Who cares?
Caring responsibility
from the perspectives of older, ill persons
and their adult children in primary healthcare

PhD dissertation

Helle Elisabeth Andersen

Health
Aarhus University
Department of Public Health
Research Unit Nursing and Health Care
PhD dissertation

Who cares? Caring responsibility from the perspectives of older, ill persons and their adult children in primary healthcare

Helle Elisabeth Andersen

Print
Fællestrykkeriet, ISSN 1602-1541

This dissertation has been accepted for defense by the Faculty of Health at Aarhus University and defended December 18, 2020

PhD committee:
Bente Martinsen, Associate Professor (chairman and moderator of the defense)
Department of Public Health, Nursing, Aarhus University, Denmark

Marit Kirkevold, Professor and Head of Department, Department of Nursing and Health Promotion, OsloMet-Oslo Metropolitan University, Norway

Monica Evelyn Kvande, Associate Professor, Lovisenberg Diakonale Høgskole, Oslo, Norway

Main supervisor:
Charlotte Delmar, Professor, FAAN, Department of Public Health, Nursing, Aarhus University, Department of Health and Care Sciences, VID Helsefag, Bergen & Oslo, Norway

Supervisors:
Bente Hoeck, PhD, RN, Postdoc, Department of Public Health, University of Southern Denmark

Dorthe Susanne Nielsen, Professor, Department of Clinical Research, University of Southern Denmark, Migrant Health Clinic and Department of Geriatric Medicine, Odense University Hospital, Odense, Denmark

Jesper Ryg, Professor, Head of Geriatric Research, Consultant, PhD, Department of Clinical Research, University of Southern Denmark and Department of Geriatric Medicine, Odense University Hospital, Denmark

Financial disclosure: The study has been funded by UCL University College with travel grants from Aarhus University and the Norwegian Research School for Municipal Health Care.
The myth of Cura

“Once when “Care” was crossing a river, she saw some clay; she thoughtfully took up a piece and began to shape it. While she was meditating on what she made, Jupiter came by. “Care” asked him to give it spirit, and this he gladly granted. But when she wanted her name to be bestowed upon it, he forbade this, and demanded that it be given his name instead. While “Care” and Jupiter were disputing, Earth arose and desired that her own name be conferred on the creature, since she had furnished it with part of her body. They asked Saturn to be their arbiter, and he made the following decision, which seemed a just one: “Since you, Jupiter, have given its spirit, you shall receive that spirit after its death; and since you, Earth, have given its body, you shall receive its body. But since “Care” first shaped this creature, she shall possess it as long as it lives. And because there is now a dispute among you as to its name, let it be called “homo”, for it is made out of humus (earth)” (Hyginus, 1976).
Acknowledgements

Thank you to Head of Department, Occupational Therapy and Nursing in Odense Lena Busch Nielsen and UCL, for giving me the opportunity to conduct this study. To my colleagues at UCL, thank you for your interest in the study and my well-being.

A special thanks to the older persons and their adult children for participating and sharing your experiences despite the life challenges you were facing. Without your contribution this work would not have been possible.

Thank you to main supervisor Professor Charlotte Delmar for sharing your great expertise with me, for encouraging, guiding and challenging me to challenge myself, and trusting my ability to accomplish my work.

Thank you to co-supervisors Bente Hoeck and Dorthe S. Nielsen for always providing constructive guidance and sharing your passion for nursing, and to co-supervisor Jesper Ryg for sharing your expertise within the geriatric field.

Thank you to fellow PhD students and (associate) professors at both Public Health, Nursing, Aarhus University and Health Sciences Research Centre, UCL for interesting discussions and sharing of experiences.

Thank you to the staff at the Department of Geriatric Medicine, Odense University Hospital for your kind collaboration during the recruitment process.

Thank you to the Norwegian Research School for Municipal Health Care. This excellent 3-year program has been enriching and revealed interesting perspectives on current and future practices in primary healthcare in the Nordic countries.

Thank you to Professor Kathleen Galvin for discussing my research and welcoming me as a guest student at the School of Health Sciences, University of Brighton March 2019.


Finally, thanks to family and friends for all the patience, encouragement, and inspiration they have offered me these three years. Thank you to my husband, Michael, and our three grown-up children Oliver, Sebastian and Sarah for being you and for always being there for me.
List of publications

The dissertation is based on the following articles:


Abbreviations

ADL  Activities of Daily Living
COPD  Chronic Pulmonary Disease
GP  General Practitioner
HCAT  Humanized Care Assessment Tool
IADL  Instrumental Activities of Daily Living
NGOs  Non-Governmental Organizations
OECD  Organization for Economic Co-operation and Development
RLR  Reflective Lifeworld Research
UN  United Nations
WHO  World Health Organization

Tables

Table 1  Aims and research questions
Table 2  Participant characteristics and variations
Table 3  Example of the analysis process
Table 4  The Humanizing Value Framework
# Content

Chapter 1 Introduction .............................................................................................................................. 1  
Chapter 2 Background .............................................................................................................................. 3  
  Population aging and policy context ................................................................................................. 3  
  Healthcare regulations ......................................................................................................................... 5  
  Aging in place ........................................................................................................................................ 6  
  Vulnerability and frailty ......................................................................................................................... 7  
  Being old, ill and living alone dependent on care .............................................................................. 8  
  Informal caregiving in Europe and Denmark .................................................................................... 10  
  Taking care of an old, ill parent ............................................................................................................. 11  
Chapter 3 Purpose and aims .................................................................................................................... 14  
Chapter 4 Methodological foundations .................................................................................................... 15  
  Reflective Lifeworld Research ............................................................................................................ 16  
  Philosophical underpinnings and concepts ....................................................................................... 18  
    Lifeworld and the natural attitude .................................................................................................... 18  
    Inseparability and intentionality ....................................................................................................... 19  
    Pre-understanding and bridling ......................................................................................................... 21  
    Intersubjectivity, empathy and essences .......................................................................................... 23  
Chapter 5 Methods .............................................................................................................................. 25  
  Participants and setting ....................................................................................................................... 25  
  Ethical and legal considerations ......................................................................................................... 28  
  Generating data .................................................................................................................................... 29  
    Diaries ............................................................................................................................................... 30  
    In-depth interviews .......................................................................................................................... 32  
  Data analysis ........................................................................................................................................ 33  
Chapter 6 Findings .............................................................................................................................. 38  
  ARTICLE I .......................................................................................................................................... 41  
  ARTICLE II ........................................................................................................................................ 57  
  ARTICLE III .................................................................................................................................... 69
Chapter 7 Discussion of findings................................................................................................................................................................................................. 102
Caring responsibility as a condition of life................................................................................................................................................................................................. 103
Caring responsibility as struggling ................................................................................................................................................................................................. 106
   Older persons’ struggles................................................................................................................................................................................................. 106
   Adult children’s struggles................................................................................................................................................................................................. 109
Caring responsibility as modes of authenticity and inauthenticity.................................................................................................................................................................. 113
Caring responsibility and healthcare systems .................................................................................................................................................................................. 118
Chapter 8 Methodological considerations.................................................................................................................................................................................. 125
Objectivity......................................................................................................................................................................................................... 125
Validity ........................................................................................................................................................................................................ 127
Generalization ........................................................................................................................................................................................................ 127
Chapter 9 Conclusions........................................................................................................................................................................................................ 129
Chapter 10 Implications ....................................................................................................................................................................................................... 132
   Implications for practice, education and policymakers.................................................................................................................................................................. 132
   Implications for further research....................................................................................................................................................................................... 133
English summary ........................................................................................................................................................................................................... 135
Dansk resumé........................................................................................................................................................................................................... 140
References...................................................................................................................................................................................................................... 145
Appendixes .............................................................................................................................................................................................................. 161
   Appendix A  Tilladelse Datatilsynet ................................................................................................................................................................. 161
   Appendix B  Information til ældre 80+ ........................................................................................................................................................ 162
   Appendix C  Information til søn/datter ........................................................................................................................................................ 163
   Appendix D  Samtykkeerklæring ældre 80+ ....................................................................................................................................................... 164
   Appendix E  Samtykkeerklæring søn/datter ....................................................................................................................................................... 165
   Appendix F  Interviewguide – ældre ........................................................................................................................................................ 166
   Appendix G  Vejledning: Dagbog til søn/datter ....................................................................................................................................................... 167
   Appendix H  Interviewguide - søn/datter ........................................................................................................................................................ 168
   Appendix I  Humanized Care Assessment Tool (HCAT) .................................................................................................................................................. 169
   Appendix J  Declaration of co-authorship .......................................................................................................................................................... 173
Chapter 1 Introduction

This dissertation presents a qualitative study describing insights into older, ill persons aged 80+ and their adult children’s experiences with the phenomenon of caring responsibility in the context of being cared for at home. As older persons seek to live out their years at home, informal caregivers like adult children are increasingly relied upon for support and wellbeing (Luichies et al., 2019, Lilleheie et al., 2020, Ploeg et al., 2019). This may be seen as a consequence of public responsibility becoming more narrowly defined, and more responsibility for care is placed on older persons in need of care and their families (Ulmanen and Szebehely, 2015, Dahlberg et al., 2018, Johansson et al., 2011). The phenomenon of caring responsibility is therefore of increasing interest in the healthcare systems, and the focus of this study.

In Denmark, the availability of formal care in primary healthcare may reduce the demands on informal caregivers. Nevertheless, informal caregivers constitute an important source of support for the care of persons in vulnerable situations with illness and growing dependence (Verbakel et al., 2017), especially after discharge from hospital (Uhrenfeldt et al., 2018). Informal caregivers or significant others are unpaid individuals representing family members, friends, neighbors or members of the same household who act as relatives or surrogates (Uhrenfeldt et al., 2018). However, the present study focusses on a special group of informal caregivers, namely adult children, because they often become primary caregivers especially when the older parent lives alone.
Older ill persons and their adult children’s concerns and perspectives on the phenomenon of caring responsibility may provide valuable insights for policymakers, healthcare professionals and healthcare educators. Their voices need to be heard to enhance understanding, planning and delivery of primary healthcare and health education. Descriptions of general structures of meanings of a phenomenon like caring responsibility encompass both essential meanings illuminating the very character of the phenomenon and the individual experiences, illuminating the phenomenon’s variations. These descriptions enable understanding of the complexity of contextual existence (Dahlberg, 2019, Wijngaarden et al., 2017). Knowledge about patients and relatives’ (such as adult children) experiences may be seen as one type of evidence (Rycroft-Malone et al., 2004).

The dissertation consists of ten chapters. Chapter 1 is a brief introduction. Chapter 2 reviews selected literature of importance to older persons and adult children’s experiences with caring responsibility in different contexts. Chapter 3 describes the study’s purpose and aims. Chapter 4 presents the dissertations methodological foundations within phenomenology and hermeneutic, and chapter 5 presents the research methods selected to achieve the aims of the inquiries. Chapter six portrays the findings outlined in three journal articles. Chapter 7 discusses the findings in a broader sense in alignment with the purpose of the study. In chapter 8 methodological considerations will be critically discussed. Chapter 9 gives the conclusions of the dissertation, and chapter 10 points to implications and further research.
Population aging and policy context

Population aging is a global demographic trend (United Nations, 2019, Murphy, 2017). WHO (2015) estimates that from 2015 to 2050, the proportion of the global population aged 60 years or more will nearly double. As the number of older persons in the population increases, the care of older ill persons becomes an issue of profound concern. In Denmark, the number of persons aged 80 years or more in 2057 is estimated to grow to 667,000 or 2½ times more than today. By 2057 more than one in ten inhabitants is expected to be 80 years or more (Statistics Denmark, 2018).

There is no universal agreed definition of old age. Attempts have been made to differentiate between persons in the younger old-age group, who are generally well and active, and those who are old-old (beginning at 80 or 85 years) and living with increasing frailty, chronic illness and disability (Rolls et al., 2011). When this division of young-old and old-old people was introduced (Neugarten, 1974), the age boundary was 75 years. Since then, life expectancy has increased significantly. In Denmark, the life expectancy in 1974 was 73.8 years, while in 2018 it was 81.3 years (World Bank, 2019). Therefore, the boundary of 80 years is used in this study to define the oldest-old. Even though aging is undoubtedly very individual, general health decline and frailty occur markedly after the age of 80. Burdens of disability due to age-related losses in hearing, seeing and moving, and chronic diseases, including heart disease, stroke, chronic respiratory disorders, cancer, dementia, multimorbidity, defined as having two or more chronic illnesses, and polypharmacy will increase (Tanderup et al., 2018, Danish
Health Authority, 2016b, WHO, 2015). Psychological, social and existential dimensions of being old-old are also important and may result in feelings of loneliness and/or feelings of depression (Bindels et al., 2015, Evans et al., 2019, Hauge and Kirkevold, 2010, Kharicha et al., 2007, Eckerblad et al., 2015).

The growth in the number of the oldest-old increases the need for healthcare and puts pressure on healthcare systems (Danish Health Authority, 2016b, United Nations, 2019). In Denmark, as in many other countries (Kodate and Timonen, 2017), formal care has gradually shifted from hospital to primary healthcare with the general practitioner (GP) as gatekeeper. In 2008, the Danish Government decided to invest in new hospitals with reduced hospital beds (Ministry of Health and Prevention, 2008). The argument was that citizens do not always have to consult the highest expertise at hospitals but should receive care and treatment in primary healthcare. Having people remain in their homes and communities for as long as possible also avoids the costly option of institutional care and is therefore favored by policymakers, health providers, and by many older persons themselves (WHO, 2007). This means that older persons are discharged earlier, and informal caregivers, like adult children, can find themselves supporting the older person who is still unwell after discharge (May et al., 2014, Slatyer et al., 2019, Bragstad et al., 2014b). Furthermore, it means that primary healthcare is becoming more extensive and complex, dealing with multiple health problems requiring advanced competencies (Vinge, 2018, Vatnøy et al., 2019) under considerable time pressure (Martinsen et al., 2018, Dale et al., 2011). Nevertheless, a Danish analysis (Rostgaard and Matthiessen, 2019) shows a 1/3 decline from 2007 to 2017 in the provided home care support, especially with practical tasks. A regression analysis shows that this reduction cannot be explained by the increased focus on rehabilitation or healthy aging in general. The decrease can be explained by new restrictive visitation practices in the municipalities. Regulations and visitation practices will be described in the next section.
Healthcare regulations

In a welfare state like Denmark, the public sector has the formal responsibility for funding and providing care for older persons. The various healthcare and social services are regulated by the Danish Health Care Act (Ministry of Health, 2019), which encompasses all legislation on benefits pertaining to public healthcare like home nursing and patient’s rights, and The Danish Social Service Act (Ministry of Social Affairs and the Interior, 2020), which specifies guidelines to provide services to persons with, e.g. physical or mental disabilities. By using words like respect, integrity, self-determination and dignity, these legislations are intended to contribute to society’s moral view of human nature as well as healthcare professionals’ responsibility in relation to people in need of healthcare. However, legislations can dictate only minimum requirements, which are always to be considered in the concrete context (Delmar et al., 2011).

In primary healthcare, the 98 municipalities are responsible for executing the various laws and regulations pertaining to healthcare and providing home nursing and home care covering personal and practical support to older persons in need in collaboration with the general practitioners. Within these laws and regulations, each of the municipalities has a politically agreed level of service regarding personal care, practical assistance and rehabilitation, defined in a so-called quality standard. The quality standard is re-defined annually and provides general information about the home care people can expect from the municipality. The visitation of home care including rehabilitation is assigned by a healthcare professional, and should be based on holistic assessments using evidence-based tools combined with professional judgement in close collaboration with the older person in need and if possible a close relative (Danish Health Authority, 2016a). Home nursing including aids and appliances
are provided when prescribed by a medical doctor or on the basis of assessment of an individual need (Ministry of Health, 2019 §138).

In Denmark, there are no legal regulations in support of relatives as in Norway (Helse- og omsorgsdepartementet, 2011) and Sweden (Socialdepartementet, 2001), for example. However, non-governmental organizations (NGOs) are lobbying to improve the rights of relatives. The Danish DaneAge association in collaboration with 29 other NGOs advocate five principles to improve relatives’ conditions at national, regional and local levels. Their aims are 1) strengthen relative’s legal status by entering their rights to obtain support in the Danish Social Service and Healthcare Act, 2) recognize, involve and inform relatives, 3) strengthen knowledge about relatives’ conditions and support efforts, 4) prevent health problems and social isolation in relatives, and 5) ensure appropriate balance between care tasks and work life (DaneAge Association et al., 2019).

Aging in place
Besides being an intended goal in Danish eldercare (Rostgaard, 2012), the term aging in place (Rowles, 1993) captures the preference of the majority of older persons to remain in own homes for as long as possible (WHO, 2007, Wiles et al., 2012, Turjamaa et al., 2014). The positive value of aging in place is closely related to most people’s strong attachment to their homes and to the things, experiences, memories and expectations embodied therein (Stones and Gullifer, 2017). Todres et al. (2009) describe home as a place where the feeling of at-homeness becomes meaningful and provides a degree of security, comfort, familiarity, continuity and unreflective ease. Others describe how home provides older persons with a sense of autonomy, independence and freedom (Hearle et al., 2005, Dahlin-Ivanoff
et al., 2007). These positive elements seem to support and encourage the idea of aging in place consistent with the earlier mentioned policy initiatives to promote primary healthcare.

Negative experiences of aging in place are also described as issues of stuck-in-place or involuntary staying in own home, stemming from social isolation with loneliness as a result (Hemberg et al., 2019, Taube et al., 2016). Being unable to leave one’s home because of disability or illness reduces social activities, which for some create a sense of meaninglessness (Hemberg et al., 2019). Negative aspects are closely intertwined with decreased freedom, limited spontaneity and increased dependence (Haak et al., 2007), and have been described as becoming a guest in your own home because it turns into a workplace for visiting healthcare professionals (Jarling et al., 2018).

Vulnerability and frailty

An interview study with older persons focusing on the meaning of vulnerability showed that with aging came a deeper sense of vulnerability involving physical, mental and social losses that made life more limited and uncertain. Vulnerability meant being unprotected or in need of protection. Thus, vulnerability as frailness could be seen in the meaning “becoming an old person” (Sarvimäki and Stenbock-Hult, 2016). Vulnerability is a human condition from which we all suffer (Kottow, 2003), and can especially be seen as an existential aspect of being old and frail, as an experience based on a particular susceptibility to threats to the self as a result of higher than normal exposure to risk, and a reduced capacity for self-protection (Høy et al., 2016). Still, frailness or frailty seem to be problematic expressions. Studies (Pan et al., 2019, Schoenborn et al., 2018, Nicholson et al., 2013) found that older people perceived the label “frail” negatively when used about themselves. They did not want to be
considered as “frail”, although they were happy to accept that they were older persons (Nicholson et al., 2013).

Nevertheless, frailty is a common used term in the geriatric field, primarily as a medical syndrome that can be identified by validated screening tests focusing on indicators such as weight loss, exhaustion, weakness, slowness and reduced physical activity (Morley et al., 2013). The degree of frailty in an individual is not static; it naturally varies over time and can be made better or worse (British Geriatrics Society and the Royal College of General Practitioners, 2015). An international consensus group has defined physical frailty as “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” (Morley et al., 2013). This narrow definition focusing on the physical aspects of frailty was chosen in this study because physical frailty was evident during the recruitment process of the older persons participating in the study through their descriptions of their vulnerable situation with chronic illnesses, recent hospitalization and dependence on home care, home nursing and informal care from adult children. However, the overall understanding of being old, ill and dependent is understood in a much broader sense in this study as described in the next section.

Being old, ill and living alone dependent on care

Being old in the context of illness and having been hospitalized has been described as stressful in physiological, psychological, social and existential ways. Physical constraints and symptoms because of disability, illness and tiredness lead to inactivity and challenge everyday activities (Andreasen et al.,
Some older persons experience daily life as a struggle, and find it difficult to ask for and receive help (Roe et al., 2001), whereas others somehow seem to find a “new normal or rhythm” in a more peaceful way (Lloyd et al., 2016, Birkeland and Natvig, 2009), and demonstrate an ability to adapt to their changing circumstances (Nicholson et al., 2013). Psychological, existential and social stressors such as loss and isolation may be foregrounded and lead to feelings of loneliness, resignation and/or concerns about an increasing need for care and support (Andreasen et al., 2015, Lloyd et al., 2016).

Older persons living alone, in this study defined as a one-person household, are considered an especially vulnerable group because of difficult living situations, limited resources or a lack of support (Haslbeck et al., 2012, Rolls et al., 2011). Living alone is associated with poor health, difficulties in activities of daily living (ADL), worse memory and mood, lower physical activity, poorer diet, worsening function, risk of social isolation, hazardous alcohol use and multiple falls (Kharicha et al., 2007). In 2017, 64% of the most vulnerable older persons in the age group 67–97 years and defined as having two or more impairments, lived alone in Denmark (Rostgaard and Matthiessen, 2019).

Being an older person living alone and becoming dependent on formal care with practical and personal activities of daily living and help with medication, wound care and other kinds of treatment has been described as a challenge to one’s self-determination (Breitholtz et al., 2013). Self-determination can be considered the most central aspect of one’s autonomy. Autonomy involves the ability to act, decide and control in accordance with one’s wishes (Abad-Corpa et al., 2012) and is closely linked to a person’s dignity (Delmar et al., 2011, Delmar, 2013c). In contrast, dependence may involve “feeling or carrying a burden”, perceptions of subordination, biographical disruption, life dissatisfaction, resignation or
resistance (Abad-Corpa et al., 2012). The dominant understanding of autonomy as independence (Walter and Ross, 2014), focusing on the individual’s choice and responsibility (Delmar et al., 2011), may enhance the negative feelings of being dependent on help from others.

The literature on what it means for older persons to receive informal care, particularly from adult children, is limited. Crist (2005) and Dale et al. (2011) uncovered positive meanings of receiving informal care, especially if the care was provided within positive relationships with family caregivers. Lindvall et al. (2016) described how older persons with multimorbidity felt gratitude toward family caregivers for their support with everyday life and for representing their interest in contact with healthcare professionals. In contrast, research by Cahill et al. (2009), Stuifbergen et al. (2010), Lewinter (2003) and Martinsen et al. (2015) showed that older persons had ambivalent feelings about receiving informal care from their children, since they did not want to burden them. Feelings of being a burden were also described by Lindvall et al. (2016). Older persons valued support given to them as a voluntary act because this confirmed their value as a person and not just a needy person.

Informal caregiving in Europe and Denmark

From an epidemiological perspective, results from 20 European countries revealed that, on average, 34.3% of the population were informal caregivers and 7.6% were intensive caregivers defined as providing care for a minimum of 11 hours a week (Verbakel et al., 2017). The prevalence rate of informal caregivers in Denmark was 42.8%. Surprisingly, informal care was more common in Nordic welfare countries and less common in Central, Eastern and Southern Europe. However, the latter
countries had a higher proportion of intensive caregivers than the Nordic countries (Verbakel et al., 2017).

A Danish study showed that 83% of adult children of home care recipients help their parents (DaneAge Association, 2015). Especially adult children of the most ill and frail older persons, who also receive the most home care in scope and frequency, help. Over a 6 months period, 87% of adult children experienced that their older parent had raised concerns to a greater or lesser extent. The study also reveals that adult children over 50 years help more compared to those under 50 years, and daughters help more often than sons, which is in line with other studies focusing on gender perspectives (Pillemer and Suitor, 2014, Grigoryeva, 2017, Verbakel et al., 2017). Adult children help with transportation, household chores, medical appointments, contact with municipalities and authorities, dressing, meals and in general, keep an eye on things (DaneAge Association, 2015). Interestingly, informal caregivers like adult children seem to be a shadow “workforce” assuming caring responsibility essential to the care and treatment of older persons and their general well-being.

**Taking care of an old, ill parent**

All humans have parents, and unless a parent dies or is absent from a person’s life, one is eventually faced with the reality of the parent aging and becoming ill and frail. This means that adult children are faced with the question if or how to assume caring responsibility and help their parent cope when the parent no longer is able to care for him/herself independently. At the same time, adult children may be at a stage in their lives where they have numerous roles and responsibilities, e.g. being a spouse, parent
Informal caregiving has been widely studied in the literature from both empirical and theoretical lenses within social sciences, medicine and nursing (Bookman and Harrington, 2007) in terms of family, filial or intergenerational responsibility for an aging family member. Empirical studies have often focused on informal caregivers as a homogeneous group within a hospital setting (Lindhardt et al., 2006, Uhrenfeldt et al., 2018), within home care (Søvde et al., 2019, Lewinter, 2003, Jarling et al., 2019) or nursing homes (Ekström et al., 2019). Informal caregiving has been associated with caregiver burden focusing on physical and emotional strain (Adelman et al., 2014, Bastawrous, 2013, Ringer et al., 2017) and coping (Del-Pino-Casado et al., 2011). However, informal caregiving has also been reported as meaningful and worthwhile (Toljamo et al., 2012, Roth et al., 2015). In a recent review of qualitative studies on adult children’s caregiving experiences, Luichies et al. (2019) highlighted the quality of the parent-child relationship as an important determinant of the adult children’s caregiving experience, and pointed out that adult children have to deal with a wide range of contradicting and conflicting norms and values.

Within nursing, Bowers (1987) developed a grounded theory with five overlapping categories of informal care based on interviews with adult children and their older parents in the context of dementia. The five categories were 1) anticipatory caregiving, 2) preventive caregiving, 3) supervisory caregiving, 4) instrumental caregiving, and 5) protective caregiving. Bowers typology was extended by Nolan et al. (1995) with three categories 6) preservative caregiving, 7) re-constructive caregiving and 8) reciprocal caregiving. Within family sociology, the motives behind intergenerational care were
described as cohesion between family members based on bonds of solidarity and norms of filial obligation (Bengtson and Roberts, 1991). However, the solidarity paradigm was criticized for lacking coverage of negative emotions and behaviors, and the intergenerational ambivalence theory was added (Luescher and Pillemer, 1998). Altruistic motivations, understood as helping others with the most need and the least ability to repay, particularly those with whom one feels most intimate, have also been investigated (Silverstein et al., 2012, Klimaviciute et al., 2017). Reciprocity has been a consistent theme in studies of parent-child relationships in the understanding of interdependent actors who contemporaneously and dynamically exchange support to each other over the life course (Silverstein et al., 2012, Klimaviciute et al., 2017). Finally, the last potential motive for intergenerational care is the family norm, which is care provided by adult children to dependent parents out of some norm inculcated during their childhood. Adult children have the feeling they are obliged to assume caring responsibility for their parents (Klimaviciute et al., 2017).

In a Nordic welfare state like Denmark, adult children could leave all care to the health and social care systems (referred to as healthcare systems in this dissertation). As stated earlier, the majority of adult children in Denmark provide help and thus seem to be a vital resource in the care and general well-being for their older parent. However, no studies were found in the literature whose specific purpose was to describe what it actually means to assume caring responsibility for an old, ill parent in a Nordic Welfare context.
Chapter 3 Purpose and aims

The background chapter leads to the purpose of the study, which is to enhance the understanding of the phenomenon of caring responsibility as it is experienced by older, ill persons aged 80 years or more and their adult children, in the context of being cared for at home. The aims are to describe insights into older persons’ and their adult children’s lived experiences with caring responsibility in the parent-child relationship, and to describe their lived experiences with caring responsibility in primary healthcare. The specific aims and research questions are presented in Table 1.

Table 1 Aims and research questions

<table>
<thead>
<tr>
<th>Inquiry I</th>
<th>Inquiry II</th>
<th>Inquiry III</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aims</td>
<td>To describe insights into the phenomenon of caring responsibility from the perspectives of persons aged 80+ living alone with illness, physical frailty and dependence on adult children.</td>
<td>To describe insights into adult children’s experiences with caring responsibility for an old, ill parent with frailty.</td>
</tr>
<tr>
<td>Research questions</td>
<td>How is it for persons aged 80+ living alone with chronic illness and physical frailty to be cared for by adult children?</td>
<td>How is it for adult children to care for their older, ill parent living alone with frailty?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>How do older persons and their adult children experience caring responsibility as exercised by healthcare professionals in primary healthcare?</td>
</tr>
</tbody>
</table>
Chapter 4 Methodological foundations

This chapter reflects the philosophical beliefs about the nature of reality situated in the purpose and aims of this qualitative study and thus explores its ontological and epistemological foundations. The departure is the everyday life of older persons and their adult children, and their experiences with the phenomenon of caring responsibility in different contexts. Since I am interested in the meaning of caring responsibility in the relationships of older parents and their adult children, and furthermore, their perceptions of caring responsibility in primary healthcare, I turned to an approach called Reflective Lifeworld Research developed by researchers with a background in nursing and philosophy (Dahlberg et al., 2008, Dahlberg and Dahlberg, 2019a). This approach emphasizes the common thread of lifeworld theory in phenomenology and hermeneutics. Furthermore, it provides open methodological principles that helped me as a novice researcher transferring from philosophy to empirical research. Especially, the concept of “bridling” provides an attempt to overcome the gap between description/phenomenology and interpretation/hermeneutics. Choosing Reflective Lifeworld Research as an approach encompasses the suggestion made by Hoeck and Delmar (2018) that knowledge development in nursing should be developed in an interchange between theory and practice and guided by philosophy. The next sections will explore Reflective Lifeworld Research and key philosophical and theoretical concepts in this approach.
Reflective Lifeworld Research

Reflective Lifeworld Research was created by the Swedish nursing professors Karin Dahlberg and Maria Nyström and their American colleague Nancy Drew and first presented in 2001 (Dahlberg et al., 2001). The book describing this research was revised in 2008 with the Swedish philosopher Helena Dahlberg as co-author. Reflective Lifeworld Research has since been refined with articles and research (Dahlberg and Dahlberg, 2019).

