chat. Togetherness without having to ‘work’. |
| Dissatisfied with the municipality. |
| Children and neighbours will help but also have theirs. |
| Giving gifts/money as appreciation. |