Reflective Lifeworld Research draws on phenomenology and hermeneutic philosophies from the German philosophers Edmund Husserl (1859–1938), Martin Heidegger (1889–1976), Hans-Georg Gadamer (1900–2002) and the French philosopher Maurice Merleau-Ponty (1908–1961) (Dahlberg et al., 2008). As a third way, Reflective Lifeworld Research tries to close the gap of the polarization between description/phenomenology and interpretation/hermeneutics by providing open flexible methodological principles (Dahlberg et al., 2008).

The overall aim of Reflective Lifeworld Research is to describe and elucidate the lived world in a way that expands our understanding of human beings and human experience (Dahlberg et al., 2008: 37). The object of the research is to make the phenomena of study appear and to describe them in a clear and comprehensible way through a continuous search for meaning (Dahlberg et al., 2008: 49). In Husserl’s words, we must “go to the things themselves” (Husserl, 2001: I/168). This phenomenological idea includes the aim to approach the world as it is experienced, in all its variety (Dahlberg et al., 2008: 32).
In Reflective Lifeworld Research, you are advised not to choose external sources like theory before you have finished the first part of the analysis, which only deals with empirical data. The aim is to be as open and true to the phenomenon as possible and to articulate, the structure of meaning, where the phenomenon of interest is being displayed with particular as well as essential meanings. In other words, to search for which meanings are more essential and which are more of nuance and variation. However, even though this part does not use external theory, it is not theory-less because it is grounded in philosophical theory and guided by principles that follow the ideas of the phenomenological and hermeneutical ontology and epistemology as outlined in Reflective Lifeworld Research.

The second part of the analysis (often referred to as the “discussion” part in journals) is the place for input of external sources, be it theory or previously reported research findings concerning the phenomenon of interest. As meaning is infinite, there is always more to uncover in the analysis of empirical data, and therefore the analysis can go on forever, including whatever external sources give new dimensions to the understanding of the phenomenon in focus. However, the incentive for including theory or another external source of data in the analysis is that the understanding of a phenomenon demands this input. It could be that the phenomenon is of such a complex nature that it simply is not possible to reach a relatively full and complete enough understanding with empirical data alone. External data such as theory serve as a spotlight; they do not really add anything but illuminate those aspects of the phenomenon that remain dark after the first (empirical) part of the analysis (Dahlberg and Dahlberg, 2019a).
In this study, caring responsibility appeared to be a very complex phenomenon, and theories were therefore included in the interpretation and discussion of the findings in articles I and II, and furthermore, in the dissertation’s discussion of the study as a whole.

**Philosophical underpinnings and concepts**

The following sections will explore key concepts in Reflective Lifeworld Research by paying attention to the original phenomenological and hermeneutic philosophies and their commonalities.

**Lifeworld and the natural attitude**

Epistemological, Reflective Lifeworld Research is grounded in lifeworld theory. The lifeworld is our everyday human world, which we take for granted. It is the pre-theoretical world of experience, which we are all acquainted with, and which we typically do not question (Zahavi, 2019: 51-52). Being part of the lifeworld is characterized by what Husserl called “the natural attitude”. We, so to speak, live the natural attitude, where we do not critically reflect on our immediate action and response to the world. We just do it, we just are. This understanding of the natural attitude is based on Husserl’s phenomenology, but we also find similarities to Heidegger’s concept “being-in-the-world” and Gadamer’s concepts “horizon” and “prejudice” (Dahlberg et al., 2008: chapter 5 & 6). Gadamer emphasizes that the lifeworld itself is tacit. It is “the world in which we are immersed in the natural attitude that never becomes an object as such for us, but that represents the pregiven basis of all experience” (Gadamer, 2013: 246-247).
In Reflective Lifeworld Research, lifeworld theory is the ontological knowledge, whereby we can understand older persons in need of care. By focusing on people’s lifeworld, we can gain understanding of what it means to be an adult child with caring responsibility for an old parent in the context of primary healthcare.

Inseparability and intentionality

In addition to the lifeworld perspective, the idea of inseparability and the theory of intentionality is central to Reflective Lifeworld Research (Dahlberg et al., 2008, Dahlberg and Dahlberg, 2019a). Husserl originally described the idea of inseparability between human beings and the world in terms of co-constitution, intentionality and lifeworld. In describing the intentional character of human experience, as well as its origin in the lifeworld, Husserl (as well as Heidegger, Merleau-Ponty, and Gadamer) rejects the common sense idea that experience is created by a subject going into the world of objects, thereby assuming an essential difference between subject and object (Dahlberg and Dahlberg, 2019a). Human experience is born from the world, directed to the world, and must be understood with the world as a background. Co-constitution means that experience neither springs from the subject as a single creator nor does it arise out of an objective world. It results from a subjective involvement in a world that is already meaningful (Dahlberg and Dahlberg, 2019a). Meaning arises from the interaction between subject/object or subject/subject, from a human engagement in a world that belongs to us and that we belong to. As human beings, we are always already involved with understanding meaning. It is an everyday matter (Dahlberg and Dahlberg, 2019).

Intentionality refers to the relationship between a person and the object or events of his/her experience (Dahlberg et al., 2008: 47). Merleau-Ponty (1995: 137) stated it this way: “Consciousness is
consciouness of something.” This means that intentionality is the idea that consciousness is characterized by being of, or about, or directed at something (Zahavi, 2019). Merleau-Ponty further explicated the lifeworld as “flesh”, meaning an ontological connectedness and mutuality. The idea that everything that is, is so because of everything else that exists (Dahlberg et al., 2008: 39). For Merleau-Ponty (1995), the lifeworld is the world that we have access to through our bodies, thus all knowledge that we develop is embodied knowledge. The starting point of understanding human beings must therefore be the intentional relation, meaning our engagement in and with the world. We can only understand the world and its things based on how they are experienced.

Inseparability and intentionality have methodological implications: 1) The world as it shows itself is already part of an experience, and I as a researcher investigating it am already part of the world. 2) Due to inseparability, I as researcher must find a way to grasp and thematize this involvement as well as to keep it in check. 3) As researcher I do not have to nor can I choose between subjectivity and objectivity. The idea of inseparability between the “subjective” and “objective” requires, however, a much more important task: that of investigating the relationship between them. For instance, the experience and meaning of caring responsibility evolves not from some private inner world but from the relationship to an intersubjective world with its shared structures such as language, traditions, norms and values. The specific experience of caring responsibility is thus not subjective or objective but a movement between them, a subjective experience in relation to or against the background of the objective and shared world (Dahlberg and Dahlberg, 2019a).

Being human and being involved in human activities imply that we have both already understood and are on our way to new understanding. This is of vital importance for research (Dahlberg and Dahlberg,
Caring responsibility from the perspectives of older, ill persons and their adult children in primary healthcare

2019), and leads in the next sections to reflections about how to exchange the taken-for-granted natural attitude in favor of a more critical scientific attitude.

Pre-understanding and bridling

As stated earlier, Husserl sought to illuminate the fact that human experience rests on a foundation that is taken-for-granted, the lifeworld, where things are always already meaningful. Heidegger (1962) insisted that pre-understanding/pre-structures are conditions for new knowledge, and Gadamer (2013) noted that pre-understanding is an unavoidable, even necessary, pre-condition for understanding and acquiring knowledge. However, because our experience already is meaningful before we start to reflect on it, it is important to explore what this “meaning” consists of and how it has evolved.

Husserl understood this undertaking as an issue of epoché/bracketing (Dahlberg et al., 2008). Importantly, Husserl never stated that we should put any presuppositions or lifeworld in brackets. That which should be put in brackets is instead our natural attitude where we take for granted that the world is as it seems to be, and start to question how it is and shows itself, and how it is meaningful. We should be present to the here and now, paying attention to how things come to be in our awareness instead of being run by memory or anticipation (Dahlberg and Dahlberg, 2019a).

The shift from a natural attitude into a phenomenological attitude of openness and reflexivity is named “bridling” in Reflective Lifeworld Research (Dahlberg et al., 2008). Bridling is a concept that functions as a bridge from philosophy to empirical research. Practicing bridling implies a questioning attitude in which we do not take for granted what it is that we perceive and understand (Dahlberg and Dahlberg, 2020). As researchers, we must bridle, thus keep an eye on and keep in check, our evolving
understanding so that it does not happen randomly or too fast. The practice of bridling openness is an art of being present and questioning one’s own understanding of a phenomenon rather than taking it for granted. Its goal is to open up for many possibilities of understanding. Bridling can be seen as a methodological answer to the practice of phenomenological empirical research. The concept of bridling partly echoes the advice from Zahavi and Martiny (2019) that qualitative researchers should forget about getting the epoché and reduction right because both notions are explicitly connected to very specific aims and pursuits in a Husserl’s transcendental philosophical project irrelevant for the purpose of qualitative research. Also Delmar (2010) emphasizes that understanding begins with openness and requires creative and systematic reflection and confrontation with one’s prejudices.

Entering into a phenomenological attitude and being in a constant process of bridling required that I as a researcher repeatedly asked myself “why do I understand it like this?” I reflected upon the influence of my pre-understandings as a nurse, lecturer/academic and researcher within humanities. The pre-understandings within my philosophical beliefs, within my personal and professional history and culture are articulated via language (Gadamer, 2013). As a way to explore and reflect upon these inseparable pre-conditions that directed my actions, I kept a research journal (Dahlberg et al., 2008) and discussed my evolving understanding of the phenomenon of caring responsibility with supervisors and peers. It was a process of constant elaboration through questioning and dwelling with own pre-understandings, data/texts and their meanings. Choosing the phenomenological approach outlined in Reflective Lifeworld Research and especially the concept of bridling forced me to engage with openness and slow down the process of understanding, thus patiently waiting for new insights.
Intersubjectivity, empathy and essences

Intersubjectivity refers to the relations between subjects (Zahavi, 2019). We belong to the same world, and we constitute the meaning of this world together. We do so by means of experiencing, acting in the world and by expressing it. This means that although everyone’s lifeworld is part of the same world, as intersubjectivity and intercorporality, the lifeworld is not the same for everyone. Every lifeworld is unique even if we have much in common (Dahlberg et al., 2008: 63). We have no direct access to another subject’s emotions; thus, we cannot directly experience what she or he is experiencing. Nevertheless, we have the possibility to understand another subject’s embodied and embedded experience due to empathy. Not empathy understood as emotional contagion, imaginative perspective-taking, sympathy or compassion (Zahavi, 2019: 92), but empathy as a basic, perceptually based form of other-understanding. I strived for this other-understanding during the whole research process, and to some extent I still strive for it because there will always remain a difference between that which I am aware of when I empathize with the other, and that which the other is experiencing.

Phenomenological and hermeneutical research relate both to the particular meanings, which includes contextual nuances, and to the more essential, or general meanings. Husserl talked about an eidetic understanding of a phenomenon as the meanings that constitute and make it this very phenomenon, and not another one. However, neither Husserl nor Reflective Lifeworld Research aims for a kind of unchanging or eternal essences. On the contrary, the themes of meaning in phenomenological and hermeneutical research, because of their inseparable relationship to the individual variations, are infinite, always on their way, becoming (Dahlberg and Dahlberg, 2019a). A description of a meaning structure, consisting of a phenomenon’s essential meanings and constituents, is something which may lead to a more comprehensive, condensed and precise account of the phenomenon and its meanings,
but one which is not yet there (Dahlberg and Dahlberg, 2019a). This also includes the findings in this study. They contribute to a more comprehensive understanding of the complex phenomenon of caring responsibility from the perspectives of older persons and their adult children in primary healthcare.
Chapter 5 Methods

Participants and setting

The participants were 11 (five woman and six men) aged 81–98 years (mean 88 years), and 12 adult children (five sons, seven daughters) aged 38 to 73 years (mean 58 years). They were selected at a department of geriatric medicine in a Region in Denmark. Patients admitted to this department all have acute illness on top of their chronic illnesses, experience loss of independence, are subjected to polypharmacy and many have cognitive impairments.

Before the selection of participants began, I informed the staff at the department about the purpose of my research. Furthermore, I spent 3 days in the clinic, wearing a nursing uniform and following different nurses as a way to get familiar with the geriatric department, the staff and the patient group. This also allowed the staff to get familiar with me, which may have enhanced the collaboration during the selection period.

Selection took place on agreed-upon days where I met in the geriatric department in the morning. I discussed potential participants with the nurses in the department’s three teams. If potential participants met the chosen inclusion criteria and were well enough to participate, I approached the older persons in their hospital room, introduced myself as a nurse/nurse educator and researcher and carefully informed orally and in writing about the purpose of the research, allowing time for reflection and questions. If the older person was interested in participating, I obtained consent to contact their chosen adult child.
Sometimes I was lucky to meet the adult child in the hospital, but mostly I contacted them by telephone. The older person and their adult child had time to discuss participation before written consent was obtained.

A purposeful sampling strategy including criterion sampling (Holloway and Galvin, 2017, Cullum et al., 2008, Suri, 2011) guided the process to ensure selection of those currently experiencing the phenomenon of caring responsibility. Older persons had to meet the following inclusion criteria: 1) older persons with chronic illness, 2) aged 80+, 3) living alone, 4) not diagnosed with dementia, and 5) having at least one adult child living nearby taking care of his/her parent. Adult children had to meet the following inclusion criteria: 1) primary caregivers, 2) daily/several times a week contact with parent, 3) read, write and speak Danish.

Rich variation in data was important to allow diverse perspectives elucidating the complexity of the phenomenon of caring responsibility (Dahlberg et al., 2008). Therefore, variation regarding gender, age, occupation and the older person’s medical condition was considered. Table 2 presents the participant characteristics and variations.

In Reflective Lifeworld Research, there is no talk about data saturation since meanings are infinite, always expanding and extending themselves (Dahlberg et al., 2008). However, generating data and doing preliminary analysis as an ongoing process revealed that lifeworld experiences from 11 older persons and 12 adult children adequately represented the meaning structures of the phenomenon of caring responsibility and the context in focus in the different inquiries. Otherwise, more data would have been generated.
Who cares?
Caring responsibility from the perspectives of older, ill persons and their adult children in primary healthcare

Table 2 Participant characteristics and variations

<table>
<thead>
<tr>
<th>Participant Older persons’ pseudonyms</th>
<th>Age/sex</th>
<th>Adult children</th>
<th>Former occupation</th>
<th>Medical conditions</th>
<th>Participant Son or daughter</th>
<th>Age</th>
<th>Occupation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ben</td>
<td>86/M</td>
<td>One son &amp; two daughters</td>
<td>Sales business</td>
<td>Heart disease and prostate cancer</td>
<td>Son 1</td>
<td>65</td>
<td>Retired, former nurse / manager</td>
</tr>
<tr>
<td>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>
<td>Daughter 2</td>
<td>58</td>
<td>Factory worker</td>
</tr>
<tr>
<td>Liz</td>
<td>92/F</td>
<td>One daughter &amp; one son</td>
<td>Cook</td>
<td>Dizziness and balance problems</td>
<td>Daughter 3</td>
<td>66</td>
<td>Retired, former civil economist and dietitian</td>
</tr>
<tr>
<td>Max</td>
<td>93/M</td>
<td>Two sons</td>
<td>Insurance business</td>
<td>Chronic obstructive pulmonary disease (COPD) and prostate problems</td>
<td>Son 4</td>
<td>62</td>
<td>Social worker</td>
</tr>
<tr>
<td>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>
<td>Son 5</td>
<td>60</td>
<td>Manager</td>
</tr>
<tr>
<td>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>
<td>Daughter 6</td>
<td>51</td>
<td>Salesperson</td>
</tr>
<tr>
<td>Jim</td>
<td>86/M</td>
<td>Two sons</td>
<td>Bus driver</td>
<td>COPD and prostate problems</td>
<td>Son 7</td>
<td>57</td>
<td>Service engineer</td>
</tr>
<tr>
<td>Eve</td>
<td>87/F</td>
<td>Three daughters</td>
<td>Cashier</td>
<td>Diabetes, rheumatoid arthritis and fall problems</td>
<td>Daughter 8</td>
<td>65</td>
<td>Cleaning assistant</td>
</tr>
</tbody>
</table>
Who cares?
Caring responsibility from the perspectives of older, ill persons and their adult children in primary healthcare

<table>
<thead>
<tr>
<th>Name</th>
<th>Age</th>
<th>Gender</th>
<th>Relationship</th>
<th>Occupation</th>
<th>Health Problems</th>
<th>Age</th>
<th>Relationship</th>
<th>Occupation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adam</td>
<td>98</td>
<td>M</td>
<td>One daughter</td>
<td>Truck driver</td>
<td>Heart and circulation problems</td>
<td>73</td>
<td>Daughter</td>
<td>Retired, former drugstore worker</td>
</tr>
<tr>
<td>Anne</td>
<td>83</td>
<td>F</td>
<td>Two sons</td>
<td>Sales business</td>
<td>Diabetes and cancer</td>
<td>57</td>
<td>Son</td>
<td>Technical engineer</td>
</tr>
<tr>
<td>John</td>
<td>81</td>
<td>M</td>
<td>One daughter &amp; one son abroad</td>
<td>Engineer</td>
<td>Stroke, fall problems and alcohol abuse</td>
<td>52</td>
<td>Daughter 11</td>
<td>Social worker</td>
</tr>
<tr>
<td>Re-admitted to hospital and passed away before interview</td>
<td>82</td>
<td>M</td>
<td>One daughter &amp; two sons</td>
<td>Bus driver</td>
<td>Rheumatoid arthritis and cancer</td>
<td>38</td>
<td>Daughter 12</td>
<td>Healthcare assistant</td>
</tr>
</tbody>
</table>

Abbreviations: M=Male, F=Female

Ethical and legal considerations

The study was approved by the Danish Data Protection Agency (reference number 2015-57-0066) (appendix 1), and data were managed in accordance with the European Union’s General Data Protection Regulation (GDPR) (Regulation (EU) 2016/679). Participants were informed about their rights concerning the processing of their personal information. Confidentiality and anonymity were secured during the entire research process. However, an issue regarding confidentiality appeared during the data generating process. This matter is elaborated on in the section about diaries.

In accordance with the ethical principles expressed in the Helsinki Declaration (The World Medical Association, 2018) and in the ethical guidelines for nursing research in the Nordic countries (Northern Nurses' Federation, 2003), ethical considerations were given high priority during the entire research process. The older persons were in stressful and vulnerable situations during the recruitment process at the hospital on top of their illness. This required a sensitive approach. I introduced myself as a
nurse/nurse educator and researcher and respectfully asked whether the older person was interested in talking to me about participating in a research project. If allowed to continue, I placed myself in a chair next to the older person and after some small talk, carefully informed about the purpose of the research, allowing time for reflection and questions. Furthermore, the older person was given written information about the study (appendix 2), specifying the option to withdraw from further participation without any consequences for care and treatment. The older person had time to discuss participation with his/her chosen adult child before giving written consent (appendixes 4 & 5). I left written information about the study to the adult child (appendix 3), who after permission from the older person was contacted and invited to participate by telephone or in person if I was lucky to meet them at the hospital. Adult children were also in stressful situations, taking care of their older parent at the hospital while taking care of other life demands. Therefore, I approached them in a very careful and respectful manner.

Generating data

Data were generated from January to September 2018 as individual in-depth interviews with 11 older persons and individual in-depth interviews with 12 adult children. Adult children completed a diary subsequent to the interview. All interviews were audio-recorded.

The idea was to combine and complement narratives like dairies with face-to-face in-depth interviews but with flexibility in mind. Generating data in Reflective Lifeworld Research must be approached with an open and bridled attitude, and it is not possible to decide in detail upon the methods in advance (Dahlberg et al., 2008).
Diaries

Originally, the plan was to use narratives in the form of a diary with all participants. A narrative is a description of lived experiences that is written down or recorded by the participant (Dahlberg et al., 2008). However, it became clear with the first older person that requiring a diary was too demanding in a situation with illness and frailty. It is important to consider that older persons tire easily, and sensory problems like impaired hearing or sight may reduce their ability to produce narratives like those requested in the diary method (Kirkevold and Bergland, 2007). Therefore, the diary method was cancelled as an introduction to interviews with older persons.

The diary method was used with the adult children. They were asked to complete a 2-week diary from the time of inclusion, and then leave the diary in a closed envelope at their parent’s home. This way the diary could be collected when interviewing the parent and used as preparation for the interview with the adult child. To accommodate different preferences the adult children had the option to choose between different formats and received an envelope with a simple audio-recorder, a notebook/pen and a written semi-structured guidance with open questions (Appendix 7). Electronic diaries were also an option.

The purpose and strengths of using a diary method were three-fold: 1) To focus the participant’s mind on the issue of caring responsibility in different contexts and stimulate subsequent interview dialogues (Dahlberg et al., 2008). 2) To allow the participant to report experiences shortly after they occurred (Jacelon and Imperio, 2005) and undisturbed by the researcher (Van Manen, 1997). 3) Finally, to generate data.
The diary method has some well-known limitations (Bolger et al., 2003) as also experienced in the present study. One concern is that the diary method is time consuming, imposing a significant burden on the participants. Furthermore, the diary method often requires detailed training sessions to ensure the participants fully understand the task (Furnes and Dysvik, 2013). Moreover, in order to obtain rich data, the diary method requires a high level of participant commitment.

The mentioned limitations became obvious because only eight participants completed a diary: two using the audio-recorder and six using a handwritten format. The diary length varied, with most being a couple of pages long (range 1–20 pages). The writing styles varied from mainly reporting facts to being more descriptive and reflective. Four participants did not complete the diary due to distress and time constraints.

Retrospectively, the idea of letting adult children leave the diary in a closed envelope at the parent’s place involved issues regarding confidentiality that should have been handled better, e.g. by picking up the envelope at the adult child’s place myself or having them send the diary to me by mail. The parent may have thought that something was going on behind his/her back and been curious about what the adult child was telling. This may have tempted the parent to open the envelope, and thus my duty as researcher to provide confidentiality was challenged. However, the adult children may also have been aware of and accepted this risk since I did not receive any complaints. Unfortunately, one of the eight envelopes had been re-opened when I received it, which is my responsibility. Luckily, the adult child in this case had used the audio-recorder, and I assume that the parent was not able to figure out how to use the machine.
In-depth interviews

Individual in-depth interviews with 11 older persons were conducted 2 to 3 weeks after hospital discharge. This time interval was chosen so that the older person had time to gain some recovery after hospitalization and expand their experiences with primary healthcare. I telephoned the older person to make an appointment. Sometimes I used the adult child as mediator if the older person did not answer the telephone. Nine older persons were interviewed in their homes, and two older persons were interviewed in a short-time rehabilitation home. The two last mentioned did not differentiate from the other interviews, since these two older persons had experience with receiving primary healthcare in their own home for a long period. During the interviews I was aware of the older person’s impairments and signs of tiredness. The interviews lasted from 35 to 83 minutes. A semi-structured interview guide with open-ended questions and prompts (appendix 6) was available to ensure the focus inherent in the different aims.

Individual in-depth interviews with 12 adult children were conducted 5 to 6 weeks after their parent’s hospital discharge. This time interval was chosen to give the adult child some time to gain further experiences with primary healthcare and with caring responsibility for their older parent. This was also done to give the adult child a break after completing the diary. Originally, the study was designed with face-to-face interviews, but it became necessary to determine time and location at the adult children’s convenience, resulting in two face-to-face interviews in the participants’ homes and ten telephone interviews conducted in the evenings. Interviews lasted 40 to 75 minutes. The diary notes were used as starting points for the interview; however, a semi-structured interview guide with open questions and prompts (appendix 8) was available to ensure the focus inherent in the different aims.
In Reflective Lifeworld Research you are advised to use open interviews when turning to the participants’ lifeworld experiences of the chosen phenomenon (Dahlberg et al., 2008). Nevertheless, as interviewer I entered the interview with specific aims, thus the encounter came to be structured in specific ways (Høffding and Martiny, 2015). As an interviewer I did not come to the interview as neutral. Although I used openness, empathy and bridling, I had to cultivate a dialogue that directed the participants’ intentionality and awareness as deeply and thoroughly as possible toward the phenomenon of caring responsibility in different contexts (Van Manen, 2014, Dahlberg et al., 2008). As an inexperienced researcher, I found it helpful to develop and memorize semi-structured interview guides (Brinkmann and Kvale, 2015), ensuring open questions about the different contexts and prompts for follow-up questions. The interview guides only acted as support for me at the end of each interview, as a way to “check” that all areas of interest were included and invariant structures of the participant’s experience were followed up.

**Data analysis**

A descriptive analysis was used to search for the phenomenon of caring responsibility’s structures of meanings in the different contexts in focus in the three inquiries. Essence is simply a phenomenon’s way of being (Dahlberg, 2006). However, it is important to note that “essences are open, infinite and expandable and they are never completely explored or described. Meaning emerges in relation to ‘events’ of the lifeworld, and when the lifeworld changes, meaning changes as well” (Dahlberg, 2006: 16). Therefore, it is important to describe the whole structure of meanings as explicit as possible because it covers the most essential parts of the phenomenon, closely intertwined with the more concrete descriptions, the constituents that further elucidate the meaning of the phenomenon. By
providing thick descriptions, the readers can judge the transferability of the findings (Lincoln and Guba, 1985).

The analysis was conducted as a dialectical tripartite movement between the initial whole – the parts – the new whole (Dahlberg et al., 2008, Andersen and Dahlberg, 2019). To get a sense of the initial whole, all interviews and diaries were transcribed verbatim by myself (except two transcribed by a student employee). I checked for accuracy by listening to all audio-records while reading the transcripts. All material was thoroughly read several times. Then the reading focused on the identification and marking of meaningful parts, called meaning units, and notes were made in the margin. Meaning units that seemed to belong to each other were then gathered into temporary clusters. These temporary clusters of meaning were discussed with all supervisors and re-grouped several times until the essential meanings and constituents reached a certain level of consistency, a new whole.

This analytical process between the whole and the parts was a constant dialogue characterized by questioning the text, focusing on the pattern of meanings of the phenomenon in focus (Dahlberg and Dahlberg, 2020). Through the analysis and the description of its findings, I worked within a “bridled” attitude characterized by openness, carefulness and reflection, being aware of my pre-understandings in the form of expectations, ideas and theories (Dahlberg et al., 2008). Table 3 presents an example of the analysis process from inquiry III. Other examples are presented in articles I and II.
Table 3 Example of analysis process from inquiry III

<table>
<thead>
<tr>
<th>Related meaning units</th>
<th>Temporary clusters</th>
<th>Constituent</th>
<th>Essential meaning</th>
</tr>
</thead>
<tbody>
<tr>
<td>A few healthcare professionals are enthusiastic souls who know what to do and do a little extra. However, the majority are temporary workers. They are nice and kind but they do not know much about caring for ill people.</td>
<td>Knowing what to do and doing something extra</td>
<td>Despite enthusiastic souls – basic human care is not enough</td>
<td>A question of being professionally competent</td>
</tr>
<tr>
<td>It is nice when you are greeted with laughter and ‘How are you’? You feel a warmth because you are sure it is not something they pretend.</td>
<td>Universal characteristics like kindness and niceness</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I do not think they are good enough at observing and interpreting things. Several times, I had to either drive my father to the GP or get the GP to visit him, 10 minutes after home care left the house. That is not very safe. Days when my father is OK, everything goes smooth and that is super; but when a sudden turn in the road appears and something unforeseen happens, they are not skilled enough to take action.</td>
<td>Unknowledgeable about caring for ill people</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Visiting my father who just had been discharged from hospital, I saw the healthcare assistant put the food bag for tube feeding in the fridge. Then I asked her, is that the food you gave my dad at 5 and 8 o’clock? Yes, the healthcare assistant answered. Then I said, look at the date, it was opened a week ago. It is clearly stated on the bag that it may only be open 24 hours.</td>
<td>Universal characteristics like warmth and genuine interest</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Lack of competencies</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Adult children compensate</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Unsafe situation</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Basic human care falls short</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Lack of skills/willingness to act</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Giving food that is too old to persons just discharged from hospital</td>
<td>Errors of commission in care</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Daughter making the healthcare assistant aware of error</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poor urinary catheter hygiene has caused my father many urinary problems.</td>
<td>Poor hygiene causing infections</td>
<td>Medication error</td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td>---</td>
<td></td>
</tr>
<tr>
<td>A home care nurse visits my father the day after his discharge from hospital but she does not react to there being no antibiotics even though they had been prescribed. The error is not discovered until 4 days later by another home care nurse.</td>
<td>Caring responsibility is not just about listening and accepting what the older person says</td>
<td>Errors of omission in care</td>
<td></td>
</tr>
<tr>
<td>They (healthcare assistants) just pop in and see if my mom is still breathing. If she is, they are happy. If the older person otherwise rejects everything, and they do so when being old and sick, the healthcare assistants just leave again. They just take note of my mother’s refusal of, e.g., food.</td>
<td>No efforts made to provide sufficient nutrition</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I have talked with the home care nurse a few times, but she does not take the role of observing; she is only there for giving medicine and ordering the medication for which my father is in short supply.</td>
<td>Non-holistic</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I have cancelled their help with a bath because they just stand there and tell me that I have to do whatever I can by myself. But can and can, I am completely devastated afterwards.</td>
<td>Task-oriented</td>
<td></td>
<td></td>
</tr>
<tr>
<td>My mother was entitled to a temporary rehabilitation home, but the municipality had no vacancies. Therefore, I think she should have stayed a few more days in the hospital. This discharge was too early.</td>
<td>Not sensing and reading the situation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I experience that no one really takes responsibility, except me as his son. My father notices it but</td>
<td>Lack of responsiveness to the person’s needs and well-being</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No vacant temporary rehabilitation home</td>
<td>Caused in the Bermuda triangle of healthcare systems</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Discharged too early</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No one really takes responsibility except the adult child</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
cannot do anything about it. He is caught between two, no rather three systems, his own GP, who is a very responsible and proper and busy GP. The only thing the GP can do is to take some blood samples and tests, and if it does not look to good, the GP will try to admit my father to the hospital, but he has to go via the emergency department. And they will try to get him out of the ward again as soon as possible but sometimes, you just have to make a special effort before older persons are discharged because they cannot handle it themselves. Communication is poor. You should not say about people that they do not care, but it is as if they so distant.

| The parent notices but cannot handle it | Caught between three systems | Discharged from hospital as soon as possible, which is difficult for older persons to handle | Poor communication and distance |
Chapter 6 Findings

The findings are briefly introduced here followed by articles I, II and III. Articles I and II present caring responsibility as a rather natural phenomenon in the parent-child relationship, whereas article III presents caring responsibility as a professional phenomenon.

**Article I:** Here we focus on the phenomenon of caring responsibility from the perspectives of 11 persons aged 80+ living alone with chronic illness, physical frailty and dependence on adult children. The essential meaning is identified as “it means everything” characterized by a strong and trusting relationship, and appreciated by the older persons 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. Caring responsibility from this perspective is further described through four constituents: 1) a life-constraining transition, 2) trusting children filling the gaps and being the glue, 3) tacit responsibility, negotiations and acceptance, and 4) dependent on children and knowing they are burdened with you. We conclude that caring responsibility is based on a trusting relationship and tacit negotiations 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 dependence 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 (Andersen et al., 2020a).

**Article II:** Here we focus on the experiences of adult children with caring responsibility for an 80+-year-old chronically ill parent with frailty. The essential meaning of caring responsibility from this perspective is identified as “a condition of life, filled with uncertainty.” Three constituents contribute: 1) balancing love, duty and reciprocity, 2) being the parent’s advocate and manager, and 3) experiencing concerns and bodily strain. We conclude that adult children work hard to provide care and enhance the well-being of their parent. Heidegger’s concept *Fürsorge* may help us understand how by showing how caring responsibility means balancing different roles vis-à-vis the parent, one’s own life and the health and social systems. Caring responsibility changes the relationship between parent and child (Andersen et al., 2020b).

**Article III:** Here we focus on the experiences with caring responsibility in primary healthcare from the perspectives of persons aged 80+ years and their adult children. The essential meaning of caring responsibility in this context is identified as “a question of being professionally competent.” Four constituents contribute: 1) despite enthusiastic souls – basic human care is not enough, 2) errors of commission in care, 3) errors of omission in care, 4) caught in the Bermuda triangle of healthcare systems. We conclude that caring responsibility carries both positive and negative meanings. Positive aspects are experienced when healthcare professionals act as decent, trustworthy, committed and competent persons able to provide professional care, thus acknowledging the older person as an individual set in a vulnerable life context with illness and frailty. Another positive aspect relates to trust in the sense that the agreed-upon care at a system level is provided in the form of professional,
qualified care and not just good service. Negative aspects of caring responsibility surface in the form of problems with insufficient care, sometimes resulting in errors of commission and omission. In such situations, responsibility becomes blurred, and the adult children have to compensate to ensure their older parent’s well-being and safety in their home. Lack of continuity, lack of holistic care and feelings of being caught in a Bermuda triangle between the GP, the hospital and the municipality also create blurred lines of responsibility. The older persons have to relate to these blurred lines of responsibility, navigating being dependent on both the healthcare systems, healthcare professionals and their adult children’s ways of assuming caring responsibility.
Who cares?
Caring responsibility from the perspectives of older, ill persons and their adult children in primary healthcare
Caring responsibility from the perspectives of older persons whose adult children are their caregivers

Helle Elisabeth Andersen MSc, RN, PhD student1,2 | Bente Hoeck PhD, RN, Postdoc3
Dorthe Susanne Nielsen PhD, RN, Professor4,5,6 | Jesper Ryg PhD, MD, Professor4,6
Charlotte Delmar PhD, RN, Professor, FAAN1,7,8

Abstract

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 11 persons aged 80+ years were conducted following their discharge. The interviews lasted 35–83 min, were audio-recorded and 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.

Implications for practice: Older persons want their adult children to be involved and acknowledged when planning care and treatment because they often seem to serve as the ‘glue’ that makes it possible for the parent to remain in his/her own home.
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 (Tanderup et al., 2018; WHO, 2015).

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 (Board & McCormack, 2018; Todres et al., 2009). 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 hospitalisation (Pimouguet et al., 2017), loneliness (Taube et al., 2016) and reduced ability to manage daily living (Ebrahim, Wilhelmson, Eklund, Moore, & Jakobsson, 2013), especially following hospitalisation (Andreasen, Lund, Aadahl, & Sørensen, 2015). Older persons with high care needs have been described as ‘invisible’ and lacking a loud collective voice (Katz, Holland, & Peace, 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 & Delden, 2011).

Although considerable empirical and theoretical attention has been paid to this issue from the adult children’s perspective (Bookman & Harrington, 2007), rather less attention has been paid to older persons’ voices on adult children’s caring responsibility (Cahill, Lewis, Barg, & Bogner, 2009; Dale, Søevedide, Kirkevold, & Søderhann, 2011). Therefore, the ambition of this phenomenological inquiry was 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’ 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’
with three categories; preservative caregiving, reconstructive care, and dependency on adult children.

2.2 Home care and home nursing

The older persons in our inquiry needed help with one or more activities of daily living (ADL), for example personal hygiene, dressing or getting outside, and with instrumental ADL (IADL), for example cooking and cleaning. In Denmark, where this inquiry is conducted, home care falls into 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 services1 are challenged by scarce resources reducing, for example, 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 neighbours (Verbakel et al., 2017), especially adult children become caregivers if the parent lives alone (Stuijfbergen & Delden, 2011). The motives behind family or intergenerational care are 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 categorisations are more or less recognisable in other research that focuses on informal caregivers as a homogeneous group within, for example, a hospital setting (Lindhardt et al., 2006; Uhrenfeldt et al., 2018), within home care (Andersen, Hoek, Nielsen, Ryg, & Delmar, 2020; Jarling, Rydstrom, Ernsth-Bravell, Nystrom, & Dalheim-Englund, 2019; Lewinter, 2003; Søvde et al., 2019) or nursing homes (Ekström et al., 2019).

Motivations of family care have been described in terms of solidarity and norms of filial obligation (Bengtson & Roberts, 1991), as ambivalence (Lendon, 2017; Luescher & Pillemre, 1998), and as altruism and reciprocity (Klimaviciute, Perelman, Pestieu, & Schoenmaeckers, 2017; Silverstein et al., 2012). In line with the theory of ambivalence, informal caregiving is often associated with caregiver burden (Adelman, Tmanova, Delgado, Dion, & Lachs, 2014; Bastawrous, 2013; Ringer et al., 2017) and cooping (Del-Pino-Casado, Frias-Osuna, Palomino-Moral, & Pancorbo-Hidalgo, 2011). In a recent review on caregiving for ageing 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 towards 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), Stuijfbergen 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 AND METHOD

To gain insights into the phenomenon of caring responsibility, our inquiry is inspired by reflective lifeworld research (RLR) (Dahlberg &
Dahlberg, 2019a; Dahlberg, Dahlberg, & Nystrom, 2008). 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, pretheoretical world of experience through a continuous search for meaning (Dahlberg & Dahlberg, 2019b). In this inquiry, the ambition of the lifeworld-based approach was to show how it is for the older persons to be cared for by adult children.

As researchers, we have to problematise and reflect on the life-world’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, 2019; Dahlberg et al., 2008).

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 & Galvin, 2017) with the following inclusion criteria: (a) older persons with chronic illness, (b) aged 80+ years, (c) living alone, (d) not diagnosed with dementia and (e) 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.

4.2 | Interviews

From January to September 2018, the first author conducted 11 semi-structured lifeworld interviews in Danish approximately 2–3 weeks postdischarge: nine in the participants’ homes and two in a short-time rehabilitation home. The interviews lasted 35–83 min, 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 (Brinkmann & Kvale, 2015; Dahlberg et al., 2008).

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

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

Note: Abbreviations: F, female; M, male.
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 (Dahlgren, 2006). The circular process involved the following phases: (a) transcripts were read several times to obtain an understanding of the whole. (b) Significant pieces of text, called meaning units, were highlighted, and initial thoughts and revelation in relation to the phenomenon were written down. (c) Meaning units that appeared to be related to one another were gathered into clusters. (d) 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 phase 2 were carried out by the first author, and phase 3 and phase 4 were 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 11 participants’ lifeworld experiences adequately represented the meaning structure of the phenomenon. An example of the analytic process is presented in Table 3.

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 characterised 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.

### TABLE 2 Interview guide

<table>
<thead>
<tr>
<th>Suggested questions/interview areas</th>
<th>Prompts</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introduction - initial briefing</td>
<td>Can you elaborate on that...</td>
</tr>
<tr>
<td>• Acknowledgements 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>Interview</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 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 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 do you feel about it?</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>• Is there anything further you would like to tell?</td>
<td></td>
</tr>
<tr>
<td>• Closing words and summarising</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 5 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 others, I try to do whatever I can (Liz)</td>
<td>Striving for participation in everyday life activities</td>
<td>Terrible and demanding to be dependent</td>
<td>Doing whatever she can</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>Leaving responsibility to the children</td>
<td>Trusting the children to fill the gaps and be the ‘glue’</td>
<td></td>
</tr>
<tr>
<td>My son takes care of everything, I could not manage without him (Ben)</td>
<td>Trusting children to take care of everything. The parent cannot manage without this support</td>
<td></td>
<td></td>
</tr>
<tr>
<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>Children accompany and take care of healthcare management</td>
<td></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>Supporting instrumental activities of daily living, ensuring sufficient nutrition</td>
<td></td>
<td></td>
</tr>
<tr>
<td>My daughter takes care of everything with money and what needs to be paid and informs me about, which is good (Maria)</td>
<td>Administrative matters and trust Being informed is good</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The help from my daughter means everything. Without her, I could not stay in my home (Adam)</td>
<td>Support from the child means everything. Could not remain in own home without this support</td>
<td></td>
<td></td>
</tr>
<tr>
<td>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)</td>
<td>Helping is natural. Responsibility not verbalized</td>
<td>Tacit responsibility, agreement and acceptance</td>
<td></td>
</tr>
<tr>
<td>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 healthcare system. However, I do not correct them or complain. I have a good relationship with the boys(Max)</td>
<td>Interference and overprotectiveness Accepting and recognizing help from children Potential conflicts. Not correcting the children Good relationship</td>
<td></td>
<td></td>
</tr>
<tr>
<td>One of my three children has to take responsibility, but it also means that the distance between my son and eldest 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)</td>
<td>Family tensions and tacit agreements and acceptance of whom of the children become the primary caregiver</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

(Continues)
Caring responsibility assumed by adult children is foregrounded by the older persons’ current situation, which is experienced as a life-constraining transition. Everyday life is affected at several intertwined levels: literally because of physical and social loss, and existentially because of the 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.

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.

Coming to terms with the transition from independence to dependency 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 persons become 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, for example, 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 dizzzy 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 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 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 & 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, 2006, 2013, 2018) and empirical perspectives (Delmar et al., 2006; Delmar, Rasmussen, & Dolmer, 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 & 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 & 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 & Ross, 2014) and the promotion of own choice and responsibility (Delmar, Alenius-Karlsson, & Mikkelsen, 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 (Cahill et al., 2009; Lewinter, 2003; 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 Tornini 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 & Guba, 1985) of the findings, different considerations were taken into account. We used clear inclusion criteria. In RLR, 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 & Guba, 1985) with the phenomenon, reflexivity and flexibility was an ongoing process (Dahlberg et al., 2008). We questioned our pre-understandings as healthcare professionals and having (had) older parents ourselves in order to find something new, not already existing in our pre-understandings (Nyström & Dahlberg, 2001). The 11 interviews appeared to be sufficient to achieve a meaning structure of the phenomenon. Otherwise, due to the flexibility in RLR, 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.

<table>
<thead>
<tr>
<th>IMPLICATIONS FOR PRACTICE</th>
</tr>
</thead>
<tbody>
<tr>
<td>• 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.</td>
</tr>
<tr>
<td>• Involving adult children in decision-making is appreciated by older persons and experienced as a relief.</td>
</tr>
<tr>
<td>• 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.</td>
</tr>
</tbody>
</table>

52
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.

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
Helle Elisabeth Andersen https://orcid.org/0000-0001-7647-5641
Bente Hoek https://orcid.org/0000-0002-8641-3062
Dorthe Susanne Nielsen https://orcid.org/0000-0002-3954-7551
Jesper Ryg https://orcid.org/0000-0001-9455-4511
Charlotte Delmar https://orcid.org/0000-0001-9455-4511

REFERENCES
Delmar, C. (2013). Beyond the drive to satisfy needs: In the context of health care. Medicine, Health Care and Philosophy, 16, 141–149.


How to cite this article: Andersen HE, Hoeck B, Nielsen DS, Ryg J, Delmar C. Caring responsibility from the perspectives of older persons whose adult children are their caregivers. Int J Older People Nurs. 2020;00:e12335. https://doi.org/10.1111/opn.12335
Who cares?
Caring responsibility from the perspectives of older, ill persons and their adult children in primary healthcare
Who cares?
Caring responsibility from the perspectives of older, ill persons and their adult children in primary healthcare
The number of people aged 80 years or more, also called the "oldest-old," is increasing worldwide. According to UN projections (UN, 2015:9), the number will have tripled to 434 million by 2050. In Denmark (population total 5.8 million), the number of oldest-old will have doubled to 500,000 by 2040 (Statistics Denmark, 2018). Caring responsibility for ageing parents is expected in most cultures (Stuifbergen & van Delden, 2011), and informal caregiving is generally well-researched. However, in Nordic welfare countries, little is known about adult children's experience of caring responsibility for the oldest-old.

This is an open access article under the terms of the Creative Commons Attribution License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited. © 2020 The Authors. Nursing Open published by John Wiley & Sons Ltd.
Advanced age is associated with increased risk of illness, frailty and use of healthcare resources (WHO, 2015). In Denmark, most of the oldest-old resides in the community; of these, 50% are living alone (Statistics Denmark, 2019) and 32% receive home care (DanAge Association, 2017a). Older people living alone are particularly vulnerable, have poor self-reported health and face everyday life challenges including mobility issues, risk of social isolation and loneliness (Birkeland & Natvig, 2009; Fisher, Baker, Koval, Lishok, & Maisto, 2007; Kharicha et al., 2007; Rolls, Seymour, Froggatt, & Hanratty, 2011; Taube, Jakobsson, Midlöv, & Kristensson, 2016). They are also at increased risk of unplanned hospitalization (Pimouguet, Rizzuto, Lagergren, Fratiglioni, & Xu, 2017).

In Denmark, health and social services are financed by general taxes and therefore free of charge (Danish Ministry of Health, 2017). Home care and home nursing are provided by the municipalities according to individual need to allow people to stay in their own homes as long as possible. Even so, relatives undertake much informal caregiving (Lewinter, 1999; 2003; DanAge Association, 2017b) like in other countries. Approximately 1/3 of the populations in 20 European countries are informal caregivers (family and friends) (Verbakel, Tamlangsönn Setup, Winstone, Fjær, & Eikemo, 2017), and informal caregiving is more common in Nordic countries than in Central, Eastern and Southern Europe (Verbakel et al., 2017).

Demands on relatives like adult children are thus high and expected to increase because of current structural changes to reduce healthcare costs. However, adult children are typically at a stage in their own lives where they face competing demands and must balance work, parenting, spousal relationships, early retirement and other life demands, while simultaneously facing caring responsibility for their older parent(s) (O’Sullivan, 2014).

Informal caregiving is associated with physical and emotional strain, the so-called caregiver burden (Adelman, Tmanova, Delgado, Dion, & Lachs, 2014; Bastawrous, 2013; Del-Pino-Casada, Frias-Osuna, Palomino-Moral, & Pancorbo-Hidalgo, 2011; Ringer, Hazzan, Agarwai, Mutsaers, & Papaloannou, 2017) but may also be experienced as worthwhile and meaningful (Roth, Fredman, & Haley, 2015; Toljamo, Perälä, & Laukkala, 2012).

Previous studies have focused mainly on hospital settings, the discharge process and home care or nursing home settings (Bridges, Flatley, & Meyer, 2010; Ekström et al., 2019; Lewinter, 2003; Rustad, Cronfalk, Furnes, & Dysvik, 2017; Sivertsen, Lawson-Smith, & Lindhardt, 2018; Sevde, Hovland, Ulleburst, & Råholm, 2019). Caregivers have been conceptualized as “conductors” responsible for maintaining the “rhythm” necessary for an older person’s well-being, whether at home or while hospitalized (Lowson et al., 2013). In a study of how relatives experienced hospitalization of older persons and collaboration with nurses in an acute ward, Lindhardt, Bolmsjö, and Hallberg (2006) found that some relatives entrusted the older person’s care into the hands of health professionals and therefore had some respite from caregiving activities; others did not and adopted controlling behaviours, closely monitoring care and treatment.

Family caregivers have often been studied as a homogeneous group (Jarling, Rydström, Ernst-Bravell, Nyström, & Dalheim-Englund, 2019; Juntunen et al., 2018; Lindhardt et al., 2006; Moral-Fernandez, Frias-Osuna, Moreno-Cámara, Palomino-Moral, & Del-Pino-Casada, 2018; Ringer et al., 2017). In a meta-analysis of spouses, adult children and children-in-law, spouses reported more depression symptoms and greater financial and physical burden than adult children and children-in-law, which was explained mostly by spouses’ higher levels of care provision (Pinquart & Sörensen, 2011). However, adult children become primary caregivers if the parent lives alone and they have a history different from that of a spousal relationship. They would have relied on their parent for support and nurturing, but now they must provide support and assistance to their parent.

Adult children’s motivation for providing informal care has been discussed in terms of pure altruism, reciprocity or family norms (Klimaviciute, Perelman, Pestieau, & Schoenmaeckers, 2017). However, what does it mean to have a caring responsibility in a Nordic welfare context? As healthcare professionals, we must gain a deeper understanding of this group of relatives who offers support across healthcare levels (Bridges et al., 2010; Lowson et al., 2013; Rustad et al., 2017) and are a vital albeit often underestimated resource in the care and well-being for older people.

To provide lifeworld insights into the experiences of adult children with caring responsibility for an 80+-year-old chronically ill parent with frailty.
ourselves. Thus, the authors continuously reflected on and discussed the evolving process of understanding, patiently waiting for the essential meaning of the phenomenon to show itself during the analysis.

4.2 | Participants

Participants were 12 adult children (five sons, seven daughters) aged 38–73 years (mean 58 years) whose parents were 81–98 years old (mean 88 years), chronically ill, living alone with frailty and therefore receiving home care support with activities of daily living (ADL), for example personal hygiene, toileting or eating and with instrumental activities of daily living (IADL), for example cleaning and cooking. Their parents also received home nursing mainly focusing on medication. We used the standard frailty definition: “A medical syndrome with multiple causes and contributors that is characterized by diminished strength, diminished endurance and reduced physiologic function that increases vulnerability for developing increased dependency and/or death” (Morley et al., 2013). Parents diagnosed with dementia were excluded.

In collaboration with staff at a geriatric department, the first author selected participants using a purposeful sampling strategy (Holloway & Galvin, 2017) to ensure selection of those currently experiencing the phenomenon of caring responsibility. Participants were included if they were primary caregivers having contact with a parent daily/several times a week; and if they could read, write and speak Danish. Variation regarding sex, age, occupation and the parent’s medical condition and care setting appeared during the selection process and thus allowed diverse perspectives to be addressed (Table 1). After consent from the parent, the first author contacted the participant. Preliminary analysis showed that the 12 participants’ lifeworld experiences adequately represented the general structure of the phenomenon of caring responsibility.

4.3 | Data collection

Data were generated from January–September 2018 using diaries and interviews. The adult children completed a 2-week diary from the time of their study inclusion. They could choose between different formats and received an envelope with an audio-recorder, a notebook and written guidance with open questions like: “Could you please tell about your experiences during your father’s/mother’s hospital stay? During the discharge process? During home care assistance?” The diary allowed participants to report their experiences shortly after they occurred and undisturbed by the researcher (Clayton & Thorne, 2000). Eight participants completed the diary: two using the audio-recorder and six using a handwritten format. The diary length varied with most being a couple of pages long (range 1–20 pages). Four participants did not complete the diary due to distress and a lack of time.

The diary was followed up with an in-depth interview (Dahlberg et al., 2008) by the first author who used an interview guide and diary notes as starting points to further explore the adult children’s experiences with caring responsibility. The guide comprised questions expanding on their experiences with caring responsibility, for example: “What is it like to help and support your mother/father? Can you give examples of the caring responsibility you experience? What does helping you parent mean to you?”

The time and location of the 12 interviews were determined at the participants’ convenience: two face-to-face interviews were conducted in the participants’ homes and 10 telephone interviews were conducted in the evenings. Interviews lasted 40–75 min and were recorded. The first author transcribed verbatim the audio-recorded/handwritten diaries and interviews for textual analysis.

4.4 | Ethical considerations

Assuming that both the parent and the adult child were in stressful and vulnerable situations, we gave high priority to ethical considerations during the entire process. Oral and written information about the study was given, including an option to withdraw from further participation at any time. Parent and child had time to discuss participation before providing written consent. Confidentiality and anonymity were assured (Nordic Nurses’ Federation, 2003). The study was approved by the Danish Data Protection Agency (reference number 2015-57-0066).

4.5 | Data analysis

All data were analysed and discussed with an open, reflective and bridled attitude following the methodological principles of RLR (Dahlberg et al., 2008). Analysis encompassed empirical data from diaries and interviews as a whole, focusing on differences and similarities in descriptions of meanings across data. This approach was cyclic; data were read thoroughly several times to gain an understanding of the overall picture. Thereafter, significant texts, called meaning units, were marked with notes of initial understanding. Related meaning units from diaries and interviews were then gathered in temporary clusters helping the researchers determine the essential structure of meanings. The clusters were then related to each other to find a pattern that described the essential meanings of the phenomenon of caring responsibility followed by descriptions of meanings further constituting the phenomenon. An example of the analysis process is presented in Table 2.

5 | FINDINGS

The essential structure of the meanings is that the phenomenon of caring responsibility is “a condition of life, filled with uncertainty.” Three closely intertwined constituents contribute to the phenomenon: (a) balancing love, duty and reciprocity; (b) being the parent’s
advocate and manager; and (c) experiencing concern and bodily strain.

5.1 A condition of life, filled with uncertainty

Adult children experience caring responsibility as a condition of life, filled with uncertainty. This state is always present and closely intertwined with affection and obligation and a feeling of giving back some of the help received from the parent earlier in life. It is a condition to be concerned with one’s parent’s well-being:

*My father is not spoiled. I am giving back a little bit of what he did for me.*

Uncertainty relates to the parent’s situation with illness, growing frailty and dependency:

*It hurts me to see my strong and proud father crumble within a few months and I am worried about what lies ahead.*

However, uncertainty also relates to concerns about how to balance caring responsibility and the caregiver role in different healthcare contexts and one’s own life. The health and social services do not always deliver the expected care, which increases uncertainty about the parent’s situation staying in his/her own home; and this sparks concerns regarding growing old and dependent oneself.

5.1.1 Balancing love, duty and reciprocity

Adult children’s feeling of caring responsibility comes from love and gratitude towards their older parents, most of whom have been there for their children and helped them in earlier years; now the children want to reciprocate. However, not all children/siblings seem to assume caring responsibility, which increases the load on those who do. Often one (or two) of the children, living nearby and having a closer relationship with the parent, becomes primary caregiver. The feeling of duty and reciprocity depends on the relationship with the parent and the family’s history:

*I may always have had a closer relationship with my parent(s) than my little brother. He does not feel so obliged to visit and help our mother.*

It is meaningful to provide informal care related to IADL, for example shopping; cleaning; taking the parent to the dentist or hospital; and administer the parent’s finances. However, assisting with intimate ADL like personal hygiene or toileting is not perceived as natural. This is experienced as being inordinate for both child and parent; thus, an unspoken agreement exists that such ADL are primarily handled by home care.

---

**TABLE 1 Characteristics of the participants and their parents**

<table>
<thead>
<tr>
<th>Participant</th>
<th>Age</th>
<th>Occupation</th>
<th>Siblings</th>
<th>Parent</th>
<th>Parent’s age</th>
<th>Parent’s medical conditions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Son</td>
<td>65</td>
<td>Retired, former nurse/manager</td>
<td>2 sisters</td>
<td>Father</td>
<td>86</td>
<td>Heart disease and prostate cancer</td>
</tr>
<tr>
<td>Daughter</td>
<td>58</td>
<td>Factory worker</td>
<td>1 brother abroad</td>
<td>Mother</td>
<td>83</td>
<td>Severe rheumatoid arthritis and osteoporosis</td>
</tr>
<tr>
<td>Daughter</td>
<td>66</td>
<td>Retired, former civil economist and dietitian</td>
<td>1 brother</td>
<td>Mother</td>
<td>92</td>
<td>Dizziness and balance problems</td>
</tr>
<tr>
<td>Son</td>
<td>62</td>
<td>Social worker</td>
<td>1 brother</td>
<td>Father</td>
<td>93</td>
<td>Chronic obstructive pulmonary disease and prostate problems</td>
</tr>
<tr>
<td>Son</td>
<td>60</td>
<td>Manager</td>
<td>1 sister and 1 brother</td>
<td>Mother</td>
<td>93</td>
<td>Osteoporosis, fall problems and gastric ulcer</td>
</tr>
<tr>
<td>Daughter</td>
<td>51</td>
<td>Salesperson</td>
<td>2 brothers</td>
<td>Father</td>
<td>93</td>
<td>Chronic obstructive pulmonary disease and heart disease</td>
</tr>
<tr>
<td>Son</td>
<td>57</td>
<td>Service engineer</td>
<td>1 brother</td>
<td>Father</td>
<td>86</td>
<td>Chronic obstructive pulmonary disease and prostate problems</td>
</tr>
<tr>
<td>Daughter</td>
<td>65</td>
<td>Cleaning assistant</td>
<td>2 sisters</td>
<td>Mother</td>
<td>87</td>
<td>Diabetes, rheumatoid arthritis and fall problems</td>
</tr>
<tr>
<td>Daughter</td>
<td>73</td>
<td>Retired, former drugstore worker</td>
<td>None</td>
<td>Father</td>
<td>98</td>
<td>Heart and circulation problems</td>
</tr>
<tr>
<td>Son</td>
<td>57</td>
<td>Technical engineer</td>
<td>1 brother</td>
<td>Mother</td>
<td>83</td>
<td>Diabetes and cancer</td>
</tr>
<tr>
<td>Daughter</td>
<td>52</td>
<td>Social worker</td>
<td>1 brother abroad</td>
<td>Father</td>
<td>81</td>
<td>Stroke, fall problems and alcohol abuse</td>
</tr>
<tr>
<td>Daughter</td>
<td>38</td>
<td>Healthcare assistant</td>
<td>2 brothers</td>
<td>Father</td>
<td>82</td>
<td>Arthritis and cancer</td>
</tr>
</tbody>
</table>
Practical tasks are often foregrounded. Care and support are time-consuming and can sometimes be burdensome, for example when a mother repeatedly calls her son whom she knows will come and help her. Thus, the older parent occasionally expects that the child will provide help when needed.

Some children are uncertain about when to involve their parents and find it difficult to balance dependence against independence and to maintain the parent’s autonomy and dignity. Others aim to protect and relieve their parent of worries by withholding information:

I feel my father is very thankful and trusting. He is quite aware of the work I do for him and he is confident in my ability. However, I am sure he is not totally aware of the colossal workload that is required. There are many interactions with individuals who are vital in his healthcare, both on a spoken and written level. If he was told this information, it would be counterproductive, so there is no point telling him.

Gratitude and a trusting relationship seem essential when one or two of the children become primary caregiver(s). They take on the role of communicating and coordinating with siblings, other family members and the health and social systems. However, communication can be a challenge, especially if the relationship between the family members is problematic:

I have started talking to my angry sister again because it is necessary to communicate and coordinate, e.g., who visits him (the parent) and when. One day, I asked her to do something very specific, so she did, but otherwise she did not do anything.

Caring responsibility is also driven by feelings of duty, closely intertwined with love for the parent:

If my brother and I did not help our mother, she could not stay in her apartment. However, I feel my life goes by helping her. It is annoying, but my conscience forbids me to act differently.

The children have true concerns about their parent’s well-being and feel a huge responsibility. They respond to the uncertain situation by supporting and doing things their parent can no longer manage alone, even if this has consequences for their own lives.

5.1.2 | Being the parent’s advocate and manager

For some children, having caring responsibility means supervising and taking on the role of being the parent’s advocate and manager, which involves mediating the best care and treatment irrespective of setting. The health and social systems are appreciated as they relieve the children from some of their worries about their parent’s basic needs. However, relief is not necessarily associated with being satisfied with the care and treatment provided. Uncertainty is still there, and sometimes, the children have to argue with doctors to arrange hospital admission for their older parents and remind nurses of basic care needs:

My father was placed in a chair for 11 hours in the emergency department. Finally, I had to call them: ‘My father needs to be put to bed, he’s old and tired and hasn’t had his medicine or even eaten yet’. That was the first time I found out they were about to send him home. When I finally got through to a doctor, who was extremely aggravated with me, I was forced to tell him exactly how I felt about the whole situation. After my conversation, my father was offered a bed and moved to the geriatric ward.

For some, the advocate/manager role means being alert and checking on healthcare professionals to mediate and ensure that the parent...
receives the right care, treatment and medication; like a daughter who refused to take her mother home from the emergency department before the nurse had inspected her mother’s urine; and further investigation revealed a kidney infection. Or another daughter who asked a home care assistant to call a nurse because the assistant was about to tube feed her father without knowing the instructions. Children also discover medication errors, especially regarding antibiotics, at discharge:

"At least twice my father has been discharged and not received the prescribed antibiotics. The home care nurse did not notice the error before I made her aware of it."

Advocating means participating in meetings with healthcare professionals, for example discussing the parent’s need for home care. A son explains how he and his brother have to participate to explain their father’s situation. Otherwise, the healthcare professionals that should help him would leave him within 2 min because their father would not admit the discomfort he experienced and would not ask for help. Being the parent’s manager implies much coordination and being the one trying to have an overview of the parent’s care arrangements:

"The love and familiarity in the relationship have not changed. However, as I know all of the people who are involved in his case, all the arrangements with individuals and council employees, all these people call me. Therefore, I feel more like his business manager."

Caring responsibility enhances being proactive on the parent’s behalf. However, uncertainty is experienced when balancing between standing firm and simultaneously not being viewed by healthcare professionals as being troublesome when questioning decisions. The children know that the health and social systems are under pressure but prefer more proactive systems and suggest that “a contact person who is affiliated with the patient would be helpful.”

5.1.3 | Experiencing concern and bodily strain

Although assuming caring responsibility is a condition of life, it is stressful watching an old parent become ill, frail and dependent and this situation is accompanied by constant concern and uncertainty about the parent’s well-being, including a touch of guilt. A daughter explains that when she leaves her father’s home, she thinks that she should turn the car and drive back to him. Uncertainty is enforced because the father is living alone with illness and frailty. This feeling is present although her father receives home care several times a day. In general, the children are concerned about their parent’s well-being and basic needs, for example whether the parent is eating and drinking sufficiently and receiving the agreed care by the health and social systems.

Adult children want to be there and help whenever necessary, but it can be difficult to find time, especially when they are still working, in which case it is very important to have a flexible employer, for example, during the parent’s hospital stay. A daughter expresses difficulties with her work this way:

"I often had to catch up hours at work because I was off a lot during my father’s hospital stay."

Some adult children set aside their own needs, like leisure activities. A daughter explains how she used to take language and dance lessons, but her mother now takes all her time and has done so for a couple of years. Even if the adult child is retired, he/she may be caught between the responsibility for his or her parent and the rest of the family. Being the only child or having a sibling abroad increases the burden. A daughter explains, crying, how she feels like being the only person her mother has. She feels like having the overall responsibility, even though her mother is an independent human being. It is quite stressful living with the uncertainty of what lies ahead, and it leads to bodily strain like constant worrying, nervousness, insomnia and forgetfulness. A son explains how he wakes up in the middle of the night thinking about all kind of things regarding his father; and a daughter expresses how her nerves are in tatters because she never knows what will meet her when she opens the door to her mother’s house. Another younger daughter with small children describes how she is under extreme pressure and sometimes has problems remembering things. She experiences that home care cannot manage her father’s complex care needs. Therefore, it is a relief for her when her father is hospitalized:

"When he is at home, there is never peace; there is always something one has to take into consideration. Now my father is in the hospital; this allows me a moment of peace. As soon as I know his condition is worsening, I revert to my stressed stage."

In addition to uncertainty and concerns regarding their older parent, some adult children describe uncertainty and concerns about ageing and becoming dependent themselves because they experience gaps in the health and social systems:

"My concerns also apply to my own life. I am not sure I want to grow old because who will take care of me? My son lives far away, lucky me."

This daughter is very sceptical about the Danish health and social systems and the policy of ageing in place.

6 | COMPREHENSIVE UNDERSTANDING AND DISCUSSION

The phenomenon of caring responsibility for an old parent with frailty and illness is experienced as “a condition of life, filled with uncertainty”. Our findings highlight adult children’s deeply rooted will to show caring responsibility for their parent. Even in a Nordic
welfare state like Denmark, caring responsibility is experienced as a condition of life. The children could leave all care to the formal health and social systems, but they do not. They want to reciprocate; expressed as wanting to give back some of the help they received from their parent(s). In line with other studies (Lindhardt et al., 2006; Lowson et al., 2013), they act as advocates and managers to protect and ensure their parents’ well-being. Our findings confirm those of Johansson and Sundström (2006), who showed that solidarity between generations, expressed as willingness to help older persons in need, is not superseded by extensive public care. On the contrary, it has gained new ground in the face of public service curtailments. This may be explained by looking closer at the concept of caring.

Caring means to be concerned about and can be understood as the basis for all human relations (Delmar, 2013, 2018; Martinsen, 1993). According to the German philosopher Heidegger (1962, p. 227), caring or “Sorge” in German is a fundamental basis of our being-in-the-world. Heidegger distinguishes between “Besorgen,” meaning our engagement with things, and “Fürsorge,” meaning our engagement with other people. “Fürsorge” is commonly translated as “solicitude,” suggesting care like in “taking care of children” (Heidegger, 1962, p. 157). Life is one’s own self-being, as well as being at the same time with others, for which caring is constitutive. Therefore, a close connection between care, self-care and solicitude exists that is inherent in adult children’s descriptions of caring responsibility as a condition of life. “Fürsorge” may explain motives of love, duty and reciprocity, which are at play between adult children and their parent in the present study. With “Fürsorge,” care manifests in our everyday life in two ways. The first kind of “Fürsorge” is substitutive; the caregiver is putting him or herself in the other person’s place for as long as it takes; the caregiver “leaps in” (einspringen) to take over responsibility for a current situation. In the second kind of “Fürsorge,” the caregiver “leaps ahead” (vorausspringen) of the care recipient to show the ways towards future possibilities and potentials. Adult children seem to assume and balance “Fürsorge” in both ways in various combinations; when they take over responsibility and become advocates and managers mediating between their older parent, the health and social services and the rest of the family; and when they balance feelings of love, duty and reciprocity enforced by the fact that the parent lives alone and needs support with IADL. “Fürsorge” is an ongoing condition of life. However, in the situation with an old, ill parent, the practical part of “Fürsorge” seems to background togetherness because the child is busy with the new roles as, for example housekeeper, chauffeur, advocate and manager, thus disrupting balanced reciprocity in the relationship. The child must navigate in this new asymmetrical relationship while still being the son/daughter, trying to maintain the parent’s autonomy and dignity.

Regarding dignity, it is noteworthy that an unspoken agreement seems to exist between parent and child that intimate ADL should be handled by home care. This is different from studies from other parts of the world, where adult children may do whatever necessary including providing financial support (Abalos, Yasuhiko Saito, Cruz, & G.T. & Booth, H., 2018; Aires et al., 2017; Mendez-Luck, Kennedy, & Wallace, 2008). However, this mutual agreement is consistent with findings of prior studies by Haberkern and Szydlik (2010) and Suanel, Groenou, and Tilburg (2012), showing that most of the population in Western European countries favours government responsibility in this respect, especially in the Netherlands and the Scandinavian countries. Interestingly, according to Verbakel et al. (2017), informal caregiving is common in Nordic countries and Denmark has the second-highest prevalence rate (42.8%) of informal caregivers among 20 European countries. This supports the findings in the present study that adult children are working hard to ensure the well-being of their parent.

Though being a condition of life, showing caring responsibility is accompanied by uncertainty. With Heidegger’s word, care means to be concerned, which implies a degree of uncertainty. The whole situation with an old, ill parent with frailty makes adult children face existential, life-constraining life phenomena (Delmar, 2013, 2018) like powerlessness and despair, causing concern and bodily strain. These findings are in line with previous research where “caregiver burden” was measured mainly through “burden scales” (Adelman et al., 2014; Bastawrous, 2013; Pinquart & Sörensen, 2011; Ringer et al., 2017). However, uncertainty also relates to how to balance growing dependency and maintaining the parent’s autonomy and dignity, balancing feelings of love and duty, when to support and participate in important decisions and when to step back, or with Heidegger’s words, when to leap in and when to leap ahead. For some children, it may be difficult to detach themselves from the caregiving role and just be “the child.” They may become entrapped, like the daughter who skipped all her leisure activities. Balancing one’s own life, including work-life if not yet retired, is a challenge. A study by Eldh and Carlsson (2010) confirms how middle-aged adult children expressed that they seemed to work all the time, either as employees or as an informal caregiver, some even decided to retire earlier than planned (Carlsen & Lundberg, 2018).

Uncertainty is constantly present as an existential concern about what lies ahead regarding the parent’s illness, frailty and dependency. Uncertainty is sometimes enforced by the perception of the health and social systems’ failure to deliver the expected care and treatment; and some children experience uncertainty when mediating between their parent and healthcare professionals. They try to leap ahead and balance obtaining the best care and treatment for their parent with the risk of being viewed as too demanding. In line with previous research (Bridges et al., 2010), adult children would prefer the healthcare professionals to be more proactive and sensitive, which would prevent some uncertainty. Adult children’s experiences with caring responsibility for an older parent raise concerns about growing old and becoming dependent, even in a welfare state like Denmark. These concerns should be considered when planning future care and policies for older people and relatives like adult children.

65
6.1 Study limitations

Using the diary method to allow descriptions of experiences shortly after they occurred was a challenge since the amount of data was minimal due to participants’ distress and lack of time. The diary method should, therefore, be considered in combination with other methods and was here complemented by in-depth interviews allowing rich lifeworld descriptions. Furthermore, telephone interviews are often depicted as a less attractive alternative to face-to-face interviews because of the absence of visual cues (Holloway & Galvin, 2017). However, in the present study telephone interviews allowed participants to feel relaxed and able to disclose sensitive information (Norvik, 2007) and describe the phenomenon of caring responsibility in terms of feelings of sadness, anger and love.

7 CONCLUSIONS

Despite support from the Danish health and social systems with ADL, IADL and home nursing, adult children in this study worked hard to ensure the right care and treatment for their older parent. The phenomenon of caring responsibility is a condition of life; however, it is accompanied by substantial uncertainty due to the parent’s illness and frailty and is enforced by the fact that the parent often lives alone. Reflections on care and Heidegger’s concept of ‘Fürsorge’ allows a deeper understanding of the phenomenon, showing how caring responsibility means balancing uncertainty while fulfilling different roles concerning the parent, one’s own life and the health and social systems, leading to constant concerns and bodily strain. Caring responsibility changes the relationship between parent and child and makes it more asymmetrical, with the child trying to leap in and leap ahead while balancing the parent’s autonomy and dignity.

7.1 Implications

Nuanced lifeworld descriptions and comprehensive understanding of the complex phenomenon of caring responsibility from the perspectives of adult children caring for an old, frail, chronically ill parent who lives alone have several implications:

- These insider views can enhance empathic understanding and allow a deeper level of care focusing on patient and family.
- Adult children play a vital role in their parent’s care and treatment; thus, it should be considered how such a role can be more actively acknowledged and how adult children can be more actively involved in planning arrangements.
- Supporting relatives like adult children in their caregiver role in a more proactive way, it would be beneficial if a contact person be affiliated with the older parent whether he or she was hospitalized or living at home.
- At a policy level, the contributions and responsibilities assumed by adult children should be recognized since they play a crucial role in the policy of ageing in place. Furthermore, their concerns regarding future elderly care should be considered.

ACKNOWLEDGEMENT

We would like to kindly thank the participants for sharing their experiences of caring responsibility and the staff at the geriatric department at Odense University Hospital for helping with recruitment.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

AUTHOR CONTRIBUTIONS

All authors: substantial contribution to and agreement on the final version of the manuscript.

ORCID

Helle Elisabeth Andersen https://orcid.org/0000-0001-5011-2295

REFERENCES


**How to cite this article:** Andersen HE, Hoeck B, Nielsen DS, Ryg J, Delmar C. A phenomenological–hermeneutic study exploring caring responsibility for a chronically ill, older parent with frailty. Nursing Open. 2020;7:951–960. [https://doi.org/10.1002/nop2.467](https://doi.org/10.1002/nop2.467)
Who cares?
Caring responsibility from the perspectives of older, ill persons and their adult children in primary healthcare
Older ill persons’ and their adult children’s experiences with primary healthcare. A Reflective Lifeworld Research approach

Helle E. Andersen, Bente Hoeck, Dorthe S. Nielsen, Jesper Ryg, Charlotte Delmar

Nordic Journal of Nursing Research, (accepted for publication 27th September 2020)

ABSTRACT

Aging in place puts ill and frail older persons in a vulnerable situation, and relatives, especially adult children, are expected to assume caring responsibilities. Healthcare professionals, like homecare nurses, play a key role in providing care to older persons needing support to live at home. However, the quality of primary homecare has been questioned. The aim of this study was to describe older persons living at home and their adult children’s lived experiences with caring responsibility assumed by healthcare professionals. We used a Reflective Lifeworld Research approach and analyzed 23 interviews and eight diaries. The COREQ checklist was followed. The findings revealed that caring responsibility is tantamount to being professionally competent and balancing immanent power to either promote or inhibit important areas of the older persons and their adult children’s lifeworld. Blurred lines of caring responsibility between the participants, the healthcare professionals, and the healthcare systems occurred and indicated that there were errors of commission and omission regarding the safety of older persons in own homes.

Keywords Caring responsibility, older persons, adult children, lifeworld, primary healthcare, safety
Introduction

Aging populations with multiple chronic conditions are an important challenge to healthcare systems worldwide.\textsuperscript{1, 2} In Europe, the percentage of people aged 80+ will increase from 5\% in 2016 to 13\% in 2070, raising issues of great concern regarding quality of care and soaring healthcare costs.\textsuperscript{3} In this age group, many will live with decreasing functional capacity, risk of frailty, and dependency on informal and formal care.\textsuperscript{1, 4} Many will also live alone, which is associated with a heightened risk of unplanned hospitalization\textsuperscript{5} and a reduced ability to manage daily living.\textsuperscript{6, 7}

Experiencing bodily limitations and frailty leading to loss of independence, growing old with illness has been described by older persons as frightening and evoking feelings of being burdensome.\textsuperscript{8} Even so, many wish to remain in their own homes as long as possible.\textsuperscript{9, 10} For many, home is a place offering security, comfort, familiarity, continuity, and unreflective ease.\textsuperscript{11, 12} However, home may turn into a challenging environment, a public arena, when dependency on care and treatment occurs. This may, in turn, make older frail people feel that they have become a guest in their own homes.\textsuperscript{13}

In this vulnerable situation, family, friends, and neighbors\textsuperscript{14, 15} often provide informal care. Adult children in particular play an important role; and due to social norms, they are expected to assume caring responsibility and become a supportive resource in their older parent’s life.\textsuperscript{16} Assuming informal caring responsibility for their older parent(s), adult children may simultaneously face competing responsibilities, e.g., balancing work, parenting, spousal relationships, or early retirement\textsuperscript{17}.

In a welfare state like Denmark, adult children could leave all care to the formal healthcare systems. However, they rarely do this because they act as advocates and managers to protect and ensure their parents’ dignity and well-being.\textsuperscript{18-22} Furthermore, adult children want to reciprocate, expressed as wanting to give back some of the help they received from their parent(s).\textsuperscript{22} Caring for
an ill old parent causes bodily strain, often referred to as a caregiver burden. Nevertheless, solidarity between generations, expressed as a willingness to help older persons in need, has gained new ground in the face of public service curtailments.

Throughout Europe and in other parts of the world, governments and healthcare providers are engaged in healthcare reforms aimed at improving the quality and safety of care, containing costs, and prioritizing cost-effective interventions. Thus, the total number of hospital beds has been reduced significantly in many European countries in the face of increased reliance on primary healthcare. Patients are therefore often discharged earlier from hospitals. Hence, the domain of primary healthcare is widening, and its tasks are becoming more complex because multiple health problems requiring advanced competencies are being dealt with simultaneously. This is also the case in Denmark, where this study was conducted.

Primary healthcare professionals play a key role in assuming responsibility for treatment and care in accordance with current policies and legislation. Nevertheless, threats to the quality of formal care for older persons needing support to live at home, especially after recent hospitalization, have been reported and linked to problems in care delivery, e.g., failure of information transfer, limited skills, unmet needs, and tensions in relationships between older persons, caregivers, and healthcare professionals. Tensions have also been reported when healthcare professionals thought that caregivers would assume high levels of responsibility than they actually did because they did not check the caregivers’ willingness or capacity to be involved.

Fundamental to our understanding of caring responsibility as exercised by healthcare professionals is insight into elements that ill older persons – and their adult children – experience as essential to be safe and secure while staying in their own home, and whether such caring responsibility is actually present. Such knowledge is important for healthcare professionals like
homecare nurses, nursing managers, and policymakers who play a key role in securing the optimal quality of care for older persons.

**Phenomenon and aim**

The phenomenon analyzed here is caring responsibility as experienced by older persons and their adult children in the context of being cared for at home. We aim to describe insights into older persons and their adult children’s lived experiences with caring responsibility as exercised by healthcare professionals in primary healthcare.

**Method**

*Research approach*

We conducted a qualitative study inspired by Reflective Lifeworld Research as outlined by Dahlberg and colleagues.\(^{35-38}\) This research draws on phenomenology and the hermeneutic philosophies of Edmund Husserl, Martin Heidegger, Hans-George Gadamer, and Maurice Merleau-Ponty,\(^{35}\) all of which target the lifeworld, our taken-for granted-world of experience.\(^{36}\) As researchers, we must question the lifeworld’s taken-for-granted assumptions and practice openness to let the phenomenon show itself more fully.\(^{38}\) In Reflective Lifeworld Research, this slow process of understanding is called “bridling” and implies ongoing reflection throughout the entire research process.\(^{39}\) Reflections are directed toward the phenomenon and meanings that emerge in the research process; consequently, these reflections include the researchers’ attention and perceptions. The idea is to let new meanings arise that otherwise might have been clouded by established meanings and the researchers’ preunderstandings,\(^{35}\) e.g., scientific theories, being healthcare professionals and having (had) older parents ourselves. The Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist was used in this research.\(^{40}\)
**Context**

The context is primary healthcare for older persons in a Danish region with a population of 1.2 million, where primary healthcare services encompass the general practitioner (GP), home care, and homecare nursing. The healthcare systems in Denmark are publicly funded services based on free and equal access to healthcare. Older persons are supposed to contact their GP with all questions related to health and illness. The GP plays an important role as a gatekeeper between the primary and the secondary healthcare systems.

Home care is offered to older persons who live at home but are unable to manage everyday life on their own. Home care is provided by registered social- and healthcare assistants and social- and healthcare helpers\(^1\). They are referred to as healthcare assistants in our study. Home care nursing services, including aids and appliances, are provided when prescribed by a medical doctor or if deemed necessary following assessment of individual needs. Registered nurses\(^2\) provide treatment and care for temporarily or chronically ill or dying older persons.

**Participants**

The participants were 11 (five women and six men) aged 81–98 years (mean 88 years) and 12 adult children (six sons and six daughters) who were primary caregivers according to their parent. The older persons were selected at a department of geriatric medicine to which the patients were admitted with acute illness on top of their chronic illnesses. All had high care needs and were entitled to primary healthcare.

We used purposeful sampling\(^3\) with the following inclusion criteria for older persons: 1) older persons with chronic illness, 2) aged 80+, 3) living alone, 4) not diagnosed with dementia, 5) had at least one adult child living nearby taking care of his/her parent.
The first author discussed with the nurse caring for the older person in the hospital whether s/he met the inclusion criteria and was well enough to be invited to participate. When the older person agreed to participate, the first author invited (face-to-face contact or telephone) the adult child whom the parent reported was the primary caregiver.

Participant characteristics are presented in Table 1. Older persons are referred to by pseudonyms and adult children by sex and numbers. Unfortunately, one of the older persons was re-admitted to hospital and passed away before the interview was conducted, but the daughter still wanted to participate.

**Table 1 Participant characteristics**

<table>
<thead>
<tr>
<th>Participant Older persons’ pseudonyms</th>
<th>Age/sex</th>
<th>Adult children</th>
<th>Former occupation</th>
<th>Medical conditions</th>
<th>Participant Son or daughter</th>
<th>Age</th>
<th>Occupation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ben</td>
<td>86/M</td>
<td>One son &amp; two daughters</td>
<td>Sales business</td>
<td>Heart disease and prostate cancer</td>
<td>Son 1</td>
<td>65</td>
<td>Retired, former nurse/manager</td>
</tr>
<tr>
<td>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>
<td>Daughter 2</td>
<td>58</td>
<td>Factory worker</td>
</tr>
<tr>
<td>Liz</td>
<td>92/F</td>
<td>One daughter &amp; one son</td>
<td>Cook</td>
<td>Dizziness and balance problems</td>
<td>Daughter 3</td>
<td>66</td>
<td>Retired, former civil economist and dietitian</td>
</tr>
<tr>
<td>Max</td>
<td>93/M</td>
<td>Two sons</td>
<td>Insurance business</td>
<td>Chronic obstructive pulmonary disease (COPD) and prostate problems</td>
<td>Son 4</td>
<td>62</td>
<td>Social worker</td>
</tr>
<tr>
<td>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>
<td>Son 5</td>
<td>60</td>
<td>Manager</td>
</tr>
<tr>
<td>Name</td>
<td>Age/Gender</td>
<td>Family Details</td>
<td>Occupation</td>
<td>Medical Conditions</td>
<td>Age</td>
<td>Relationship</td>
<td>Profession</td>
</tr>
<tr>
<td>---------------</td>
<td>------------</td>
<td>----------------</td>
<td>--------------------</td>
<td>----------------------------------------------------------</td>
<td>-----</td>
<td>--------------</td>
<td>------------------</td>
</tr>
<tr>
<td>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>
<td>Daughter 6</td>
<td>51</td>
<td>Salesperson</td>
</tr>
<tr>
<td>Jim</td>
<td>86/M</td>
<td>Two sons</td>
<td>Bus driver</td>
<td>COPD and prostate problems</td>
<td>Son 7</td>
<td>57</td>
<td>Service engineer</td>
</tr>
<tr>
<td>Eve</td>
<td>87/F</td>
<td>Three daughters</td>
<td>Cashier</td>
<td>Diabetes, rheumatoid arthritis, and fall problems</td>
<td>Daughter 8</td>
<td>65</td>
<td>Cleaning assistant</td>
</tr>
<tr>
<td>Adam</td>
<td>98/M</td>
<td>One daughter</td>
<td>Truck driver</td>
<td>Heart and circulation problems</td>
<td>Daughter 9</td>
<td>73</td>
<td>Retired, former drugstore worker</td>
</tr>
<tr>
<td>Anne</td>
<td>83/F</td>
<td>Two sons</td>
<td>Sales business</td>
<td>Diabetes and cancer</td>
<td>Son 10</td>
<td>57</td>
<td>Technical engineer</td>
</tr>
<tr>
<td>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>
<td>Daughter 11</td>
<td>52</td>
<td>Social worker</td>
</tr>
<tr>
<td>Re-admitted to hospital and passed away before interview</td>
<td>82/M</td>
<td>One daughter &amp; two sons</td>
<td>Bus driver</td>
<td>Rheumatoid arthritis and cancer</td>
<td>Daughter 12</td>
<td>38</td>
<td>Healthcare assistant</td>
</tr>
</tbody>
</table>

Abbreviations: M=Male, F=Female

**Data collection**

Data were generated by the first author from January to September 2018. An individual in-depth interview with 11 older persons were conducted 2–3 weeks post-discharge, nine in the participant’s homes, two in a short-time rehabilitation home. The interviews lasted from 35 to 83 minutes.

An individual in-depth interview with 12 adult children was conducted 5–6 weeks after their parent’s discharge. The time and location of the interview were at the adult child’s convenience,
resulting in the 12 interviews being conducted (2 face-to-face interviews in the participant’s home and 10 telephone interviews conducted in the evenings). Interviews lasted 40 to 75 minutes.

Before being interviewed, the adult children completed a 2-week diary allowing them to focus their minds on caring responsibility in different contexts and to report their experiences approximately two to three times a week or shortly after they occurred and undisturbed by the researcher.35, 43, 44 Eight participants completed the diary. The diary length varied, most being a couple of pages long (range 1–20 pages). Four participants did not complete the diary due to a lack of time and because they were distressed.

Interviews were conducted with open-ended questions and a bridled attitude. In the opening phase of the interviews, an opening question35 to the older persons was to describe an ordinary day at home. Both older persons and their adult children were asked to describe their experiences with home care and homecare nursing. To deepen their descriptions and reflections, suggested prompts were asked such as: What happened…? What do you mean by…? What does it mean to you…?35, 45 Eight interviews were conducted with the diary notes as starting points. Interviews were audio-recorded and transcribed verbatim by the first author (except two transcribed by a secretary). Transcripts included the diary notes.

Ethical considerations
The study was approved by the Danish Data Protection Agency (reference number 2015-57-0066) and designed in accordance with the ethical guidelines for nursing research in the Nordic countries.46 The participants were informed orally and in writing and had time to discuss participation before written consent was obtained. Confidentiality and anonymity were secured, specifying the option to withdraw from further participation at any time without consequences for their care and treatment.46
Data analysis

We followed the methodological principles of Reflective Lifeworld Research for descriptive data analysis. As a part of practicing bridling, we emphasized openness and reflection as a circular process between the whole and the parts, keeping at all times the phenomenon in mind and being careful not to conclude too quickly or too carelessly. In this on-going bridling process, we asked questions such as: What is it that we understand? Why do we understand it this way? This circular process contained the following phases: 1) All 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 about 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 to find a pattern describing the essential meaning of the phenomenon followed by descriptions of meaning that further constitute the phenomenon. The first author carried out phases 1 and 2 and then discussed phases 3 and 4 with all authors.

Findings

In accordance with Reflective Lifeworld Research, we first present the essential meaning of the phenomenon of caring responsibility as exercised by healthcare professionals and experienced by older persons and their adult children as “a question of being professionally competent”. The phenomenon is further described by four intertwined constituents, allowing more contextual nuances and individual meanings of the phenomenon to surface. The constituents are 1) despite enthusiastic souls – basic human care is not enough, 2) errors of commission in care, 3) errors of omission in care, 4) caught in the Bermuda triangle of healthcare systems.
A question of being professionally competent

Older persons and their adult children appreciate the fact that primary healthcare cares for and to some extent protects the older person from the threats accompanying illness and frailty. The participants feel strongly about the importance of healthcare professionals assuming caring responsibility. In fact, responsibility seems to be the very essence of caring. Caring responsibility is experienced when healthcare professionals act as decent, trustworthy, and committed people who are able to read and acknowledge the older person as an individual in a vulnerable life context with illness and frailty. What is meant here is that caring responsibility is tantamount to being professionally competent and making good judgments, balancing immanent power to either promote or inhibit important areas of the older persons and their adult children’s lifeworld.

Expectations regarding caring responsibility also involve being able to trust that the agreed-upon care at a system level is provided as professional care and not just as good service.

Nevertheless, blurred lines of caring responsibility appear at both individual and system levels. At the individual level, blurred lines appear between the participants and healthcare professionals when the older person’s expectations and needs are not met and when errors of commission and omission occur. At the individual level, blurred lines also seem to appear between the older persons’ and their adult children’s expectations. Some older persons hesitate to criticize healthcare professionals and seem to accept the situation, relying on further support from their children, while the adult children assume that professional care and responsibility can be improved.

At a system level, blurred lines of caring responsibility appear between the participants and the healthcare systems. Early discharge combined with worries about service levels, lack of competencies and continuity in primary healthcare cause insecurity and uncertainty. Caring responsibility needs to be experienced as being more than basic human care and good service to ensure a feeling of safety and well-being for the ill and frail older person living unattended in her or
his home most of the day. The older persons are at the mercy of healthcare professionals and the healthcare systems for care and sustenance. Adult children feel that they have to advocate the interests of their older parent and be proactive to ensure that their parent receives adequate care and treatment.

*Despite enthusiastic souls – basic human care is not enough*

The participants described that the majority of healthcare assistants are responsible people capable of providing basic human care, perceived as universal human characteristics like kindness, warmth, and being positive and interested in the older person’s well-being.

*It is nice when you are greeted with laughter and “How are you?” You feel a warmth because you are sure it is not something they pretend. (Ben).*

Evidence of display of basic human care is seen, for example, in relation to activities of daily living like personal care (e.g. bathing, dressing, toileting, mobilization) and practical help (e.g. cleaning and laundering). It is valuable for participants that healthcare assistants take care of these basic human needs and do what needs to be done. Some healthcare professionals even do more than is prescribed in the municipality’s directives; for example, a healthcare assistant goes shopping for yogurt for the older person with poor appetite or does the dishes even if this is not her job because she senses that the older person cannot handle it by himself. Another example is a healthcare professional who prioritizes having a chat with the older person or a more serious conversation about difficult things like loneliness and depression. Some participants call such a person “an enthusiastic soul”, and such a person is very much appreciated. However, providing basic human care and being committed often fall short in situations with illness and frailty at home. Especially adult children do not think that the healthcare assistants in home care are competent enough to observe and interpret situations characterized by instability.
I do not think they are good enough at observing and interpreting things. Several times, I had to either drive my father to the GP or get the GP to visit him, 10 minutes after home care left the house. That is not very safe. Days when my father is OK, everything goes smoothly and that is super; but when a sudden turn in the road appears and something unforeseen happens, they are not skilled enough to take action. (Son 4)

The lack of being able to sense and interpret situations like this evoke feelings of insecurity and distrust, causing adult children to take more responsibility and be very proactive to ensure the parent’s dignity and well-being. The provided basic human care falls short of both expectations and needs, especially in unpredictable situations. Some healthcare assistants lack the competences and willingness to act, such as calling, e.g., a homecare nurse for help. The experience of not being able to trust that healthcare assistants will take action causes blurred lines of caring responsibility between adult children and healthcare professionals. Adult children fear for the safety and well-being of their older parent.

**Errors of commission in care**

Both older persons and their adult children experience major quality differences in the care provided by individual caregivers; sometimes resulting in errors of commission, understood as doing something wrong. In general, healthcare professionals are perceived as trusting and competent people. Nevertheless, the participants also describe experiences with, e.g., healthcare assistants who do not know what kind of care they are supposed to provide. The older persons describe how this is frustrating and how they sometimes try to train and advise the staff. A daughter explains her experiences with a healthcare assistant who was supposed to empty her father’s catheter bag but did not know what a catheter was. This healthcare assistant was just a temporary worker coming right off the streets. The same daughter explains how a healthcare assistant was
going to give her father tube feeding without knowing the procedure. The daughter asked if she had tried this before.

*No, but it could not be that difficult to pour something into a bottle and then give it to him in his tube.* (Daughter 11)

The daughter had to stop the healthcare assistant and ask her to call a homecare nurse for advice and training. Due to the healthcare assistant’s errors of commission, the daughter felt that to protect her father, she had to take responsibility in this situation. If the daughter had not been there, advocating and being proactive, the healthcare assistant would have proceeded without knowing what she was doing and the older person was too weak and dependent to comment himself. A situation like this fosters distrust and concerns about the safety of staying in one’s own home.

Medication is another issue of great concern where errors of commission are experienced, especially in the discharge process because of failure to transfer information.

*At least twice my father has been discharged with an antibiotic for his pneumonia, but didn’t get it, and the home care nurse first noticed this 4 days later.* (Daughter 9)

Not being treated properly for an infection fosters concerns about the consequences and the potential risk of hospital re-admission. Concerns about medication also relate to irregular visits resulting in, e.g., morning medication and breakfast being offered at 11.30 am. This displaces the circadian rhythm, which is difficult for an ill, older person and affects his/her wellbeing. This is experienced as errors of commission regarding the older person’s medical treatment.

Errors of commission due to lack of competence in providing basic and complex care contribute to mistrust. Adult children try to compensate and assume responsibility in situations if they become aware of such errors of commission, even if it is an obvious professional responsibility to handle tube feeding or dispense the right medication, for instance. These experiences with errors
of commission cause blurred lines of responsibility and raise concerns, especially among adult children, about their parents’ safety and security.

**Errors of omission in care**

Concerns are expressed, primarily by adult children, about whether primary healthcare provides sufficient professional care to their ill, older parent. Our data show that caregivers have experienced healthcare assistants offering food and beverages and then hurry out the door without noticing whether the older person consumes what is being served. Adult children wonder why no effort is being made in regard to providing sufficient nutrition. Some try to compensate for this by preparing small meals and buying food they know their parent prefers. Adult children wonder why rejections are often accepted by healthcare assistants. This is experienced as a non-holistic approach, as the opposite of responsible care; indeed, as errors of omission by failing to do what is right and necessary in such situations. The immanent power is not balanced in the older person’s favor.

> I have told them that it is very good that they are responsive and listen to what the older persons want. However, if, as professionals, they just listen to what my father verbally expresses, e.g., that he will move from there to there but what he does is nothing, then they must push him a little. That is to be a professional, I would think. (Son 1)

Responsible care has also been brought into question as far as homecare nursing is concerned. The home care nurse is appreciated but not experienced as a contact person or someone who can prevent, e.g., hospital admission. On the contrary, s/he is often experienced as quite anonymous and task-oriented because s/he mainly takes care of medication issues during her/his visits.
I have talked with the home care nurse a few times, but she does not take the role of observing; she is only there for dosing medicine and ordering the medication for which my father is in short supply. (Son 4)

When asked about what older persons talk with their home care nurse about during visits, Maria, an 83-year-old woman, explains that the homecare nurse just administered medicine.

*We do not talk about anything at all.* (Maria)

Maria cannot recall the home care nurse asking about her well-being or her everyday life even if she feels isolated and has thoughts about moving to a nursing home to receive more care and company. Jim, an 87-year-old man with severe chronic obstructive pulmonary disease, gives another example. He is entitled to help with his bath; however, the healthcare assistant just stands watching during his bath because s/he thinks this is part of the rehabilitation, meaning Jim has to re-learn how to do it by himself. Jim explains that he is totally exhausted afterward and would rather use his energy on other things and get some help with his bath, but if the healthcare assistant just stands there watching, he prefers to cancel their “help”. His son says:

*They do not read the situation. This is misunderstood rehabilitation.* (Son 7).

Not being mindfully cared for is experienced as lack of interest and inability to determine what is right and necessary in such situations. Unfortunately, the participants have experienced healthcare professionals who are hasty, “just doing the job” and hurry out the door. This prevents sensing and doing what is right and necessary, and may involve just asking a question about the older person’s well-being or helping with a bath. This is lack of responsiveness to the older person’s needs and wishes, and some older persons seem to accept this. However, the expected professional care and responsibility are missing due to this kind of behavior. This raises concerns, minimizes confidence in primary healthcare, and causes feelings of blurred responsibility.
Caught in the Bermuda triangle of healthcare systems

The older persons and their adult children also experience blurred lines of responsibility and accountability within the healthcare systems because of the way it is organized. Metaphorically, some experience this as being caught in a “Bermuda triangle”; between their GP, the hospital, and the municipality. The healthcare systems’ directives and service levels seem to be provider-centered, which leaves little room for consideration of the older person’s well-being and sense of continuity. Feelings of being let down by the healthcare systems produce uncertainty about the decision of the older person regarding staying alone in own home.

At times, the older person and their adult child may attend a productive discharge meeting with a representative from the municipality at the hospital where future home care and home care nursing are agreed upon. However, some participants expressed concerns because in their view, the older person is discharged too early and they fear that home care and home care nursing cannot handle the caring responsibility.

*My mother was entitled to a temporary rehabilitation home, but the municipality had no vacancies. Therefore, I think she should have stayed a few more days in the hospital. This discharge was too early.* (Daughter 3)

*In a way, I think I was discharged too early. Just because I can manage things at the hospital, they also think I can do it at home. However, everything is more troublesome when I am home and have to do it myself.* (Maria)

Being home again with physical constraints and symptoms is a vulnerable situation fostering concerns about how to manage when left unattended most of the day. These concerns are also linked to the older person’s previously mentioned experience of being caught in a Bermuda triangle. The GP is appreciated; but as a gatekeeper, s/he has to argue strongly with doctors at the hospital to ensure further examination and treatment. Hospitalized older persons are discharged as soon as
possible because the number of beds has been reduced at most geriatric departments and because policies state that when hospital treatment is completed, the patient must be discharged to the municipality. This leaves the older person and adult children with feelings that nobody seems to take responsibility and follow up on things. The older persons cannot handle all the information themselves, so the adult children assume caring responsibility and try to compensate by taking the role of “manager” to follow up on things.

Sometimes you just have to make a special effort before older persons are discharged because they cannot handle it themselves. Communication is poor. You should not say about people that they do not care, but it is as if they have so much distance. (Son 1)

This distance is also noticed when the older persons or their adult children try to contact the municipality. It is difficult to navigate the system, and they often have to go through many steps before reaching a relevant employee. They would prefer a contact person who knows the older person and the situation. They associate caring responsibility with continuity, but experience a lack of such continuity and think that the absence of continuity has a negative effect on the quality of care and hinders timely interventions that could prevent hospitalization.

If it were possible that the same healthcare professionals visited my dad, that they knew my dad, then they would also be able to observe that my father is much worse off than yesterday, that something is wrong. If a new employee visits him, s/he will just think that this is probably the way he is and then s/he is out the door again. (Son 4)

Both older persons and their adult children acknowledge that healthcare professionals are bound by policies and resources, and that they work under time constraints and restrictions.

I think they are very busy, I think so. (Liz)

Combined with healthcare professionals’ various commitments and competencies, this awareness is also exactly why older persons and adult children are concerned about safety and
security at home. Therefore, some of the participants would prefer a nursing home as the best solution.

*I have been re-admitted to the hospital several times; therefore, my sons and I agreed that home care cannot take care of me...My sons do not think that I can manage at home anymore, and maybe they are right.* (Max)

*Home care cannot deliver the necessary care despite the fine principles of aging in place. My father formulated it quite well...I am not afraid to die, I am afraid of not living, having a life.* (Son 1)

The adult children in particular doubt whether the parent receives proper care and treatment while living alone with multiple chronic conditions and frailty. They find it very difficult to watch their older parent being caught between the different healthcare systems and policies. This is frustrating and often gives rise to feelings that caring responsibility is delivered as a standard package characterized by objectification of the older person, that minimum service rather than professional care is provided. The older persons have to live with it, being at the mercy of how caring responsibility is assumed by the healthcare systems, healthcare professionals, and their adult children. Some have a wish for more assistance, but mainly they just wish to receive responsible, qualified care.

**Discussion**

Caring responsibility appears to be a very complex phenomenon that captures the very essence of care provision. Caring and responsibility have previously been described as two sides of the same coin, highlighting the embedded duty to act in specific ways within a certain area of responsibility.48
In our inquiry, caring responsibility as exercised by healthcare professionals was described by participants in terms of personal characteristics like decency, trustworthiness, commitment, and professional competencies including the ability to read the older person and the situation and make good decisions accordingly. These lived descriptions are in line with previous studies focusing on quality in care.\textsuperscript{49-52} However, in our study, we also found expressions of the opposite, which blurred the lines of caring responsibility between the participants and healthcare professionals in primary healthcare and between the participants and the healthcare systems. These blurred lines of caring responsibility are incongruent with the commonly shared understanding of quality of care as being safe, effective, patient-centered, timely, equitable, integrated, and efficient.\textsuperscript{53}

Caring responsibility assumed by healthcare professionals and adult children is evident in many ways, and the older person depends on this. Overall, the participants appreciated the care provided in primary healthcare; however, the responsibility inherent in care became blurred when it did not match the participants’ needs and expectations of professional care; for example, when the older persons tried to train the staff or when the adult children compensated and advocated the interests of their parent in areas of both basic and complex care.

Caring responsibility for an older parent has previously been described as a “condition of life filled with uncertainty”\textsuperscript{22} and is often associated with the concept of “caregiver burden”;\textsuperscript{23-26} however, it is also perceived as meaningful and worthwhile.\textsuperscript{54, 55} In our study, the participants shared responsibility with the healthcare professionals, but concerns were foregrounded, especially in situations where basic care and good service were not enough to secure the well-being and safety of the older person in his or her own home.

The participants pointed to major individual differences in the quality of provided care that sometimes resulted in errors of commission and omission because of limited competencies or failure of information transfer. Errors of commission and omission are often referred to with
synonyms such as missed care, care left undone, task incompletion, unmet nursing care needs, and implicit rationing of nursing care. Several studies confirm errors in both hospital settings and primary healthcare. The participants (especially the adult children) experienced errors in essential clinical procedures like tube feeding, monitoring/observation, and medication dispensing, threatening the safety of the older person. These experiences are congruent with those reported in a Norwegian study measuring the competence necessary to provide safe care to frail, older patients among nursing staff in nursing homes and home care services. This study reveals a large gap between the maximum score and the achieved mean score in areas such as patient observations, advanced procedures, and documentation; the study also indicates that nursing staff as a group does not have sufficient competence to ensure the required care to older patients living with comorbidity and polypharmacy. Medication errors seem to occur frequently in primary healthcare according to the experiences of registered nurses.

The relationship with healthcare professionals is another important aspect of caring responsibility. In line with the literature and policies emphasizing the importance of person-centered care, the participants in our study appreciated when healthcare professionals acknowledged the older person as an individual set in a vulnerable life context. Unfortunately, the opposite was also evident, as reflected in experiences with disinterested healthcare professionals displaying no mindful attention to the situation. Hasty and task-oriented healthcare professionals foster feelings that caring responsibility is exercised as a standard package where the older person is objectified, as a kind of minimum service instead of professional holistic care.

The participants linked caring responsibility with continuity and saw this as a way to strengthen familiarity with the older person and his/her situation. Especially adult children problematized the fact that lack of continuity made it difficult to observe and intervene adequately
in regard to the older person’s health situation. These findings are partly consistent with those reported in a study by Gjevjon et al.\textsuperscript{67}, stating that older persons did not consider a high number of healthcare professionals to be a problem if they were informed and skilled. However, relatives were more critical of the number of healthcare professionals; still, the overall quality of care was more important.

Being discharged too early was another concern and blurred lines of responsibility as did also the municipalities’ lack of temporary rehabilitation homes. The participants’ fear that homecare and homecare nursing could not handle the caring responsibility echoes previous findings and underpins arguments that discharge and integrated care can be improved if interventions address family inclusion, interdisciplinary communication, and ongoing support after discharge, among others.\textsuperscript{68, 69} Nevertheless, congruent with research by Kristensson et al.\textsuperscript{70}, our findings show that participants had feelings of being “in the hands of the organizations”, which was metaphorically expressed as being caught in a Bermuda triangle between the GP, the hospital, and the municipality. The metaphor of the Bermuda triangle characterized by absence of a holistic view and coordination is well known,\textsuperscript{28} and this problem challenges many healthcare systems.

In a welfare state, like Denmark, expectations of professional care and system responsibility may be high; however, in line with a study by Lilleheie et al.,\textsuperscript{64} the participants also expressed an understanding that healthcare systems were subject to pressure and needed more resources and competencies. The older persons and their adult children seemed to accept living with the consequences of more extensive and complex care and treatment being transferred from hospitals to primary healthcare. Experiences with errors of commission and omission in primary healthcare raise particular concerns about safety and security when being old, ill, and living with frailty in one’s own home.
Strengths and limitations

The strength of our study is that we give a rare voice to a vulnerable group of 80+-year-old persons living alone with illness and frailty and a specific group of relatives, their adult children. Their lifeworld experiences with caring responsibility, as exercised by healthcare professionals, are important because healthcare reforms introduce more extensive and complex care and treatment in primary healthcare. The use of in-depth interviews allowed us to obtain rich lifeworld descriptions, which is a key strength in our study. The variation in the participants’ medical conditions, background, gender, and age increased the richness of our data, which is important in a phenomenological-hermeneutic study.

The limitations are that the participants lacked ethnic and racial diversity, and our study did not include even more vulnerable groups of older persons, namely those without relatives and those diagnosed with dementia. Furthermore, using the diary method to allow adult children to describe their experiences shortly after they occurred was challenged by adult children’s distress and lack of time. Therefore, the diary method should be considered in combination with other methods, like in-depth interviews.

The majority of adult children preferred a telephone interview in the evening, which prevented use of visual cues. Therefore, telephone interviews are often described as less attractive than face-to-face interviews. However, in our study, telephone interview was chosen by the adult children themselves, presumably because it allowed them to feel relaxed and able to disclose sensitive information like feelings of appreciation, sadness, and anger. Another limitation is that we did not include the healthcare professional’s perspectives on caring responsibility. Further investigation is needed to explore their experiences.
Conclusions

Caring responsibility, as exercised by healthcare professionals in primary healthcare and reflected in older persons and their adult children’s perspectives, is a phenomenon that carries both positive and negative meanings. Positive aspects are experienced when healthcare professionals act as decent, trustworthy, committed, and competent people able to provide professional care, thus acknowledging the older person as an individual set in a vulnerable life context with illness and frailty. Another positive aspect relates to trust in the sense that the agreed-upon care at a system level is provided in the form of professional, qualified care and not just good service.

Negative aspects of caring responsibility surface in the form of problems with insufficient care, sometimes resulting in errors of commission and omission. In such situations, responsibility becomes blurred and the adult children have to compensate to ensure their older parent’s well-being and safety in own home. Lack of continuity, lack of holistic care, and feelings of being caught in a Bermuda triangle between the GP, the hospital, and the municipality also create blurred lines of responsibility. The older persons have to relate to these blurred lines of responsibility, navigating being dependent on both the healthcare systems, healthcare professionals, and their adult children’s ways of assuming caring responsibility.

Implications

The insights obtained from older persons and their adult children into what is encompassed in the phenomenon of caring responsibility as exercised by healthcare professionals in primary healthcare represent important knowledge for healthcare professionals, nursing managers, and policymakers.

After early discharged from the hospital, older persons as well as their adult children want to be able to trust that primary healthcare can handle the caring responsibility and provide safe and secure care. Our study has several implications:
• There is a need for education, increased competencies, and more resources in primary healthcare.

• It is necessary to align expectations in relation to the division of caring responsibility for older persons between their adult children, healthcare professionals, and healthcare systems. We suggest that a caring responsibility agreement be made at the beginning of a care trajectory and as an ongoing process involving those responsible for care to prevent blurred lines.

• A healthcare professional who knows the older person and his/her situation must be appointed as a proactive contact person.

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

Funding
We received no financial support for this research.

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


98


---

i In Denmark, the training to become a registered social- and healthcare assistant takes 2 years, 9 months, and 3 weeks. Training to become a social- and healthcare helper takes 1 year, and 2 months.

ii Training to become a registered nurse takes 3 years and 6 months.

iii In Reflective Lifeworld Research, there is no talk about data saturation since meanings are infinite. However, generating data and doing preliminary analysis as an ongoing process revealed that lifeworld experiences from 11 older persons and 12 adult children adequately represented the meaning structures of the phenomenon. Otherwise, more data would have been generated.
Chapter 7 Discussion of findings

This chapter reflects and discusses the main findings across the three inquiries in comparison with other research and theory to nuance the understanding and reach a deeper level of interpretation. Caring responsibility appeared to be a very complex phenomenon, and theories about relational autonomy (Mackenzie and Stoljar, 2000, Mackenzie, 2008) and caring (Heidegger, 1962) were included in articles I and II for a more comprehensive understanding. These theories were not developed for a specific context but instead regard relational autonomy and caring as something universal.

Mackenzie and Stoljar (2000) understand “relational autonomy” as an umbrella term that rejects traditional, individualistic and rationalistic notions of autonomy that focus on the importance of independence, free choice and responsibility. They argue that a theory of autonomy must be based on recognition of the ways in which our identities and values are constituted and by our interpersonal relationships and social environment (article I) (Mackenzie and Stoljar, 2000, Mackenzie, 2008).

Heidegger interprets care (Sorge) as the basic structure of our being-in-the-world (Heidegger, 1962: 157). He further distinguishes between Besorgen meaning our engagement with things, and Fürsorge, meaning our engagement with other people (article II). Heidegger describes two extreme possibilities of Fürsorge or solicitude as “leaping-in” (Einspringen) and “leaping-ahead” (Vorrausspringen), which I will elaborate during the discussion. Thus, the relation between the more philosophical and theoretical
meanings of caring responsibility, and older persons and their adult children’s lived experience of caring responsibility in the context of primary healthcare will guide this chapter.

Caring responsibility as a condition of life

Both older persons and their adult children express caring responsibility as a condition of life. For the older persons “it means everything” to be cared for by their adult children because they compensate and become the “glue” that makes it possible for the older person to stay in own home (article I). Adult children also describe uncertainty in the process of assuming caring responsibility for their older, ill parent (article II). These perceptions are further enhanced by the blurred caring responsibilities experienced in primary healthcare (article III).

Inherent in the older persons and their adult children’s lifeworld experiences with caring responsibility as a condition of life, caring may be understood as a form of existence, as a basis for all human relations (article II) (Martinsen, 1993, Delmar, 2013a, Delmar, 2018b, Heidegger, 1962). Caring responsibility as a condition of life may therefore have parallels to Heidegger’s ontological analysis of care, which shows that care manifests itself in our different ways of being. Therefore, I will begin with discussing the notion of caring responsibility as a form of existence, since caring and responsibility are described as being closely intertwined (article III) (Delmar, 2018a).

In his main work from 1927, Heidegger analyzes “being”, or Dasein in German, because he believes that in our culture, we have somehow lost the feeling of being. His philosophical analysis attempts to recapture this feeling by explaining how the human being is, how we exist in the world. Not how I
happen to live or you live but our very way of being that is common to all people. However, what does
being mean? Here, Heidegger launches the notion of care as a human’s way of being in the world
(Heidegger, 1962: 225). Care (Sorge) is understood as a deeper and more general phenomenon than the
specific care we show in different situations as, for example, in caring for older parents. This could end
this discussion; however, an applied interpretation of Heidegger’s analysis of Dasein as care may be
helpful in reaching a deeper understanding of lifeworld perspectives on caring responsibility as a
condition of life.

Caring responsibility as a condition of life has an inherent meaning of care based on being-there, as
giving meaning to existence, because it is a way of being in the world, in the relationship with oneself
and with others, which Heidegger names being-with (Mitsein). The adult children in this study show a
deeply rooted will to assume caring responsibility for their older ill parents even though they could
leave all care to healthcare professionals in a welfare state like Denmark (article II). They worry about
their parents, and they are concerned about the care and treatment provided by the healthcare systems
(article III). If we take a closer look at the German word Sorge it is translated to “care” in English.
However, while care seems to be a nice and pleasant word in English (Van Manen, 2002, Dalpezzo,
2009), the German word Sorge as well as the Danish word om-sorg in contrast contains important
aspects such as being burdened by worries, anxiety and concern, and at the same time an emotional
commitment and an intention to look after or provide for (Cambridge Dictionary, 2020, Ordnet, 2020).
Adult children are indeed concerned about the general well-being of their older parents they look after
and provide for (articles II and III). They worry about their parents’ illnesses and frailties, and the
safety of living alone in own homes. They worry about the treatment and care provided in primary
healthcare. They worry about their responsibility and about becoming old and dependent themselves.
The older persons worry too (article I). They worry about their life-constraints, about being dependent on informal and formal care, they worry about burdening their children because they care and are concerned about the children’s well-being.

Van Manen (2002: 265) gives an example of this double meaning of care: “A parent who looks with caring-zorg\(^1\) at his/her child seems to be loving, yes, but also always in some sense worried.” This is also the case in this study from both the parent and the adult child’s perspective. They try to balance this caring-sorge for each other. Van Manen (2000) asserts that care as worry is a human response to vulnerability in others. Thus, the vulnerability of the older parent, the vulnerable situation with illness and frailty is a worrying condition that makes a demand on the adult child. A call for responsibility because the parent is most vulnerable to the adult child. Van Manen (2000) argues that the more one cares for a person the more one worries, and the more one worries the stronger one’s desire to care for this person. This may explain the notions of love, concern and uncertainty as descriptions of caring responsibility in the older person-adult child relationship. They experience the double meaning of caring responsibility, namely as anxious worrisome care (Sorge) and care as soliciitude (Fürsorge), as interventions of leaping-in and leaping-ahead (article II).

For Heidegger, anxious, worrisome care (Sorge) represents our struggle for survival and for favorable standing among our fellow human beings, and we immerse ourselves in everydayness’ triviality and conventionality to conceal from ourselves the question of being (Heidegger, 1962). When adult children assume responsibility for their older ill parents, this may also be motivated by standing

---

\(^1\) Zorg is the Dutch word for Sorge in German
favorably among other human beings, as the caring daughter or son, and thus fulfilling general norms and expectations in society (Luichies et al., 2019, Stuijbergen and Delden, 2011). In this sense, caring responsibility means a duty (article II). The older ill parents may also want to stand favorable among other human beings by being acknowledged of having raised a caring daughter or son who assumes responsibility as something “natural”, as a condition of life.

Caring responsibility as struggling

In articles I, II and III notions of struggling are described in various ways. Importantly, caring responsibility in the parent-child relationship in this study is characterized by trust, mutual understandings, willingness and acceptance from both parts, often practiced in tacit ways, which may not always be the case in other families.

Older persons’ struggles

Caring responsibility is foregrounded by the older persons’ current vulnerable situation with illness and frailty. The older persons are faced with physical, social and existential loss and growing dependence as described in the constituent “a life-constraining transition” in article I. The older persons struggle to establish a balance between how they see or used to see themselves (their existential self-image), and their actual performance restricted by old age, illness and frailty. In doing so, they strive to actively participate in everyday life by doing whatever their failing physical capacity allows them to. This life-constraining transition, characterized by different kinds of loss causing feelings of loneliness, isolation, emptiness and sadness, is congruent with findings from a qualitative interview study with 20 older persons with multimorbidity living in own homes (Eckerblad et al., 2015). However, in the study by
Eckerblad et al. (2015), the participants had lost their strength to participate in a more actively manner and took on a more passive role, probably because they had a higher symptom burden than the older persons in our study. Research by Birkeland and Natvig (2009), Nicholson et al. (2013) and Skilbeck et al. (2018), on the other hand, confirm that older persons actively try to create new daily rhythms and adapt as they experience loss. They struggle to learn to live with and incorporate the loss and limitations into their deep-rooted self-image as an independent person.

Nevertheless, coming to terms with the transition from independence to dependence is a struggle (article 1) (Delmar et al., 2006). In a synthesis of qualitative evidence on older persons’ adaption to dependence (Abad-Corpa et al., 2012), independence is defined in terms of autonomy, personal integrity, life satisfaction, self-care capacity and not needing a helping relationship. According to Hammarström and Torres (2010) and van Thiel and van Delden (2001), autonomy is often used synonymous with independence. In contrast and as mentioned in the background chapter, dependence is defined with regard to the perception of subordination, biographical disruption, life dissatisfaction, feeling or carrying a burden to themselves and everyone else, and the establishment of a relationship of care based on accommodation, resignation or resistance (Abad-Corpa et al., 2012). The findings in article I show how these different notions of independence and dependence are at play when the older persons are struggling to balance a continuum between an individualistic understanding of autonomy as independence (Walter and Ross, 2014, Delmar et al., 2011) and a relational understanding of autonomy as interdependence (Mackenzie and Stoljar, 2000, Delmar, 2018b) or being-with (Mitsein) as Heidegger (1962: 149) names it. The former fosters feelings in older persons of being a burden to others when in need of help, while the latter can explain receiving help from adult children as something natural, as a condition of life. The older persons struggle with these two different
understandings of humanity in relation to autonomy as either individualistic or relational. The older persons are in a vulnerable situation, and to some extent lack or have reduced capacity to protect themselves and their interests, thus they need to rely on the caring responsibility assumed by their adult children and the formal healthcare systems. However, the older persons have not lost their ability to be self-governing (Mackenzie and Rogers, 2013), which refers to their ability to make choices and enact decisions that express or are consistent with their values, beliefs and commitments. They still wish to be included and decide over their own situation (Hammarström and Torres, 2010, Rustad et al., 2016) in cooperation with their children (article I). Therefore, it is important that they participate in decisions and are informed along the way because they experience this a way of maintaining autonomy and integrity. So instead of looking at independence/dependence as dichotomies, one should look at them as a continuum floating over the life course (Hammarström and Torres, 2010) closely intertwined with the notions of interdependence and reciprocity. Reciprocity will be discussed in the next section about adult children’s struggles.

Finally, the older persons struggle to have an overview of their illness and care needs. They struggle to navigate the healthcare systems (Rustad et al., 2016) and receive the expected necessary qualified care (article III). Therefore, it also “means everything” that their adult children participate and assume caring responsibility. It is experienced as a relief, as a sign of love and care (article I). Thus, healthcare professionals should be aware that relatives like adult children play an important role in relation to their parents’ general well-being. The older persons cooperate with their children to find solutions and appreciate their help and support while at the same time being worried about becoming too dependent on them. It is a relief for the parents that the children leap-in and thus share a concern for the resolution
Adult children’s struggles

In article II, the findings reveal that adult children likewise experience caring responsibility as a struggle. They struggle with uncertainty and worries about the parents’ situation living alone with illness and growing frailty and dependence. They are faced with this vulnerable situation that appeals to assuming caring responsibility in different intertwined ways. At a practical level, they struggle to meet the needs of their parents by doing tasks related to IADL such as shopping, cleaning, gardening and helping with transport, they struggle with administration and medical appointments while taking care of their own lives. These findings are consistent with a recent review including 19 qualitative studies of caregiving experiences of adult children (Luichies et al., 2019). Findings from articles I and II show that although these practical tasks are straightforward, they are often foregrounded, leaving less time for meaningful togetherness.

Beyond the practical level of caring responsibility, adult children struggle with emotions like love, gratitude and duty, sometimes including feelings of guilt (article II). Inherent in this struggling is a deep sense of commitment and reciprocity carrying normative meanings in the parent-child relationship expressed as “wanting to give back” (article II). Gouldner (1960: 173) refers to this social norm as; “people should help those who help them, and therefore, those whom you have helped have an obligation to help you.” Whereas in Martinsen’s philosophy of care “the act of giving is an altruistic reciprocity where the charity is given as a gift without expecting something in return” (Delmar, 2013a: 22, Martinsen, 1993). Variations of these two perceptions of reciprocity as a social or family norm and
as altruism seem to be at play in adult children’s deeper struggle between love and duty, which is in line with a study by Klimaviciute et al. (2017), and the older persons’ struggles with perceptions of autonomy (article I). Interestingly, previous research shows that adult children object to the notion of being obliged by government or social norms to assume caring responsibility (Guberman et al., 2012). They try to interpret parent support as voluntary (Funk, 2015). However, the previously mentioned decline in the provision of formal home care support in Denmark (Rostgaard and Matthiessen, 2019) combined with a high prevalence rate (42.8%) of informal caregivers in Denmark (Verbakel et al., 2017) (article II) and a survey revealing that 83% of adult children provide parent support as a supplement to home care (DaneAge Association, 2015) may point to elements of caring responsibility assumed by adult children that are due to necessity rather than choice. Adult children’s willingness to assume caring responsibility may inadvertently support more or less hidden political and economic goals that promote and increase the need for family care of older persons as stated by Funk (2015).

While it is beyond the scope of this dissertation to answer the above assumptions, it is evident in this study that adult children struggle to fill the gaps left by the healthcare systems (articles II and III), and maintain their parents’ dignity and general well-being. In doing so, they struggle with healthcare systems and take on roles as advocates and managers to achieve the best care and treatment for their older parents. This adds to research by Lindhardt et al. (2006), Lowson et al. (2013), Bragstad et al. (2014a), Sivertsen et al. (2018) showing how significant others act as “quality securer” or “conductors” aiming at safeguarding the older persons and the quality of care. In the phenomenological study by Lindhardt et al. (2006), the role as case-manager was particularly evident in the transitions between primary and secondary healthcare by the adult children ensuring that messages were passed on and plans carried out as agreed. In article II, we show that the role as manager is, for adult children,
extended, involving striving for an overview of the parents’ care arrangements and coordinating with individuals vital in the parents’ healthcare, while at the same time communicating and coordinating with siblings and other family members. The findings in article II point to advocating as a central role in striving for what is best for the older parents. In line with the research by Lindhardt et al. (2006), Lowson et al. (2013) and Bragstad et al. (2014a), adult children try to be the voice of their older parents, especially, if the parents seem too optimistic about their health and ability to manage everyday life, like the son in article II explaining how his father would not admit to the discomfort he experienced. This son further explained how the healthcare professionals would have left without agreements regarding further home care support if they had just listened to his father’s version of the situation. This could be interpreted as a rather controlling or paternalistic behavior of the son and as a potential conflict in the parent-child relationship caused by interference and overprotectiveness. With Heidegger’s words, the son leaps-in, but importantly, the son does so because he cares and worries about his father’s vulnerable situation living alone in his own home. As stated in article I, this kind of controlling behavior from adult children can be annoying for the parents, but they try to avoid conflict and manage their ambivalent feelings by responding with silence and/or passivity. Findings from a qualitative interview study by Funk (2010) illustrate that adult children sometimes justify violating the ideal of parent autonomy in the context of high parental needs. Yet, a controlling or paternalistic approach is only adopted in particular, limited situations and otherwise avoided. In article II, the findings describe how adult children struggle to balance when to involve and when to protect and relieve their parents of worries, for example, by withholding information.

Heidegger describes leaping-in as a dominating kind of care that risks creating dependence in the care-recipient (Heidegger, 1962: 158). Thus, this kind of care seems to demand a special intersubjective
space in which a sureness of the intervention does not humiliate the care-recipient (Tomkins and Simpson, 2015). Importantly, leaping-in is mostly described by the older persons in this study as a welcome relief when a task has become too difficult to manage. With reference to Henderson (1972), one can say that the caregivers, whether being adult children or healthcare professionals, assist the older persons in the performance of those activities that they would perform unaided if they had the necessary strength, will or knowledge. Leaping-in can, therefore, be a constructive experience if the older persons recognize their need for help because it gives them the opportunity to step back and let someone else take over for a while (Article I). Importantly, leaping-in as substitutive care requires the caregiver to handle sensitively and thus to recognize the older persons as autonomous existences in vulnerable situations.

Adult children struggle with concerns, uncertainty and worries about their older parents’ vulnerable situation and what lies ahead when living alone with illness, growing frailty and dependence. These struggles also manifest in a bodily manner, as strain causing insomnia and forgetfulness (article II). These embodied feelings of caring responsibility as a burdensome experience is well documented (Luichies et al., 2019, Dahlrup et al., 2015, Bastawrous, 2013, Ringer et al., 2017). In article II, the findings reveal, in line with research by Luichies et al. (2019), how adult children may become entrapped, skipping other activities, resulting in feelings of life passing them by while taking care of older parents, and thus affecting their perceptions of quality of life (Dahlrup et al., 2015).

The findings in articles II and III point to adult children’s struggles to balance contradicting and at times conflicting and intertwined values and decisions concerning their own lives and the older parents’
lives. In the next section, I will discuss how all participants struggle with experiences of what Heidegger calls authentic and inauthentic ways of being.

Caring responsibility as modes of authenticity and inauthenticity

In the title of this dissertation I ask “Who cares?” The answer to that question is both simple and complex. The simple answer with reference to Heidegger and the myth of Cura presented at the beginning of the dissertation is that we all care because care is our fundamental way of being-in-the-world. This also implies taking care of oneself and taking responsibility toward one’s potential as an authentic being, as being one’s true self (Heidegger, 1962). The complex answer is that care and especially the responsibility inherent in care manifests in many different ways as shown in articles I, II and III. I will discuss some of those ways with reference to Heidegger and his understanding of authentic and inauthentic ways of being (Heidegger, 1962: 78).

As mentioned earlier, according to Heidegger, we humans exist with each other as “Mitsein.” We cannot exist without the others. Heidegger describes this through the notion of the anonymous “they” or “Das Man” in German (Heidegger, 1962: 150). The “they” is all of us and dictates our everydayness: “We take pleasure and enjoy ourselves as “they” take pleasure; we read, see and judge about literature and art as “they” see and judge; likewise we shrink back from the ‘great mass’ as “they” shrink back; we find shocking what “they” find shocking, The “they” which is nothing definite, and all are, though not as a sum, prescribes the kind of Being of everydayness” (Heidegger, 1962: 164). The “they” is thus an expression of the average, where you do not really have to vouch for any of what you do, as you more or less just flow with the current. Authenticity is not about detaching oneself from
the “they” because we are always in co-existence with others (“Mitsein”). We become authentic when we are ourselves in the “they”, by opening up to ourselves, relating to ourselves and the world around us and by making choices. Through our choices, we choose who we are and want to be (Lawler and Ashman, 2012). Importantly, we cannot use introspection to find knowledge about our authenticity because we are already thrown into a socio-historical context. Seeking authenticity must then be an outward project of facing up to the social norms and standards we are thrown into and take responsibility for the possibilities and potential of the future for ourselves and others (Heidegger, 1962, Nyberg and Sveningsson, 2014). The core of authenticity may thus be the question: What is our purpose and the purpose of others? Authenticity can be seen as an ideal in which we not only act as ourselves but express ourselves through our actions. On the other hand, inauthenticity is a tendency toward turning away from our authentic being to seek security in the anonymous crowd, the “they” (Heidegger, 1962), and the expectations of public opinion (Reich, 1995).

Even if care is our fundamental way of being-in-the-world, we mostly care for others in the deficient modes of solicitude (Fürsorge). “Being for, against, without one another, passing by one another, not mattering to one another – these are possible ways of solicitude” (Heidegger, 1962: 158), and these deficient or indifferent modes characterize everyday average encounters with others. Care maintains itself proximally, to what is near to us. Heidegger describes how the positive modes of solicitude (Fürsorge) have two extreme possibilities of caring. In article II, we discuss how adult children assume and balance caring responsibility by leaping-in and thus take over responsibility for a current situation, and by leaping-ahead of the older parents to show the way toward future possibilities and potentials. One can speculate whether leaping-in is the foundation and perhaps even the motivation, for leaping-ahead because it allows the caregiver to put oneself in the care recipient’s position and get a glance at
his/her perspective of the world, which may make it easier to advocate for the care recipient’s situation? Maybe leaping-in and leaping-ahead should be seen as a continuum as suggest by Tomkins and Eatough (2013). Nevertheless, Wu (2016) and Peters (2019) discuss these two modes of solicitude (Fürsorge) as inauthentic care (leaping-in) and authentic care (leaping-ahead). Authentic care refers to the occasion of disclosing the other’s possibilities for self-being, while inauthentic care refers to the occasion of closing the other’s possibilities to exist as a self.

Inauthentic care appears when the adult children are doing jobs for the older parents (which they could do by themselves) and dominating them, wrongly doing this in the name of love and care. Examples of this kind of inauthentic care in the parent-child relationship were limited in this study, probably because the older persons were unable to do many everyday activities by themselves. In article I, we describe how adult children sometimes try to interfere and be overprotective. This kind of care has been described within nursing as sentimental overprotectiveness (Delmar, 2012, Martinsen, 2006), where the caregiver becomes so emotionally affected by the situation that the case and the person takes second place in relation to the caregiver’s own concerns. While the adult children unconsciously and unintentionally may practice this kind of overprotectiveness, the consequences may be further constraints in the older parent’s life situation. Findings from article I show that the older persons often respond to overprotectiveness with silence and/or passivity to avoid conflict. They justify their children’s behavior as sign of love and care even though their adult children practice inauthentic care in various combinations. They seem to do so because they trust that their children act out of notions of what they think is of best interest to promote the general well-being of their parents, also if this includes preventing obstacles to the parents’ good, like, e.g., being the parents’ voice in contacts with the healthcare system. Importantly, the older persons’ want to cooperate and be informed as a way to
maintain their autonomy, and the adult children strive to cooperate in this manner as evidence of protecting their parents’ dignity. Thus, the findings in articles I and II mainly describe signs of authentic care, where the adult children leap-ahead and try to prevent illness exacerbation, increase safety, supervise and check on medication and nutrition, but importantly, they do so in respectful cooperation to protect their parents’ autonomy and dignity and because they want to reciprocate and enhance their parents’ general well-being. These different ways of assuming caring responsibility are in line with the different caregiving descriptions by Bowers (1987) and Nolan et al. (1995) presented in the background section of this dissertation.

Hitherto, I have mainly discussed caring responsibility as a condition of life, as a rather natural phenomenon in a close relationship between the older parent and adult child. Now I will turn to the findings in article III and discuss caring responsibility as a professional phenomenon exercised by healthcare professionals in primary healthcare. In relation to authenticity, only the individual healthcare professional can assess whether or not they are behaving in accordance with their true self. Yet, I will argue in accordance with the lifeworld approach in this study and the notions of intersubjectivity that there are relational constituents in being authentic. Therefore, it is important to include older persons and their adult children’s perspectives when considering caring responsibility as a professional phenomenon in relation to modes of authenticity and inauthenticity.

As described in article III, responsibility seems to be the very essence of caring, as two sides of the same coin, as suggested by Delmar (2018a). Older persons and their adult children experience caring responsibility in authentic ways when the healthcare professionals are:
Who cares?
Caring responsibility from the perspectives of older, ill persons and their adult children in primary healthcare

- Committed and acknowledge the older person as an individual within a vulnerable situation. Do what needs to be done and sometimes even more.

- Genuine interested in the older persons’ well-being shown as universal human characteristics like trustworthiness, kindness and warmth.

- Attentive to the older persons and their adult children’s expectations and worries.

- Capable and knowledgeable with regard to providing safe care and make good judgements that protect from the threats accompanying illness and frailty.

Contrariwise, caring responsibility is experienced in inauthentic ways when healthcare professionals are:

- Lacking in commitment, are disinterested, hasty and task-oriented. The older persons are objectified.

- Inattentive, untrustworthy and incapable of reading the older persons and their situation.

- Incapable and unknowledgeable, resulting in errors of omission and commission.

- Not providing the agreed upon care.

Inauthentic care thus seems to be characterized as indifference, or even neglect. In inauthentic modes, healthcare professionals seem mainly to be task-oriented. They practice Fürsorge as leaping-in, but in a way that focuses on the “what”, the task, and not on the older persons and their existence. Heidegger states that Fürsorge is guided by considerateness and forbearance (Heidegger, 1962: 159). Taking care of an older ill person without considerateness could then be interpreted as not being Fürsorge but rather a kind of Besorgen, focusing on the task, the things. This sort of minimal taking care requires few qualities, mainly circumspection, so that the “service” is done correctly (Reich, 1995). Yet, this study
illuminates that even care in this sense lacks circumspection. Evidence of errors of omission and commission displays that the “service” is not provided or provided incorrectly. Even basic human care provided as kind and genuine interest in the older persons’ well-being is not enough if the healthcare professionals are incapable of observing and making good judgements as described in article III.

The problem seems to be that authentic responsible care is seldom provided as solicitous care in the meaning of leaping-ahead (Vorrausspringen) (Heidegger, 1962: 158), where the healthcare professionals are attentive to both the older persons and the vulnerable situation to enhance comfort and security. Some examples from article III are lack of being attentive to issues of nutrition, loneliness, medication or personal hygiene, which are consistent with other studies pointing at problems with quality of care in primary healthcare (Gregory et al., 2017, Bing-Jonsson et al., 2015, Berland and Bentsen, 2017, Svanström et al., 2013).

Caring responsibility and healthcare systems

Hitherto, caring responsibility has mainly been discussed at an individual and interpersonal level, but as described in article III, caring responsibility is also of concern at a system level. Our findings show that older persons and their adult children find it difficult to navigate the healthcare systems, and metaphorically experience being caught in a Bermuda triangle between the GP, the hospital and the municipality where no one really seems to take the necessary responsibility except the adult children. This well-known phenomenon is a challenge in many healthcare systems (Ahgren, 2014, Buch et al., 2018). It discloses experiences with having to argue for hospital admittance for further examination, and early discharge fostering uncertainty about the situation of living alone in one’s own home, and
uncertainty about the caring responsibility assumed in primary healthcare. Not being able to trust that care is provided in an appropriate manner makes adult children compensate, and thus their caring responsibility increases (Ulmanen and Szebehely, 2015, DaneAge Association, 2015, Verbakel et al., 2017).

Even though, Scandinavian healthcare systems strive for inter-organizational integration and collaboration through national reforms and legislation (Ahgren, 2014), it seems to have a weak impact at an operational level. In line with descriptions by Riiskjær (2019) and McGilton et al. (2018), the older persons and their adult children in this study do not experience seamless and integrated healthcare systems. The Danish governance model seems to pose challenges for aligning the management and improvement of quality of care in both primary and secondary healthcare systems. An example of this is the co-ordination between the regional and municipal governments. Although they are obliged to agree in so-called health agreements renegotiated every fourth year (Region Syddanmark og de 22 kommuner, 2019), several barriers have previously been identified such as lack of integrated IT systems and misaligned economic incentives (OECD, 2013). While it is beyond the scope of this dissertation to discuss solutions to these structural challenges, they seem to have an important impact on the lifeworld experiences of the older persons and their adult children’s struggles for receiving authentic responsible care (article III).

Another main concern in the findings is the safety of the older persons. One can wonder why problems with medication errors still occur even though The Shared Medication Record (Fælles Medicinskort) has been implemented across the healthcare systems because it contains information on all Danish citizens’ medicine dispensed during the previous 2 years as well as an updated list of every patient’s current
medication (OECD, 2013). However, research on post-hospital medication management exposed some of the complexity involved in safe medication, indicating a close connection with the care of the patient’s basic needs, which should be transparent in the nurses’ activity and time registrations (Kollerup et al., 2018). Furthermore, Kollerup et al. (2018) stressed the importance of the nurse’s knowledge about the patient and continuity among the various healthcare professionals involved in the patient’s care. Lack of continuity and competencies was a concern expressed by the adult children in this study.

The lifeworld descriptions of errors of omission and commission are examples of unsafe and unacceptable care that indicate a lack of a professional sound level in primary healthcare, which points back to management, leadership and education at macro-, meso- and micro-levels. Management is important (Toor and Ofori, 2008) because it ensures the right capacity of healthcare professionals with the right competencies and sufficient time to provide high quality care for older persons within complex vulnerable situations. Furthermore, management provides a sense of striving for continuity when organizing care for the benefits of both the older persons, their relatives and healthcare professionals.

Leadership is necessary (Alilyyani et al., 2018, Tomkins and Simpson, 2015) in the sense of establishing caring cultures where healthcare professionals are supported to provide authentic responsible care that is patient- and family-oriented instead of provider-oriented. Leadership that encourages healthcare professionals to take pride in their work. However, managers and leaders who regulate the practices of healthcare professionals need to understand that caring responsibility in a deeper sense can only occur where contexts, structures, healthcare professional-patient ratios and
schedules provide the opportunity for the occurrence of genuine responsible caring relations, even though these cannot be controlled or predicted (Van Manen, 2000, Provis and Stack, 2004).

Finally, a crucial factor in assuming caring responsibility and quality of care to older persons with multimorbidity and polypharmacy is an adequately skilled and motivated workforce (OECD, 2013). Nevertheless, this study shows examples of blurred lines of caring responsibility fostering uncertainty about the whole situation of staying in own home when being old, ill and frail. Bing-Jonsson et al. (2015) found similar discrepancies in their comparison of actual and expected nursing staff competence in Nordic countries, noting a competence gap and a general lack of opportunities for competence development in primary healthcare. Thus, adequate training and continuous improvement of competencies in primary healthcare need more focus at both macro-, meso- and micro-levels. Emphasize must be on both “caring for” in the sense of providing competent and safe care, and “caring about” in the sense of meeting patients and families in a humanly sensitive way (Galvin et al., 2018, Delmar, 2013b, Delmar, 2013d).

Through a phenomenologically oriented reflection Todres et al. (2009) have developed a lifeworld-led Humanizing Value Framework, which, among other things, was inspired by Husserl, Heidegger and Merleau-Ponty. The framework consists of eight dimensions of humanization and corresponding dehumanization (Table 4) and expresses a spectrum of possibilities which can be useful for managers, leaders, educators, healthcare professionals and researchers. The framework can help reflecting about the nature of responsible caring practices in the sense of “caring about”, e.g. older persons and their adult children/significant others, in vulnerable situations with illness and frailty. The table does not indicate an either/or category in each case.
Who cares?
Caring responsibility from the perspectives of older, ill persons and their adult children in primary healthcare

Table 4 The Humanizing Value Framework

<table>
<thead>
<tr>
<th>Forms of humanization</th>
<th>Forms of dehumanization</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Insiderness:</strong> The dimension of being human and living in a personal world that carries a sense of how things are for the person.</td>
<td><strong>Objectification:</strong> People are made into objects, labeled and dealt with in ways that do not fully take account of their insiderness.</td>
</tr>
<tr>
<td><strong>Agency:</strong> The dimension of experiencing oneself as having the freedom to be and act within certain limits.</td>
<td><strong>Passivity:</strong> In passivity, there is excessive emphasis on attitudes and practices that render the person passive in relation to their condition and treatment.</td>
</tr>
<tr>
<td><strong>Uniqueness:</strong> No matter how much we are part of larger influences and contexts, there is something unique in space and time about this particular person in this particular moment that characterizes their particular individuality.</td>
<td><strong>Homogenization:</strong> In homogenization, there is excessive focus on how the uniqueness of the person is de-emphasized in favor of how they fit into a particular group.</td>
</tr>
<tr>
<td><strong>Togetherness:</strong> To be human is to be in a community. Our uniqueness exists in relation to others, and there is always an ongoing dialogue or “play” between what we have in common, and how we organize and make sense of this in very personal and unique ways.</td>
<td><strong>Isolation:</strong> We feel ourselves separated from our sense of belonging with others. Our everyday social connections are disrupted and we can feel lonely. What we have in common with others recedes from view and we can feel like strangers.</td>
</tr>
<tr>
<td><strong>Sense making:</strong> To be human is to care for the meaning of things, events and experiences for personal life. Such sense-making involves a motivation to bring things together, to find significance and to make wholes out of parts. Within this context, we are story makers and storytellers.</td>
<td><strong>Loss of meaning:</strong> In loss of meaning, human beings become numbers and statistics. When we are counted as a statistic, our treatment often does not make sense to us because what is important statistically does not necessarily connect with individual human experience.</td>
</tr>
<tr>
<td><strong>Personal journey:</strong> We live forward from the past; how we are at any moment, which needs to be understood in the context of a before and a next. We move through time meaningfully and do not exist in a vacuum; to be human is to be connected to a sense of continuity. To be human is to be connected to the familiarity of the past as</td>
<td><strong>Loss of personal journey:</strong> Loss of personal journey can happen when health care practices do not pay sufficient attention to the history and future possibility of a person’s life.</td>
</tr>
</tbody>
</table>
well as to move into the unfamiliarity of the future.

| **Sense of place:** To be human is to come from a particular place; such a habitat is not just a physical environment measured in quantitative terms but a place where the feeling of at-homeness becomes meaningful. Such a sense of place is not just a collection of colors, textures and objects but rather gathers around that which constitutes the kind of belonging that provides a degree of security, comfort, familiarity, continuity and unreflective ease. |
| **Dislocation:** In dislocation, a form of dehumanization occurs where a sense of place is lost or obscured and a sense of strangeness arises. In this circumstance people are challenged to find a sense of place in a new and unknown culture where norms and routines are alien to them, and where spatial re-orientation must take place if they are to fit in. |
| **Embodiment:** To be human means to live within the fragile limits of human embodiment. When un-preoccupied with the vicissitudes of bodily attention, embodiment supports us in moving out into the world, attentive to people, places and tasks in life. Consistent with this dimension, a humanizing perspective will view well-being as a positive quality that makes life worthwhile and not just as an absence of illness, with the body viewed as merely an object to fix. |
| **Reductionism:** In a reductionist view of the body, there is an overemphasis upon signs and symptoms and the body as separate from its broader contexts. There is an excessive emphasis on tissue, organ, hormones, electrolytes and a neglect of a more relational view of the body in its broader meaningful context such as psychological, environmental, social, and spiritual forms. |

**Source:** (Todres et al., 2009) partly paraphrased by me.

These eight dimensions have been further developed into the Humanized Care Assessment Tool (HCAT) (appendix I), a questionnaire with over 100 items. This sounds overwhelming at a first glance but the whole idea is to bring into view aspects of care that are humanizing and dehumanizing and open up practice development strategies that are meaningful to patients, their families/significant others and healthcare professionals including managers and leaders. The Humanized Care Assessment Tool offers one way to reconnect healthcare professionals with dimensions of care that they value, and which can easily become obscured when working in busy clinical environments where services sometimes seems to be primarily business or efficiency driven (Galvin et al., 2018). The tool provides a new vocabulary.
coupled with practical directions for everyday care because the items point to specific directions to
interact with patients in humanly sensitive ways. It forces a focus on the considerateness and
forbearance inherent in Fürsorge (Heidegger, 1962). Thus, I will argue that the Humanizing Value
Framework and the HCAT can be useful tools to enhance caring responsibility among managers,
leaders, educators, students and clinical healthcare professionals, and is thus one way to improve
quality in care and enhance caring responsibility for older persons and their adult children in primary
healthcare.
Chapter 8 Methodological considerations

This section will reflect my considerations regarding the scientific value of the study. Dahlberg (2019) states that all research that is considered scientific must relate to the claim of evidence because if evidence is not involved, it is not about science but something else, e.g. fiction or journalism. However, according to Dahlberg (2019), qualitative research cannot build upon the foundation designed for a radically different kind of research that focuses on decontextualized, standardized knowledge and places randomized control trails as the highest standard for scientific rigor. The positivistic assumptions within quantitative research such as dualism, atomism and reductionism represent values that are not compatible with the intentions of qualitative research, which aim to adopt a more complex and meaning-oriented perspective that includes existential and social contexts. Nevertheless, in line with Brinkmann and Kvale (2015), Dahlberg et al. (2008) use the more traditional concepts objectivity, validity and generalization but rethought from a phenomenological/hermeneutical perspective to discuss the scientific quality in Reflective Lifeworld Research. Dahlberg et al. (2008) claim that these concepts do not belong to a particular paradigm of research but stand for ideas that distinguish scientific research from other similar everyday activities. Consequently, I will discuss the scientific quality of this study within this framework.

Objectivity

A common sense conception of objectivity as being pure and free of bias refers to an understanding of knowledge as truth and implies the possibility of carrying out science and research from a position that
is outside the actual research sphere (Dahlberg et al., 2008, Brinkmann and Kvale, 2018). However, in Reflective Lifeworld Research, the conception of objectivity concerns the relation between the researcher and the phenomenon in question (Dahlberg, 2019) and concerns the researcher’s honesty and openness. As a researcher, I am not in a detached position but already involved with others in a world of values, relationships and all kinds of meaning, namely the lifeworld characterized by intentionality. Objectivity therefore means to be aware of this ontological fact (Dahlberg, 2019) and look at objectivity as intersubjective agreement and a negotiation of meaning between me as a researcher and the participants (Brinkmann and Kvale, 2018). As stated in Chapter 4, this demands from me as a researcher to shift from the natural attitude to a phenomenological attitude of (self-) reflection by practicing “bridling” and thus being as open and sensitive as possible to the participants and to the phenomenon during the whole research process. So how did I practice bridling? As mentioned earlier, a reflective research journal was a helpful tool in combination with on-going dialogues with my supervisors, an external auditor, peers and journal reviewers. Openness was a continuous investigation of my point of departure, my pre-understanding as well as an on-going process of asking questions like: What is it that I understand? Why is it I understand it this way? Openness was practiced during the data generating process by formulating open questions in the diary guide and by striving for an open dialogue throughout the interviews. Openness was practiced during the analysis by being attentive to the phenomenon investigated in the three inquiries. This way I strived to be open for the new and bridle the process of understanding so that it did not happen to hastily (Dahlberg and Dahlberg, 2019).
Validity

In Reflective Lifeworld Research, objectivity and validity are likely to occur if I as a researcher approach the phenomenon as well as the whole research study in an open bridled way (Dahlberg et al., 2008). In ordinary language, validity refers to the truth, the correctness and the strength of a statement, and the issue of whether the chosen methods investigate what they purport to investigate. This demands that I as a researcher present plausible findings based on an inner logic, also labeled a coherence criterion, which means that I have to make it possible for the reader to follow my reasoning throughout the study (Dahlberg et al., 2008, Dahlberg, 2019). I have strived for validity by being transparent about the different choices during the study. I have used method triangulation (diaries and interviews), researcher triangulation, especially in the analysis process and article writing, and theory triangulation in the interpretations and discussions of the different findings (Guba, 1981). Furthermore, I have used peer-debriefing by discussing the study design, findings and interpretations with peers, and using the various journals’ review process. A kind of member checking was also inherent in the study since the findings and understandings from the diaries were used as point of departure in the interviews with adult children. I strived for transparency by providing dense descriptions of the research process and including guides regarding diaries and interviews and examples of the analysis processes. These strategies should enhance the credibility and thus the validity of the study according to Guba (1981) and Lincoln and Guba (1985).

Generalization

As mentioned earlier, the findings in Reflective Lifeworld Research are always contextual and infinite and thus never to be understood as universal (Dahlberg et al., 2008, Dahlberg, 2019). Is a discussion of
generalization or transferability then relevant? Dahlberg (2019) argues that all research findings should be meaningful to more people that just those involved in the study. The descriptions of the essential meanings of a phenomenon like, e.g., caring responsibility, means that the findings are lifted above the concrete level but still within a certain context (Dahlberg et al., 2008: 344). Also Delmar (2010) states that any situation can be said to be typical and unique at the same time and thus include communalities and similarities that can be recognized across cases. However, in line with Lincoln and Guba (1985), Delmar (2010) argues that findings should be recognized and confirmed by others, as a kind of member checking. With reference to Gadamer, Dahlberg et al. (2008) also emphasize the importance of Anwendung, in English “application or usability”, displaying the idea that generalization is a question of how research findings can come into play and how they can be used and practiced.

I this study I have aimed at providing descriptions that make transferability judgements possible for the reader because it is the reader who on the basis of these contextual descriptions judges whether the findings may be generalized to new situations (Brinkmann and Kvale, 2018). Some examples are the use of a purposeful criterion based sampling strategy aiming at ensuring variation and including participants having experiences with the phenomenon of caring responsibility. Furthermore, descriptions of the participant characteristics were provided, and so were different examples of the analysis process. Quotes from the participants were used to support claims, illuminate experience and evoke emotion. Finally, several theories were used in combination with other research for a more comprehensive and broader understanding.
Chapter 9 Conclusions

The purpose of this study was to enhance the understanding of the phenomenon of caring responsibility as it is experienced by older, ill persons aged 80 years or more and their adult children, in the context of being cared for at home. The aims were to describe insights into 1) the older persons’ lived experiences with caring responsibility in the parent-child relation, 2) the adult children’s lived experiences with caring responsibility in the parent-child relation, and 3) the older persons’ and their adult children’s lived experiences with caring responsibility as exercised by healthcare professionals in primary healthcare. Caring responsibility appeared to be both a natural and a professional phenomenon leading to the following conclusions.

As a natural phenomenon in the parent-child relationship, the essential meaning of caring responsibility is described as a condition of life that means everything to the older persons and the possibility to remain in their own homes despite illness and frailty. Metaphorically, the adult children become the “glue” that keeps things together and ensures the parents receive the right care. Caring responsibility is a condition built on trust, tacit responsibility, negotiations and acceptance, where the older persons struggle between their growing dependence and feelings of being a burden to their children. The older persons struggle between a deep-rooted traditional, individualistic perception of autonomy as independence and a relational perception of autonomy where it is natural to help each other. It is often a relief for the older persons to leave the caring responsibility to their children as long as the older
persons are included in decisions and thus maintain their dignity and self-image as an autonomous human being.

As a natural phenomenon, caring responsibility is also a condition of life filled with uncertainty. This uncertainty may be a condition if one cares and worries about one another. Thus, uncertainty is made greater by the older parent’s illness and frailty and the fact that the parent lives alone, and furthermore, by not being able to trust that primary healthcare will provide appropriate responsible care. The adult children assume great caring responsibility, balancing between feelings of love, duty and reciprocity. They take care of practical tasks, participate in various meetings, try to be the voice of their older parent, create an overview, keep things on track, and inform and cooperate with other relatives. They act as advocate and manager while taking care of their own life demands. Adult children experience the double meaning of caring responsibility as anxious worrisome care (Sorge) and care as solicitude (Fürsorge). Furthermore, providing care as solitude (Fürsorge) means struggling when to leap-in and take over for their older parents and when to leap-ahead and prepare the situation so that the parents can take over by themselves. They struggle between what Heidegger names inauthentic and authentic care, and experience a constant concern followed by bodily strain such as insomnia, nervousness and forgetfulness, including concerns of becoming old and dependent on the healthcare systems themselves. Adult children work hard to ensure their older parents’ general well-being and dignity even though the older parents receive support from primary healthcare regarding ADL and IADL and from home nursing. Caring responsibility changes the parent-child relationship and makes it more asymmetrical because the child has to take care of practical things leaving less time for meaningful togetherness.
As a professional phenomenon exercised by healthcare professionals in primary healthcare and reflected in older persons and their adult children’s perspectives, caring responsibility carries both positive and negative essential meanings. Positive meanings are experienced when healthcare professionals act as decent, trustworthy, committed and competent people able to provide authentic professional care, thus acknowledging the older person as an individual set in a vulnerable life context with illness and frailty. Another positive aspect relates to trust in the sense that the agreed-upon care at a system level is provided in the form of professional, qualified care and not just good service. Negative meanings of caring responsibility surface in the form of problems with insufficient and inauthentic care, sometimes resulting in errors of commission and omission. In such situations, responsibility becomes blurred, and the adult children have to compensate and assume more caring responsibility to ensure their older parent’s general well-being and safety in own home. Lack of continuity, lack of holistic care and feelings of being caught in a “Bermuda triangle” between the GP, the hospital and the municipality also create blurred lines of responsibility. The older persons have to relate to these blurred lines of responsibility, navigating being dependent on both the healthcare system, healthcare professionals and their adult children’s ways of assuming caring responsibility.

The theories of relational autonomy and care (Sorge and Fürsorge) enhance the understanding of caring responsibility as being both a natural and a professional phenomenon. They show us the importance of interdependence and the struggles between providing and receiving natural and professional authentic and inauthentic care. When to leap-ahead and when to leap-in in ways that are experienced as relief and safe care without humiliating the older persons.
Chapter 10 Implications

Implications for practice, education and policymakers

The lifeworld insights into older ill persons and their adult children’s experience with caring responsibility in primary healthcare have several implications, intertwined for both practice, education and policymakers.

The findings can enhance empathic understanding of what it means for persons aged 80+ years living alone with illness and frailty to be dependent on their adult children and formal care. Older persons do not want to be experienced as a burden by their children, but they appreciate that the children assume caring responsibility. Handing over some responsibility to the children, provided they are informed along the way, is experienced as a relief. Older persons want their children to be involved and acknowledged when planning care and treatment because the children manage complex issues on behalf of their parents.

Adult children play a crucial role in the policy of aging in place. They appear to be the “glue” that makes it possible for the parent to remain in his/her own home. They struggle to fill gaps left by the healthcare systems and ensure the general well-being and safety of their older ill parent. They struggle when to leap-in and when to leap-ahead while maintaining their parent’s autonomy and dignity. The
caring responsibility they assume should be recognized. Furthermore, their concerns about future eldercare should be taken seriously.

Older persons and their adult children want to be able to trust that primary healthcare can handle their caring responsibility and provide safe and secure care that recognizes the older persons being in a vulnerable situation. Problems with errors of omission and commission point to a need for increased competencies and training, more resources and stronger management and leadership in primary healthcare focusing on the responsibility inherent in authentic care. The Humanized Care Assessment Tool could be one way to enhance awareness of providing authentic care.

To prevent blurred lines of caring responsibility, it is necessary to align expectations in relation to the division of caring responsibility for older persons between their adult children, healthcare professionals and healthcare systems. Some suggestions are to appoint a healthcare professional as a proactive contact person who knows the older person and his/her situation, and to discuss the adult children’s resources, opportunities and willingness to assume caring responsibility by making a kind of caring responsibility agreement at the beginning of a care trajectory and as an ongoing involving process. Furthermore, at a policy level, Denmark could work on developing legal regulations in support of relatives, as mentioned in the background section.

Implications for further research

This dissertation has provided new insights into the phenomenon of caring responsibility from the perspectives of a special group of older persons, namely those aged 80 years or more, who are ill and
frail, and live alone in own home depending on formal and informal care. These findings should be supplemented with research into perspectives from other groups of dependent persons, including those who may not have significant others who assume caring responsibility.

Furthermore, this dissertation provides perspectives on caring responsibility from a special group of relatives, namely adult children, who are primary caregivers for their older parent. Importantly, the adult children in this study all had good relationships with their parents, which may not always be the case. Therefore, more research into this group of relatives and their caregiving roles in a Nordic welfare context is needed.

The context has been primary healthcare. Research into the phenomenon of caring responsibility focusing on other contexts like nursing homes or hospitals may also contribute significantly to knowledge about the phenomenon of caring responsibility.

Research focusing on caring responsibility from the perspectives of different groups of healthcare professionals, managers and leaders at both an individual and a system level is required to expand our understanding of this complex phenomenon. Finally, research focusing on validation and translation of the Humanizing Value Framework and the Humanized Care Assessment Tool into Danish would be interesting and required if the tools are going to make a difference in a Danish context.
English summary

Introduction
As older persons seek to live out their years at home, informal caregivers like adult children are increasingly relied upon for support and well-being. This may be seen as a consequence of public responsibility becoming more narrowly defined, and more responsibility for care is placed on older persons in need of care and their families.

Purpose and aims
The purpose of this study was to enhance the understanding of the phenomenon of caring responsibility in primary healthcare from the perspectives of older, ill persons 80+ and their adult children. The study aimed to describe insights into their experiences with the phenomenon of caring responsibility in the context of being cared for at home presented through three inquiries.

Methodological foundations
The study is inspired by Reflective Lifeworld Research as outlined by the Swedish Professor and nurse Karin Dahlberg and colleagues. Reflective Lifeworld Research draws on phenomenology and the hermeneutic philosophies focusing on the lifeworld.

Methods
Data were generated through individual in-depth interviews with 11 older persons aged 81 to 98 years 2 to 3 weeks after discharge from hospital, and through individual in-depth interviews with 12 adult children aged 38 to 73 years 5 to 6 weeks after their parent’s discharge. Before being interviewed, the
adult children completed a 2-week diary. Selection of participants took place at a department of geriatric medicine with the following inclusion criteria for older persons: 1) older persons with chronic illness, 2) aged 80+, 3) living alone, 4) not diagnosed with dementia, 5) had at least one adult child living nearby taking care of his/her parent. Data were analyzed according to the methodological principles of Reflective Lifeworld Research for descriptive analysis.

**Findings**

The older persons and their adult children experience caring responsibility in the context of illness and frailty while being cared for at home as both a natural (articles I and II) and a professional phenomenon (article III).

Article I: From the older persons’ perspective, the essential meaning of caring responsibility in the parent-child relationship is described as “a condition of life that means everything”. Four constituents illuminate caring responsibility in this context: 1) a life-constraining transition, 2) trusting children filling the gaps and being the glue, 3) tacit responsibility, negotiations and acceptance, and 4) dependent on children and knowing they are burdened with you.

Article II: From the adult children’s perspective, the essential meaning of caring responsibility is described as “a condition of life filled with uncertainty.” Three constituents illuminate caring responsibility in this context: 1) balancing love, duty and reciprocity, 2) being the parent’s advocate and manager, and 3) experiencing concerns and bodily strain.
Conclusions

As a natural phenomenon in the parent-child relationship, the essential meaning of caring responsibility is described as a condition of life that means everything to the older persons and the possibility to remain in their own homes despite illness and frailty. Metaphorically, the adult children become the “glue” that keeps things together and ensures the parents receive the right care. Caring responsibility is a condition built on trust, tacit responsibility, negotiations and acceptance, where the older persons struggle between their growing dependence and feelings of being a burden to their children. As a natural phenomenon, caring responsibility is also a condition of life filled with uncertainty. This uncertainty may be a condition if one cares and worries about one another. This uncertainly is thus made greater by the older parent’s illness and frailty and the fact that the parent lives alone and not being able to trust that primary healthcare will provide appropriate responsible care. The adult children assume great caring responsibility, balancing between feelings of love, duty and reciprocity. Adult children experience the double meaning of caring responsibility as anxious worrisome care (Sorge) and care as solicitude (Fürsorge). Furthermore, providing care as solitude (Fürsorge) means struggling when to leap-in and take over for their older parents and when to leap-ahead and prepare the situation so that the parents can take over by themselves. They struggle between what Heidegger calls inauthentic and authentic care, and experience a constant concern accompanied by bodily strain such as

137
insomnia, nervousness and forgetfulness, including concerns of becoming old and dependent on the healthcare system themselves.

As a professional phenomenon exercised by healthcare professionals in primary healthcare and reflected in older persons and their adult children’s perspectives, caring responsibility carries both positive and negative essential meanings. Positive meanings are experienced when healthcare professionals act as decent, trustworthy, committed and professionally competent persons able to provide authentic care, thus acknowledging the older person as an individual set in a vulnerable life context with illness and frailty. Another positive aspect relates to trust in the sense that the agreed-upon care at a system level is provided in the form of professional, qualified care and not just good service. Negative meanings of caring responsibility surface in the form of problems with insufficient and inauthentic care, sometimes resulting in errors of commission and omission. In such situations, responsibility becomes blurred, and the adult children have to compensate and assume more caring responsibility to ensure their older parent’s general well-being and safety in own home.

**Implications**

- Older persons want their children to be involved and acknowledged when planning care and treatment.
- Older persons and their adult children want to be able to trust that primary healthcare can handle their caring responsibility and provide safe care and recognize the older persons being in a vulnerable situation.
• Problems with errors of omission and commission point to a need for increased competencies and
  training, more resources and stronger management and leadership in primary healthcare focusing
  on the responsibility inherent in authentic care.

• Expectations in relation to the divisions of caring responsibility for older persons should be
  discussed and aligned between their adult children, healthcare professionals and healthcare system,
  for example, as a caring responsibility agreement at the beginning of a care trajectory and as an
  ongoing involving process.

• Older persons and their adult children would prefer a healthcare professional in the role as a
  proactive contact person who knows the older person and his/her situation.
Dansk resumé

Titel
Ældre og deres voksne børns erfaringer med fænomenet pleje- og omsorgsansvar i primærsektor.

Introduktion
Når ældre mennesker bliver boende længst muligt i eget hjem, bliver de ofte tiltagende afhængige af, at pårørende såsom voksne børn påtager sig et pleje- og omsorgsansvar. Dette kan ses som en konsekvens af, at det offentliges ansvar og tilbud indskrænkes, og mere pleje- og omsorgsansvar placeres hos de ældre og deres familier.

Formål og mål
Formålet med dette studie er at øge forståelsen af fænomenet pleje- og omsorgsansvar, som det erfares af ældre, syge mennesker 80+ og deres voksne børn i primærsektor. Målet er at beskrive deres erfaringer med pleje- og omsorgsansvar gennem tre undersøgelser med hver deres perspektiv.

Metodologi
Studiet er inspireret af Reflective Lifeworld Research, som er udviklet af den svenske professor og sygeplejerske Karin Dahlberg og kolleger og baseret på fænomenologisk og hermeneutisk filosofi.

Metode
Data blev genereret via individuelle dybdeinterview med 11 ældre mennesker i alderen 81-98 år, to til tre uger efter deres udskrivelse fra hospitalet, og via individuelle dybdeinterviews med 12 voksne børn.
i alderen 38-73 år, fem til seks uger efter deres forælders udskrivelse fra hospitalet. Inden de voksne børn blev interviewet førte de dagbog i to uger. Udvælgelsen af informanter foregik på en geriatrisk afdeling ud fra følgende inklusionskriterier for de ældre: 1) ældre med kronisk sygdom, 2) 80+, 3) bor alene, 4) ingen demensdiagnose, 5) har mindst et voksents barn, som bor i nærheden og yder pleje- og omsorg til hans/hendes forælder. Data blev analyseret med udgangspunkt i de metodologiske principper i Reflective Lifeworld Research for beskrivende analyse.

Resultater

De ældre og deres voksne børn oplever pleje- og omsorgsansvar i forbindelse med den ældres sygdom og tiltagende skrøbelighed i eget hjem som værende både et naturligt (artikel I og II) og et professionelt (artikel III) fænomen.

Artikel I: Fra de ældres perspektiv beskrives den essentielle betydning af fænomenet pleje- og omsorgsansvar i forælder-barn relation som et vilkår i livet, der betyder alt. Fire konstituenter belyser pleje- og omsorgsansvar i denne kontekst: 1) en livsindskrænkende overgang, 2) tillid til at børnene tager over og får tingene til at hænge sammen, 3) stiltiende ansvar, forhandlinger og accept og 4) at være afhængig af børnene og vide, at du er en byrde for dem.

Artikel II: Fra de voksnes børns perspektiv beskrives den essentielle betydning af pleje- og omsorgsansvar som et vilkår i livet fyldt med usikkerhed. Tre konstituenter belyser pleje- og omsorgsansvar i denne kontekst: 1) at balancere kærlighed, pligt og reciprocitet, 2) at agere forælderens advokat og manager, 3) at opleve bekymringer og kropslige belastninger.
Artikel III: Den essentielle betydning af pleje- og omsorgsansvar, som det udøves af de sundhedsprofessionelle og erfares af de ældre og deres voksne børn, beskrives som et spørgsmål om at være professionel kompetent. Fire konstituenter belyser pleje- og omsorgsansvar i denne kontekst: 1) trods ildsjæle er grundlæggende pleje ikke nok, 2) at opleve fejl i pleje og behandling, 3) at opleve undladelser af det rigtige og nødvendige, 4) at føle sig fanget i sundhedsvæsenets Bermuda-trekant.

Konklusioner

også kropslige belastninger såsom søvnløshed, nervøsitet og glemsomhed, inklusiv en bekymring for selv en gang at blive gammel og afhængig af sundhedsvæsenet.

Som et professionelt fænomen fremtræder både positive og negative essentielle betydninger af de ældre og deres børns erfaringer med pleje- og omsorgsansvar udøvet af de sundhedsprofessionelle i primærsektor. Positive betydninger erfares, når de sundhedsprofessionelle agerer som anstændige, pålidelige, engagerede og kompetente mennesker, der er i stand til at yde autentisk professionel pleje- og omsorg, som anerkender den ældre som et menneske i en sårbar livssituation med sygdom og skræbelighed. Et andet positivt aspekt er tilliden til, at den aftalte pleje fra systemets side ydes i form af professionel, kvalificeret pleje og ikke blot som god service. Negative betydninger erfares som problemer med inautentisk og utilstrækkelig pleje, som undertiden resulterer i fejl og undladelser. I sådanne situationer bliver pleje- og omsorgsansvaret uklart, og de voksne børn må kompensere og påtage sig mere ansvar for at sikre deres forældres trivsel og sikkerhed i eget hjem.

**Implikationer**

- De ældre ønsker, at deres børn involveres og anerkendes i forbindelse med planlægning af pleje og behandling.
- De ældre og deres voksne børn ønsker tillid til, at primærsektor kan varetage pleje- og omsorgsansvaret og yde en sikker pleje, som anerkender den ældres sårbare situation.
- Problemer med fejl og undladelser peger på et behov for yderligere kompetencer og uddannelse, flere ressource og stærkere lederskab i primærsektor med fokus på det ansvar som er indeholdt i autentisk pleje.
• Forventninger til pleje- og omsorgsansvaret for de ældre bør drøftes og afstemmes mellem de voksne børn, de sundhedsprofessionelle og sundhedsvæsenet, for eksempel via en pleje- og omsorgsaftale i starten af et plejeforløb og via en løbende involverende proces.

• De ældre og deres voksne børn ønsker en sundhedsprotein i rollen som en proaktiv kontaktperson, der kender den ældre og hans/hendes situation.
Who cares?
Caring responsibility from the perspectives of older, ill persons and their adult children in primary healthcare

References


BRAGSTAD, L. K., KIRKEVOLD, M., HOFOSS, D. & FOSS, C. 2014b. Informal caregivers' participation when older adults in Norway are discharged from the hospital. Health Soc Care Community, 22, 155-68.

BREITHOLTZ, A., SNELLMAN, I. & FAGERBERG, I. 2013. Older people’s dependence on caregivers’ help in their own homes and their lived experiences of their opportunity to make independent decisions. International Journal of Older People Nursing, 8, 139-148.

BRINKMANN AND KVALE 2018. Doing Interviews, 55 City Road, SAGE Publications Ltd.

Who cares?
Caring responsibility from the perspectives of older, ill persons and their adult children in primary healthcare


DAHLBERG, H. & DAHLBERG, K. 2020. Phenomenology of Science and the Art of Radical Questioning. *Qualitative Inquiry*.


Who cares?
Caring responsibility from the perspectives of older, ill persons and their adult children in primary healthcare


Who cares?
Caring responsibility from the perspectives of older, ill persons and their adult children in primary healthcare


DELMAR, C. 2013b. Beyond the drive to satisfy needs: in the context of health care. *Medicine, Health Care and Philosophy*, 16, 141-149.

DELMAR, C. 2013c. The interplay between autonomy and dignity: summarizing patients voices. *Medicine, Health Care, and Philosophy*, 16, 975-81.


Who cares?
Caring responsibility from the perspectives of older, ill persons and their adult children in primary healthcare


Who cares?
Caring responsibility from the perspectives of older, ill persons and their adult children in primary healthcare


Who cares?
Caring responsibility from the perspectives of older, ill persons and their adult children in primary healthcare


KIRKEVOLD, M. & BERGLAND, Å. 2007. The quality of qualitative data: Issues to consider when interviewing participants who have difficulties providing detailed accounts of their experiences. International Journal of Qualitative Studies on Health and Well-being, 2, 68-75.


Caring responsibility from the perspectives of older, ill persons and their adult children in primary healthcare


LILLEHEIE, I., DEBESAY, J., BYE, A. & BERGLAND, A. 2020. Informal caregivers’ views on the quality of healthcare services provided to older patients aged 80 or more in the hospital and 30 days after discharge. BMC Geriatr, 20, 97.


Who cares?
Caring responsibility from the perspectives of older, ill persons and their adult children in primary healthcare


Who cares?
Caring responsibility from the perspectives of older, ill persons and their adult children in primary healthcare


Who cares?
Caring responsibility from the perspectives of older, ill persons and their adult children in primary healthcare


Who cares?
Caring responsibility from the perspectives of older, ill persons and their adult children in primary healthcare


STONES, D. & GULLIFER, J. 2017. 'At home it's just so much easier to be yourself': older adults' perceptions of ageing in place - CORRIGENDUM. Ageing and Society, 37, 219-219.


Who cares?
Caring responsibility from the perspectives of older, ill persons and their adult children in primary healthcare


VAN MANEN, M. 2002. Care-as-Worry, or “Don’t Worry, be Happy”. Qualitative Health Research, 12, 262-278.

VAN MANEN, M. 2014. Phenomenology of Practice: Meaning-giving methods in phenomenological research and writing, Walnut Creek, Left Coast Pr.


Appendixes

Appendix A  Tilladelse Datatilsynet

Tilladelse jf. Datatilsynets udtalelse – journalnr. 2015-57-0016
University College Lillebælt giver hermed Helle Elisabeth Andersen tilladelse til at arbejde med fortrolige personhenførbare
data i henhold til den indsendte anmeldelse:

<table>
<thead>
<tr>
<th>Forskningsprojekt (titel)</th>
<th>Adult children having care responsibility of a parent 80+ living alone with complex care requirements</th>
</tr>
</thead>
<tbody>
<tr>
<td>Starttidspunkt</td>
<td>4. januar 2018</td>
</tr>
<tr>
<td>Sluttidspunkt</td>
<td>30. september 2020</td>
</tr>
<tr>
<td>Tidspunkt for oplysningernes sletning/anonymisering/overførsel Rigsarkivet</td>
<td>30. september 2020</td>
</tr>
<tr>
<td>Dataansvarliges navn</td>
<td>Helle Elisabeth Andersen</td>
</tr>
<tr>
<td>Dataansvarliges e-mail</td>
<td><a href="mailto:hean@ucl.dk">hean@ucl.dk</a></td>
</tr>
</tbody>
</table>

Der behandles følgende følsomme oplysninger

- Helbredsmæssige forhold
- Racemæssig eller etnisk baggrund
- Politisk overbevisning
- Filosofisk overbevisning

Der behandles følgende andre oplysninger om enkeltpersoners rent private forhold

- Væsentlige sociale problemer
- Andet (afhængigt af informanternes svar)

Den fulde anmeldelse er arkiveret i Teamshare, arbejdsområde nr. 0100-13853-2015

Godkendelses nr. er: Datatilsyn/UCL-2015-57-0016-023

Nummeret skal påføres alle materialer, som skal i sikringskab, og nummeret skal påføres alle relevante elektroniske
dokumenter og opgørelser.

Godkendelsen gives under forudsætning af, at følgende instrukser i University College Lillebælt overholdes:
(http://mit.ucl.dk/viden-og-vaerktojer/informations-og-datasikkerhed/forsknings-og-udviklingsprojekter/)
- Forvaltning af forskningsdata
- Instrukt for projekter/undersøgelser, der behandler fortrolige personhenførbare data

Den dataansvarlige myndighed, University College Lillebælt

Dato: 18. december 2017
Appendix B Information til ældre 80+

**Invitation til at deltage i undersøgelse af oplevelsen af pleje- og omsorgsansvar**

Jeg henvender mig til dig for at spørge, om du vil deltage i en undersøgelse af, hvordan du oplever pleje- og omsorg på sygehuset, ved udskrivningen og i eget hjem? Undersøgelsen har fokus på patienter, der er 80 år eller ældre, og som bor alene. Hvis du ønsker at deltage, vil jeg invitere din voksne søn eller datter til også at deltage i undersøgelsen.

**Formålet** med undersøgelsen er at få en dybere forståelse for netop dine oplevelser, erfaringer og forventninger til pleje- og omsorg i forskellige sammenhænge. Undersøgelsen skal hjælpe os med at udvikle sygeplejen til ældre og deres pårørende.

**Undersøgelsens gennemførelse:**

Hvis du ønsker at deltage, vil jeg gerne tale med dig om dine oplevelser ca. to uger efter din udskrivelse fra sygehuset. Denne samtale kan foregå hjemme hos dig eller det kan foregå som en telefonsamtale.

**Anonymitet og frivillighed:**

Dine oplevelser anonymiseres, så de ikke kan genkendes af andre. Jeg har tavshedspligt og det er frivilligt at deltage. Du kan til enhver tid afbryde undersøgelsen, og det vil naturligvis ikke få konsekvenser for den fortsatte pleje- og behandling.

Undersøgelsen foregår i samarbejde med Aarhus Universitet, Geriatrisk afdeling, Odense Universitetshospital og University College Lillebælt.

Hvis du siger ja til at deltage i undersøgelsen, vil jeg bede dig underskrive en samtykkeerklæring.

Venlig hilsen

Helle Andersen, sygeplejerske og ph.d. studerende,
Aarhus Universitet, Tlf.: xx xx xx xx
Appendix C  Information til søn/datter

Invitation til at deltage i undersøgelse af oplevelsen af pleje- og omsorgsansvar


Formålet med undersøgelsen er at få en dybere forståelse for netop dine oplevelser, erfaringer og forventninger til pleje- og omsorgsansvar i forskellige sammenhænge. Undersøgelsen skal hjælpe os med at udvikle sygeplejen til ældre og deres pårørende.

Undersøgelsens gennemførelse:

- Hvis du ønsker at deltage, vil jeg bede dig i ca. 2-3 uger indtale eller skrive dagbog om dine oplevelser. Dagbogen indtales/skrives ca. hver uge og du skal forvente at bruge i alt ca. 20-30 minutter til denne del af undersøgelsen. Du får udleveret en diktafon/notesbog til dette.

- Ca. 2-3 uger efter aflevering af dagbogen, vil jeg gerne interviewe dig med udgangspunkt i dagbogen. Interviewet varer ca. en time. Interviewet kan foregå telefonisk, hjemme hos dig eller på UCL, Niels Bohrs Allé 1, 5230 Odense M.

Anonymitet og frivillighed:

Dine oplevelser anonymiseres, så de ikke kan genkendes af andre. Jeg har tavshedspligt og det er frivilligt at deltage. Du kan til enhver tid afbryde undersøgelsen, og det vil naturligvis ikke få konsekvenser for den fortsatte pleje- og behandling.

Undersøgelsen foregår i samarbejde med Aarhus Universitet, Geriatrisk afdeling, Odense Universitetshospital og University College Lillebælt.

Hvis du siger ja til at deltage i undersøgelsen, vil jeg bede dig underskrive en samtykkeerklæring.

Venlig hilsen
Helle Andersen, sygeplejerske og ph.d. studerende
Aarhus Universitet, tlf.: xx xx xx xx
Jeg giver hermed tilsagn om, at jeg har fået udleveret og gennemgået skriftligt informationsmateriale om undersøgelsen: Voksne børn med pleje- og omsorgsansvar for en forælder 80+, der bor alene med komplekse plejebehov.

Jeg ved, at det er frivilligt at deltage, og jeg kan altid trække mit samtykke tilbage uden at miste mine nuværende eller fremtidige rettigheder til pleje og behandling.

Jeg bekræfter, at jeg gerne vil deltage i undersøgelsen, og at informationerne må anvendes i undersøgelsens samlede resultater.

Navn:_______________________________________________________________

Adresse:_____________________________________________________________

Telefonnummer:______________________________________________________

Data og underskrift:___________________________________________________
SAMTYKKEERKLÆRING
Søn/datter

Jeg giver hermed tilsagn om, at jeg har fået udleveret og gennemgået skriftligt informationsmateriale om undersøgelsen: Voksne børn med pleje- og omsorgsansvar for en forælder 80+, der bor alene med komplekse plejebehov.

Jeg ved, at det er frivilligt at deltage, og jeg kan altid trække mit samtykke tilbage uden at miste mine nuværende eller fremtidige rettigheder til pleje og behandling.

Jeg bekræfter, at jeg gerne vil deltage i undersøgelsen, og at informationerne må anvendes i undersøgelsens samlede resultater.

Navn:_____________________________________________________________

Adresse:_________________________________________________________

_______________________________________________________________

Telefonnummer:_________________________________________________

Data og underskrift:________________________________________________
Appendix F  Interviewguide – ældre

<table>
<thead>
<tr>
<th>Vejledende interviewspørgsmål</th>
<th>Stikord</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Introduktion til interviewet</strong></td>
<td></td>
</tr>
<tr>
<td>- Tak fordi du vil deltage i undersøgelsen.</td>
<td></td>
</tr>
<tr>
<td>- Formål med undersøgelsen og interview, herunder brugen af åbne spørgsmål.</td>
<td></td>
</tr>
<tr>
<td><strong>Baggrund og nuværende situation</strong></td>
<td></td>
</tr>
<tr>
<td>- Vil du fortælle lidt om dig selv og din baggrund?</td>
<td>Fortæl mere om…</td>
</tr>
<tr>
<td>- Vil du beskrive, hvordan du oplever det at blive ældre? Sygdomme?</td>
<td>Kan du uddybe det?</td>
</tr>
<tr>
<td>- Vil du beskrive, hvordan du har haft det siden udskrivelsen fra hospitalet?</td>
<td>Kan du sige mere om det?</td>
</tr>
<tr>
<td>- Vil du beskrive, hvordan du klarer dig i hverdagen/en typisk dag?</td>
<td>Hvordan oplever du?</td>
</tr>
<tr>
<td>- Du modtager hjemmepleje og hjemmesygepleje, vil du uddybe dine oplevelser med den hjælp du modtager?</td>
<td>Hvad tænker du om det?</td>
</tr>
<tr>
<td>- Hvad betyder det for dig at modtage hjemmepleje og hjemmesygepleje?</td>
<td>Hvad skete der?</td>
</tr>
<tr>
<td>- Vil du beskrive, hvilken form for hjælp du får fra dine børn, og hvor ofte de hjælper?</td>
<td>Hvad tænkte/følte du?</td>
</tr>
<tr>
<td>- Hvordan oplever du at få hjælp og støtte fra dine børn?</td>
<td></td>
</tr>
<tr>
<td>- Hvad betyder det for dig at modtage hjælp fra dine børn? Hvordan har du det med det?</td>
<td></td>
</tr>
<tr>
<td>- Hvordan vil du beskrive forholdet til dine børn?</td>
<td></td>
</tr>
<tr>
<td><strong>Indlæggelse</strong></td>
<td></td>
</tr>
<tr>
<td>- Vil du fortælle om dine oplevelser under din seneste indlæggelse på sygehuset?</td>
<td></td>
</tr>
<tr>
<td>- Kan du give eksempler på den pleje, behandling og omsorg du oplevede fra sundhedspersonalet?</td>
<td></td>
</tr>
<tr>
<td>- Kan du give eksempler på, hvad din søn/datter hjalp med under indlæggelsen?</td>
<td></td>
</tr>
<tr>
<td>- Hvordan havde du det med den hjælp og støtte du fik fra din søn/datter?</td>
<td></td>
</tr>
<tr>
<td><strong>Udskrivelsen</strong></td>
<td></td>
</tr>
<tr>
<td>- Vil du fortælle om dine oplevelser i forbindelse med udskrivelsen fra sygehuset?</td>
<td></td>
</tr>
<tr>
<td>- Kan du give eksempler på den pleje, behandling og omsorg du oplevede fra sundhedspersonalet?</td>
<td></td>
</tr>
<tr>
<td>- Kan du give eksempler på, hvad din søn/datter hjalp med ifm. udskrivelsen?</td>
<td></td>
</tr>
<tr>
<td><strong>Afrunding</strong></td>
<td></td>
</tr>
<tr>
<td>- Er der noget, du gerne vil sige/tilføje?</td>
<td></td>
</tr>
<tr>
<td>- Opsummering, afrunding og tak for deltagelse i undersøgelsen.</td>
<td></td>
</tr>
</tbody>
</table>
Appendix G Vejledning: Dagbog til søn/datter

Tak, fordi du vil deltage i denne undersøgelse, som skal hjælpe med at udvikle sygeplejen til ældre og deres pårørende. Der er fokus på det pleje- og omsorgsansvar du oplever i forbindelse med din mors/fars indlæggelse, udskrivelse og tiden efter i din mors/fars eget hjem.

Du har dagbogen i ca. 2-3 uger og du skal forvente at bruge i alt ca. 20-30 minutter til denne del af undersøgelsen. Indtal gerne lidt hver uge og indtal gerne dato eller ugedag, når du starter/fortsætter din fortælling.

**Ordet er dit, men nedenfor er listet nogle områder, som du gerne må komme ind på:**

**Første optagelse/notat med dato:**

**Fortæl lidt om dig selv, herunder:**
- Hvor og hvornår er du født?
- Hvordan er dine familieforhold, herunder forholdet til din mor/far?
- Hvad er dit evt. erhverv og evt. fritidsinteresser?
- Hvilke sygdomme lider din mor/far af - hvordan påvirker det din fars/mors dagligdag?

**Løbende optagelser/notater med dato:**

**Fortæl om dine oplevelser under din mors/fars indlæggelse på sygehuset, herunder:**
- Giv gerne eksempler på den pleje, behandling og omsorg du oplever.
- Giv gerne eksempler, hvordan du oplever samarbejdet med din mor/far under indlæggelsen.
- Hvad er vigtigt for dig som pårørende i forbindelse med indlæggelsen?

**Fortæl om dine oplevelser i forbindelse med din mors/fars udskrivelse fra sygehuset, herunder:**
- Giv gerne eksempler på den pleje, behandling og omsorg du oplever.
- Giv gerne eksempler på, hvordan du oplever samarbejdet med din mor/far i forbindelse med udskrivelsen.
- Hvad er vigtigt for dig som pårørende i forbindelse med udskrivelsen fra sygehuset?

**Fortæl om dine oplevelser med pleje og omsorg i din mors/fars eget hjem, herunder:**
- Giv gerne eksempler på den pleje, behandling og omsorg du oplever.
- Giv gerne eksempler på, hvordan du oplever samarbejdet med og forholdet til din mor/far i forbindelse med pleje og omsorg i din mors/fars eget hjem.
- Hvad er vigtigt for dig som pårørende i forbindelse med pleje og omsorg i din mors/fars eget hjem?

Har du spørgsmål til dagbogen, er du velkommen til at kontakte Helle Andersen på telefon 24 96 41 92 eller e-mail hean@ucl.dk

Dagbogen modtages efter aftale. På forhånd tak for hjælpen.
## Appendix H  Interviewguide - søn/datter

<table>
<thead>
<tr>
<th>Introduktion til interviewet</th>
<th>Stikord</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Tak for dagbogsdelen og fordi du vil deltage i undersøgelsen.</td>
<td>Fortæl mere om…</td>
</tr>
<tr>
<td>• Formål med undersøgelsen og interview, herunder brugen af åbne spørgsmål.</td>
<td>Kan du uddybe det?</td>
</tr>
</tbody>
</table>

**Vil du fortælle lidt om din baggrund og dit forhold til din far/mor?**

**Vil du beskrive, hvordan du oplever din fars/mors alderdom og sygdom?**

**Vil du fortælle om dine oplevelser under din mors/fars seneste indlæggelse på sygehuset?**
- • Kan du give eksempler på den pleje, behandling og omsorg du oplevede fra sundhedspersonalet?
- • Vil du beskrive, hvordan du var involveret og hvad du evt. hjalp med under indlæggelsen?
- • Vil du uddybe, hvad der var vigtigt for dig som pårørende under indlæggelsen?

**Vil du fortælle om dine oplevelser i forbindelse med din fars/mors udskrivelse fra sygehuset?**
- • Kan du give eksempler på den pleje, behandling og omsorg du oplevede fra sundhedspersonalet ifm. udskrivelsen?
- • Vil du beskrive, hvordan du var involveret og hvad du evt. hjalp med ifm. udskrivelsen?
- • Vil du uddybe, hvad der var vigtigt for dig som pårørende ifm udskrivelsen?

**Vil du fortælle om dine oplevelser med hjemmeplejen?**
- • Kan du give eksempler på den pleje, behandling og omsorg du oplever fra hjemmeplejen?
- • Vil du beskrive, hvordan du er involveret og hvad du evt. hjælper din far/mor med derhjemme?
- • Vil du uddybe, hvad der er vigtigt for dig som pårørende ift. hjemmeplejen?

**Hvad betyder det for dig at hjælpe og støtte din far/mor?**
- • Kan du give eksempler?
- • Vil du beskrive, hvordan du samarbejder med evt. søskende/familien?

**Afrunding**
- • Er der noget, du gerne vil tilføje?
- • Kort opsummering og tak for deltagelse.
**Appendix I  Humanized Care Assessment Tool (HCAT)**

This questionnaire is designed to assess what things your current work environment enables you to do in order to focus on the human aspects of care. Please read over the following questions and consider each item in terms of, on average, how often your current work environment enables the following behaviours. Please then circle your answer on the scaled response between 1 and 5, for example with 1 being ‘always’ and 5 being ‘never’

<table>
<thead>
<tr>
<th>My work environment enables me to…</th>
<th>Always</th>
<th>Most of the time</th>
<th>Some of the time</th>
<th>Rarely</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>(1) Attend staff development events</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(2) Ask the patient how they assess their own health</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(3) Remember small details about patient’s personal stories</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(4) Ask patients about their expectations of care and treatment</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(5) Make sure patients know your name and role</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(6) Give patients the confidence to manage their own conditions</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(7) Use non-clinical language when talking with patients</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(8) Where safety concerns allow, adapt the environment to make it as homely/personal as possible</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(9) Use patients’ preferred name</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(10) Ask patients how it is going for them</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(11) Where possible offer patients choices about what happens to them next</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(12) Show patients you are pleased to see them when they arrive for treatment</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(13) Consider how the environment (e.g., noise, images, smells, friendliness) could make patients uncomfortable</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(14) Help patients to stay close to their own everyday routines</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(15) Ensure that the patient has a means of communication with a named health service provider on discharge</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(16) Try to involve significant others as the patient wants</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(17) Assure patients that they can always call for advice</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(18) Try to find out information that the patient wants on their behalf</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(19) Be prepared to change direction if treatment is not working for the patient</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(20) Notice what can support patients to take a role in care and treatment decision-making</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(21) Consider how the surroundings (e.g., noise, images, smells, friendliness) makes patients feel comfortable</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(22) Keep patients informed at regular intervals when they are awaiting results</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(23) Provide information about how the service works (mealtimes, etc.)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(24) Remember small details about patient’s personal care preferences</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(25) Notice barriers that can get in the way of patients feeling welcome</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(26) Consider how patient’s future aspirations may be affected by their current treatment.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(27) Show patients and family members the hospital complaints policy</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(28) Encourage patients to support each other, wherever possible and when wanted</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(29) Actively seek promotion</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(30) Give patients the skills to manage their own conditions</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(31) Ensure families and friends feel welcome</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(32) Understand the everyday consequences of treatments or care plans, which have to be carried out by the patients themselves</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

(Continues)
<table>
<thead>
<tr>
<th></th>
<th>Always</th>
<th>Most of the time</th>
<th>Some of the time</th>
<th>Rarely</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>(33) Update patients on treatments regularly</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>(34) Consider how generic treatment pathways fit with the individual patient</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>(35) Introduce patients to others who share their condition, when wanted</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>(36) Notice what affects your patient’s mood</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>(37) Encourage other staff to introduce themselves by name and role</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>(38) Help patients understand the changes that may be happening to them</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>(39) Seek out how care could be adapted to suit the individual patient’s situation</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>(40) Encourage patients to complete patient satisfaction forms</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>(41) Consider how the care setting we operate in can be initially unfamiliar to patients</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>(42) Create a welcoming environment</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>My work environment enables me to...</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>(43) Notice barriers that can get in the way of families feeling welcome</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>(44) Seek out flexibility in the system to respond to patients priorities</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>(45) Offer support to patients moving through a system they are unfamiliar with</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>(46) Recognise the importance of a regular review of care with the patient</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>(47) Be able to set clear goals</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>(48) Be able to support colleagues</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>(49) Read a professional journal frequently</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>(50) Show visitors how to use soap dispensers</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>(51) Have the time to reflect on my own feelings</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>(52) Consider how the environment (e.g., noise, images, smells, friendliness) could make patient’s significant others feel uncomfortable</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>(53) Show that you want to know about patients fear about their situation</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>(54) Find ways to help patients stay in touch with important things from their everyday life</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>(55) Consider the patients feelings about being isolated</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>(56) Have a sense of a human connection with the patient</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>(57) Ask patients how they are finding their journey through care</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>(58) Be aware of the physical impact on me, of giving bad news</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>(59) Show patients where they can find peaceful spaces</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>(60) Explain to patients where there is no flexibility in the system and why</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>(61) Take steps to put patients at ease</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>(62) Focus on making the patient feel at home</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>(63) Feel supported by colleagues</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>(64) Help patients feel comfortable enough to ask questions</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>(65) Check all equipment is accessible before seeing patients</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>(66) Notice patients at particular risk of isolation</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>(67) Support patients to have a say in their care or treatment</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>My work environment enables me to...</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>(68) Notice what makes the patient feel energised</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>(69) Make sure patients are treated by a named or consistent member of staff.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>(70) Take an interest in what patients tell me about how they like things done</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Always</td>
<td>Most of the time</td>
<td>Some of the time</td>
<td>Rarely</td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td>--------</td>
<td>------------------</td>
<td>------------------</td>
<td>--------</td>
</tr>
<tr>
<td>71</td>
<td>Be aware of the anxiety patients can experience when waiting for results</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>72</td>
<td>Regularly check that treatment is going okay from the patient’s point of view</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>73</td>
<td>Frequently ask patients how they are</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>74</td>
<td>Consider the different responses patients can have to the same illness or condition</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>75</td>
<td>Provide care that is not only technical/task focused</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>76</td>
<td>Appreciate that how a patient sees the severity of their illness or condition may differ from my own</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>77</td>
<td>Gain experience treating a variety of cases</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>78</td>
<td>As far as possible facilitate contact with important people in the patient’s life</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>79</td>
<td>Create a sense of calmness (when possible)</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>80</td>
<td>Try to see the person behind the illness or condition</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>81</td>
<td>Be aware of the personal meaning any bodily (physical) changes for the patient</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>82</td>
<td>Give patients time to talk about their emotional response to their illness/condition</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>83</td>
<td>Provide patients with information on peer support</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>84</td>
<td>Consider how the surroundings (e.g., noise, images, smells, friendliness) makes staff feel comfortable</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>85</td>
<td>Keep updated on the latest policies in your field</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>86</td>
<td>Understand what prevents patients asking for help/information</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>87</td>
<td>Be aware of the physical impact of bad news for the patient</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>88</td>
<td>Acknowledge, with each patient, the fear that can come with health conditions</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>89</td>
<td>Offer sensitive explanations on what is happening (now and in the future)</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>90</td>
<td>Focus on what is of concern to the patient (even if outside or unrelated to treatment)</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>91</td>
<td>Notice what makes the patient feel tired</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>92</td>
<td>My work environment enables me to...</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>93</td>
<td>Show that you want to know ‘what it’s like’ from the patient’s perspective</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>94</td>
<td>Consider the emotional aspects of the patient’s treatment or condition</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>95</td>
<td>Understand what prevents staff asking for help/information</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>96</td>
<td>Discuss each patient as a person (not just health condition or case) when sharing information with other health professionals</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>97</td>
<td>Notice how staff behaviours could create embarrassment, shame or vulnerability, during treatment</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>98</td>
<td>Update your training regularly</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>99</td>
<td>Be organised when booking annual leave</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>100</td>
<td>Consider how the surroundings (e.g., noise, images, smells, friendliness) makes families or significant others feel comfortable</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>101</td>
<td>Where possible, to help patients to have some meaningful possessions close at hand</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>102</td>
<td>Repeat information about what is happening to patients regularly</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>103</td>
<td>Care about the well-being of my colleagues</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>104</td>
<td>Build trusting relationships with patients and their significant others</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>105</td>
<td>Check that patients are comfortable</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Always</td>
<td>Most of the time</td>
<td>Some of the time</td>
<td>Rarely</td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td>--------</td>
<td>------------------</td>
<td>------------------</td>
<td>--------</td>
</tr>
<tr>
<td>(105) Encourage patients to ask what is happening and why</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>(106) Think of the patient as a person and more than just a body</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>(107) Make space to listen to the patients worries, even if they cannot be resolved</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>(108) Notice what makes the patient feel relaxed</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>(109) Be aware of hospital dignity/health and safety/cleanliness (i.e., any type of policy) policy</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
Appendix J  Declaration of co-authorship

Declaration of co-authorship concerning article for PhD dissertations

Full name of the PhD student: Helle Elisabeth Andersen

This declaration concerns the following article/manuscript:

<table>
<thead>
<tr>
<th>Title:</th>
<th>Caring Responsibility from the perspectives of Older Persons whose Adult Children are their Caregivers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Authors:</td>
<td>Andersen, H.E., Hoeck, B., Nielsen, D.S., Ryg, J. &amp; Delmar, C.</td>
</tr>
</tbody>
</table>

The article/manuscript is: Published ☑ Accepted ☐ Submitted ☐ In preparation ☐


If accepted or submitted, state journal:

Has the article/manuscript previously been used in other PhD or doctoral dissertations?

No ☑ Yes ☐ If yes, give details:

Your contribution

Please rate (A-F) your contribution to the elements of this article/manuscript, and elaborate on your rating in the free text section below.

A. Has essentially done all the work (>90%)
B. Has done most of the work (67-90 %)
C. Has contributed considerably (34-66 %)
D. Has contributed (10-33 %)
E. No or little contribution (<10%)
F. N/A

**Category of contribution** | **Extent (A-F)**
--- | ---
**The conception or design of the work:** | A

*Free text description of PhD student’s contribution (mandatory)*
The PhD student has essentially done all the work regarding the design of the research

**The acquisition, analysis, or interpretation of data:** | B

*Free text description of PhD student’s contribution (mandatory)*
The PhD student has generated all data and done most of the work regarding analysis and interpretation

**Drafting the manuscript:** | A

*Free text description of PhD student’s contribution (mandatory)*
The PhD student has drafted all three articles and discussed this with supervisors. Dissertation draft discussed with main supervisor

**Submission process including revisions:** | A
Free text description of PhD student's contribution (mandatory)
PhD student has essentially done all work

Signatures of first- and last author, and main supervisor

<table>
<thead>
<tr>
<th>Date</th>
<th>Name</th>
<th>Signature</th>
</tr>
</thead>
<tbody>
<tr>
<td>16/8 2020</td>
<td>Helle Elisabeth Andersen</td>
<td>Helle Andersen</td>
</tr>
<tr>
<td>19/8 2020</td>
<td>Charlotte delmar</td>
<td>Charlotte delmar</td>
</tr>
</tbody>
</table>

Date: 19/8-2020

Signature of the PhD student
Declaration of co-authorship concerning article for PhD dissertations

Full name of the PhD student: Helle Elisabeth Andersen

This declaration concerns the following article/manuscript:

<table>
<thead>
<tr>
<th>Title:</th>
<th>A Phenomenological-Hermeneutic Study Exploring Caring Responsibility for a Chronically Ill, Older Parent with Frailty</th>
</tr>
</thead>
<tbody>
<tr>
<td>Authors:</td>
<td>Andersen, H.E., Hoeck, B., Nielsen, D.S., Ryg, J. &amp; Delmar, C.</td>
</tr>
</tbody>
</table>

The article/manuscript is: Published ☒ Accepted ☐ Submitted ☐ In preparation ☐


If accepted or submitted, state journal:

Has the article/manuscript previously been used in other PhD or doctoral dissertations?

No ☒ Yes ☐ If yes, give details:

Your contribution

Please rate (A-F) your contribution to the elements of this article/manuscript, and elaborate on your rating in the free text section below.

A. Has essentially done all the work (>90%)
B. Has done most of the work (67-90 %)
C. Has contributed considerably (34-66 %)
D. Has contributed (10-33 %)
E. No or little contribution (<10%)
F. N/A

<table>
<thead>
<tr>
<th>Category of contribution</th>
<th>Extent (A-F)</th>
</tr>
</thead>
<tbody>
<tr>
<td>The conception or design of the work:</td>
<td>A</td>
</tr>
<tr>
<td><em>Free text description of PhD student’s contribution (mandatory)</em></td>
<td></td>
</tr>
<tr>
<td>The PhD student has essentially done all the work regarding the design of the research</td>
<td></td>
</tr>
<tr>
<td>The acquisition, analysis, or interpretation of data:</td>
<td>B</td>
</tr>
<tr>
<td><em>Free text description of PhD student’s contribution (mandatory)</em></td>
<td></td>
</tr>
<tr>
<td>The PhD student has generated all data and done most of the work regarding analysis and interpretation</td>
<td></td>
</tr>
<tr>
<td>Drafting the manuscript:</td>
<td>A</td>
</tr>
<tr>
<td><em>Free text description of PhD student’s contribution (mandatory)</em></td>
<td></td>
</tr>
<tr>
<td>The PhD student has drafted all three articles and discussed this with supervisors. Dissertation draft discussed with main supervisor</td>
<td></td>
</tr>
<tr>
<td>Submission process including revisions:</td>
<td>A</td>
</tr>
</tbody>
</table>
Free text description of PhD student's contribution (mandatory)
PhD student has essentially done all work

Signatures of first- and last author, and main supervisor

<table>
<thead>
<tr>
<th>Date</th>
<th>Name</th>
<th>Signature</th>
</tr>
</thead>
<tbody>
<tr>
<td>16/8 2020</td>
<td>Helle Elisabeth Andersen</td>
<td></td>
</tr>
<tr>
<td>19/8 2020</td>
<td>Charlotte Delmar</td>
<td></td>
</tr>
</tbody>
</table>

Date: 19/8 - 2020

Signature of the PhD student
Declaration of co-authorship concerning article for PhD dissertations

Full name of the PhD student: Helle Elisabeth Andersen

This declaration concerns the following article/manuscript:

<table>
<thead>
<tr>
<th>Title:</th>
<th>Older ill persons and their adult children's experiences with primary healthcare. A Reflective Lifeworld Research approach</th>
</tr>
</thead>
<tbody>
<tr>
<td>Authors:</td>
<td>Andersen, H.E., Hoeck, B., Nielsen, D.S., Ryg, J. &amp; Delmar, C.</td>
</tr>
</tbody>
</table>

The article/manuscript is: Published ✗ Accepted ☐ Submitted ☐ In preparation ☐

If published, state full reference:

If accepted or submitted, state journal: Nordic Journal of Nursing Research

Has the article/manuscript previously been used in other PhD or doctoral dissertations?

No ☐ Yes ✗ If yes, give details:

Your contribution

Please rate (A-F) your contribution to the elements of this article/manuscript, and elaborate on your rating in the free text section below.

A. Has essentially done all the work (>90%)
B. Has done most of the work (67-90%)
C. Has contributed considerably (34-66%)
D. Has contributed (10-33%)
E. No or little contribution (<10%)
F. N/A

<table>
<thead>
<tr>
<th>Category of contribution</th>
<th>Extent (A-F)</th>
</tr>
</thead>
<tbody>
<tr>
<td>The conception or design of the work:</td>
<td>A</td>
</tr>
<tr>
<td>Free text description of PhD student's contribution (mandatory)</td>
<td></td>
</tr>
<tr>
<td>The PhD student has essentially done all the work regarding the design of the research</td>
<td></td>
</tr>
<tr>
<td>The acquisition, analysis, or interpretation of data:</td>
<td>B</td>
</tr>
<tr>
<td>Free text description of PhD student's contribution (mandatory)</td>
<td></td>
</tr>
<tr>
<td>The PhD student has generated all data and done most of the work regarding analysis and interpretation</td>
<td></td>
</tr>
<tr>
<td>Drafting the manuscript:</td>
<td>A</td>
</tr>
<tr>
<td>Free text description of PhD student's contribution (mandatory)</td>
<td></td>
</tr>
<tr>
<td>The PhD student has drafted all three articles and discussed this with supervisors. Dissertation draft discussed with main supervisor</td>
<td></td>
</tr>
<tr>
<td>Submission process including revisions:</td>
<td>A</td>
</tr>
</tbody>
</table>
Free text description of PhD student's contribution (mandatory)
PhD student has essentially done all work

Signatures of first- and last author, and main supervisor

<table>
<thead>
<tr>
<th>Date</th>
<th>Name</th>
<th>Signature</th>
</tr>
</thead>
<tbody>
<tr>
<td>16/8-2020</td>
<td>Helle Elisabeth Anderson</td>
<td>[Signature]</td>
</tr>
<tr>
<td>19/8 2020</td>
<td>Charlotte Delmar</td>
<td>[Signature]</td>
</tr>
</tbody>
</table>

Date: 19/8 - 2020

Signature of the PhD student

178
PhD dissertations published by Research Unit for Nursing Science, Department of Public Health, Faculty of Health Sciences, Aarhus University

Helle Elisabeth Andersen: Who cares? Caring responsibility from the perspectives of older, ill persons and their adult children in primary healthcare. 2020

Mai-Britt Hägi-Pedersen: “The PreHomeCare study”. A multicenter randomized early in-home care intervention study comparing video and in-hospital consultations for parents of premature infants and two qualitative perspectives on the intervention. 2020

Randi Steensgaard: Promoting patient participation in rehabilitation – caring for the patient’s perspective. 2020

Ingrid Villadsen Kristensen: Living with ambivalence while facing the future: The existential experiences of patients living with end-stage renal disease before and after a kidney transplantation with a living donor. 2020

Diana Skaaning: Breastfeeding duration in premature infants – Influence of oral stimulation intervention, the infant’s suction & maternal concerns. 2020

Hanne Mørkenborg Bové: Bridging acute nursing care to patients suffering from alcohol use disorders. A lifeworld perspective. 2020

Cecilie Norby Thisted: Work participation among employees with depression. Clarifying the perspectives of employers and highly educated employees with depression. 2019

Rikke Madsen: Transitions during courses of incurable cancer: A review and interview study exploring experiences of patients and significant others. 2019

Anne Bendix Andersen: The Puzzle of Coherence – An Ethnographically Inspired Study of Intersectoral Collaboration in the Danish Healthcare System. 2018

Caroline Trillingsgaard Mejdahl: Patient-reported outcome measures in outpatient follow-up. A multi-perspective interpretive description. 2018

Gitte Susanne Rasmussen: Identifying young people’s needs for support to manage moderate to severe psoriasis in daily life. An interpretive description. 2018

Tina Wang Vedelø: Exploring the needs of patients with malignant brain tumour – A Case Study of participating in an Integrated Brain Cancer Pathway. 2018

Trine Ellegraard: Patient-controlled admission in mental health hospital practice: Experiences of patients and mental health professionals. 2017


Janni Lisander Larsen: Grasping the Existential Experience of Living with Systemic Lupus Erythematosus – A Hermeneutic-Phenomenological Study. 2017

Malene Beck: Hospital Meals: An Asylum for People in a Vulnerable Situation A phenomenological-hermeneutic study about patients’ experience of mealtimes during hospitalization with a neurological disease. 2017

Camilla Askov Mousing: Improving the palliative care of people with chronic obstructive pulmonary disease in home care. A participatory action research project. 2017

Susanne Friis Søndergaard: Exploring the interplay between perioperative nurses’ documentation practice, and the conditions for their practice – A Realistic Evaluation. 2017

Marianne Eg: Significant factors for achieving sustained weight loss in adolescents participating in a weight-loss programme. 2016

Ingeborg Hedegaard Kristensen: Video feedback promotes early relations between infants and vulnerable first-time mothers. Characteristics of first-time mothers and the health visitors supporting them. 2016
Ingrid Maria Susanne Nilsson: Less is more. Early discharge following birth - How do we support mothers to effective breastfeeding? 2016


Dorthe Hasfeldt-Hansen: Noise in the operating room and patients’ sense of coherence - A literature review and a cross-sectional study, 2016

Charlotte Paaske Simoný: Towards a new foothold in life. A Phenomenological-Hermeneutic Study of patients’ lived experiences during the trajectory of Cardiac Rehabilitation. 2015

Connie Timmermann: The meaning of sensory impressions in the hospital environment, 2014

Annesofie Lunde Jensen: Multifaceted group education in patients with osteoporosis - implementing a bone healthy lifestyle, 2014

Anne Sophie Ågård: Long-Term Impact of Acute, Critical Illness and Admission to an Intensive Care Unit. Perspectives of Patients and Partners. 2013

Lene Sondergård Larsen: A companionship between strangers – Patient-patient interaction in oncology wards. 2013

Dorthe Sørensen: Nurse-patient collaboration during non-invasive ventilation in patients with acute respiratory failure due to COPD. 2013

Lene Bastrup Jørgensen: Coping with breathlessness in daily life. 2012

Vibeke Bregnballe: From child to adult with cystic fibrosis. 2011

Selina Kikkenborg: Comprehensive rehabilitation for patients with ICD. 2011

Lotte Ørneborg Rodkjær: Hiv and depression. 2011

Lena Aadal: Intensiv neurorehabilitering forstået som læring. 2010

Hanne Konradsen: From silent problem to interactional integration. 2010

Anita Haahr: Living with Parkinson’s disease before and after Deep Brain Stimulation. 2010

Pia Riis Olsen: Towards a theory of network-focused nursing. 2009


Sanne Angel: Kampen for et liv, der er værd at leve: Processen mod et meningsfuldt liv efter en traumatiske rygmarvsskade. 2008

Lisbeth Uhrenfeldt: Leadership, job satisfaction and clinical wisdom: A hermeneutic study of charge and clinical nurses’ perceptions. 2007

Bente Høy: Health-Promoting Care of the Elderly Patient. 2007

Elisabeth O.C. Hall (doctor’s degree): When a newborn or small child is critically ill. Nurses’, parents’ and grandparents’ experiences and dynamics in family-centred care. 2007

Hanne Kronborg: Tidligt ammeophør - kan det forebygges? Et forskningsprojekt i sundhedsplejens praksisfelt. 2006

Erik Elgaard Sørensen: Sygeplejefaglig ledelse. En empirisk undersøgelse af samspil mellem ledelse og faglighed i ledende sygeplejerskers praksis i dansk sygehusvæsen. 2006

Kirsten Lomborg: Nurse-patient interactions in assisted personal body care. A qualitative study in people hospitalised with severe chronic obstructive pulmonary disease (COPD). 2004

Lise Hounsgaard: Potentiel sygdom sætter spor. Kvinders oplevelse af sygdom i et forløb med celleforandringer efter screening for livmoderhalskræft. 2004

Vibeke Zoffmann: Guided Self-Determination. A life skills approach developed in difficult Type 1 diabetes. 2004

Inger Moos: Narration og identitet i interaktioner mellem pleejemsbeboere med Alzheimers demens og plejepersonale. 2004

Birthe D. Pedersen: Sygeplejepraksis. Sprog & Erkendelse. 1999

Elisabeth O.C. Hall: Fra afdeling til afdeling. En fænomenologisk undersøgelse af indholdet i sygeplejen ved et lille barns overflytning til eller fra intensiv afdeling. 1999

Jette Joost Michaelsen: Kommunikation i den primære sundhedstjeneste. En kvalitativ undersøgelse af relation og interaktion mellem hjemmesygeplejersken og den ”vanskelige” patient. 1999
