


# Becoming a Family Caregiver to a Person With Dementia: A Literature Review on the Needs of Family Caregivers

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## Abstract

**Introduction:** The dementia disease affects both the family caregivers' health and social and psychological well-being. The aim of this review was to identify and describe the needs of family caregivers living with a person with dementia at home.

**Method:** The literature review, conducted using the matrix method, was also inspired by Thomas and Harden's thematic synthesis.

**Results:** Three themes were identified: (1) the family caregiver's new roles and relationships; (2) caregiver burdens; and (3) the caregiver's need for information and support.

**Conclusion:** When family caregivers gradually lose their reciprocal relationship with the person with dementia, and sometimes also with family and friends, the need for other kinds of social contact arises e.g. with others in a similar situation. They also need to have some respite to provide room to pursue their own interests and take care of their own health. Also, a high level of individually tailored information is needed.

## Keywords

family caregivers, dementia care, caregiver burden, caregiver needs

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In recent years, dementia has become a worldwide important issue as estimates indicate that the number of individuals living with dementia worldwide will increase from 47 million people in 2015 to 75 million in 2030 and 135 million people by 2050 (Alzheimer's Disease International, 2018; World Health Organization, 2017). Higgs and Gilleard (2017) argue that conditions concerning dementia go beyond its epidemiological significance and lead to loss of a personal basic infrastructure that supports one's agency, awareness, communication judgement and reasoning. Confronted with this scenario the person living with dementia fears to lose his mind, and his place in the adult world leading to having a considerably influence on his life but also on the lives of his family (Higgs & Gilleard 2017).

In the European Union (2012) relatives are becoming an increasingly important resource in providing care for family members due to political incentives designed to

reduce severe constraints on fiscal policy (Bremer et al., 2017; Colombo et al., 2011).

Thus, family caregivers represent a pillar in future care, for which reason it becomes relevant to reflect on how family caregivers manage this new life situation involving both practical and emotional challenges concerning conditions due to dementia.

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Thus, transitioning into becoming a family caregiver entails major individual consequences, often leading to intertwined changed roles and reshaping of the caregiver's life course (Pearlin, 2010). Previous research shows that caring for a person living with dementia can affect health and social and psychological well-being of caregivers; often referred to as the caregiver burden (Brodaty & Donkin, 2009; Campbell et al., 2008; Lethin et al., 2020). The literature, however, often overlooks how family caregivers experience their own individual challenges and needs (Bangertner et al., 2019) for which reason the elucidation of the needs of the individual family caregiver can be important to promoting quality of life, decreasing stress and delaying hospitalisation of the person with dementia (Brodaty & Donkin, 2009).

The aim of this article is to identify and describe the challenges and the needs that emerge among family caregivers living together with a person with dementia.

This target group is chosen as they are being confronted 24/7 with new challenges and changed behaviour of a beloved family member which is assumed having a considerable impact on daily living and well-being of the family caregiver.

The existing literature use various terms for family caregivers, e.g. relatives, caregiver or informal caregiver synonymously. This review consistently uses the term family caregiver, regardless of the terms used in the articles referred to.

## Literature Search

To secure a firm structure, the Matrix Method was used as the overall approach to the literature review (Gerrard, 2007). This method consists of four parts: A paper trail to keep track of the search and selection process, a compilation of digital versions and hardcopies of all selected articles, a matrix to get an overview over them and, lastly, a written synthesis based on a thorough analysis.

We conducted a block search with key terms divided into four blocks including the Boolean operators AND and OR as shown in Figure 1.

We ran the block search in PubMed, Embase, PsycINFO, Idunn and SweMed+, supplemented with snowball technique, which is a metaphoric term referring

to – like a snowball that gathers more and more layers of snow – the process of gathering new layers of references by following relevant references in the articles' reference lists (Gerrard, 2007).

## Inclusion and Exclusion Criteria

Articles focusing on family caregivers living with a person with dementia written in Danish, English, German, Norwegian, Spanish and Swedish were included. Studies focusing on family caregivers, who did not live with the person living with dementia, were excluded. We applied no criteria for publication dates or research methods but only peer-reviewed articles were included. No further quality assessments were applied.

## Selection of Articles

Our searches resulted in 2050 articles, which were examined for suitability based on review of titles, abstracts, and full text, leading to a gradual selection of 34 scientific articles as shown in Figure 2, and they were registered into a matrix (Gerrard, 2007) as shown in Table 1.

## Analysis

Since the Matrix Method does not offer a specific process for the analysis itself, our analysis is inspired by the thematic synthesis developed by Thomas and Harden (2008), who consider all text under the headings findings or results as data. Based on our research interest, we extracted 267 excerpts about the challenges and needs of family caregivers that were either directly mentioned or indirectly embedded in the text. To secure rigour in the analysing process each article was labelled with a letter A, B, C etc. At the end of the alphabet, we doubled the letters AA, BB, CC. . . AAA, BBB etc. Excerpts were identified and numbered. The first excerpt in the first article was given A-1, the next A-2. The first excerpt in the fourth article was given D-1 etc. By labelling every excerpt we ensured the possibility to find the original context no matter how far we went in the decontextualizing process.

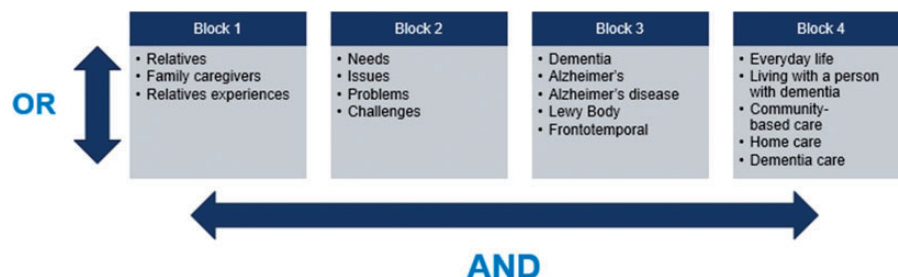
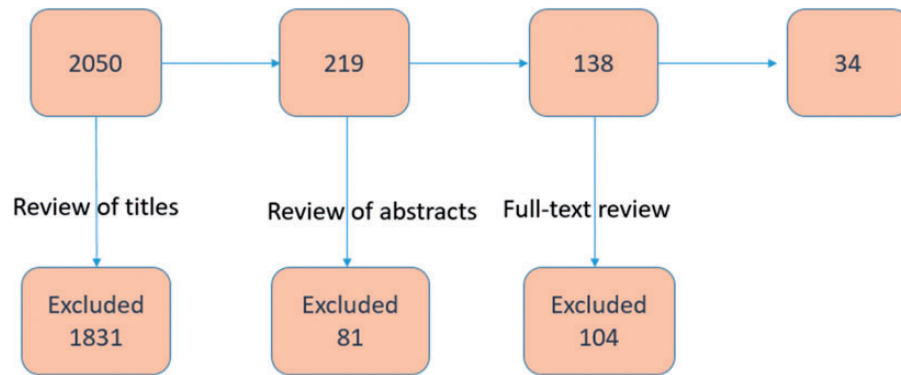


Figure 1. Search Strategy.



**Figure 2.** Flowchart.

Step one of the analysis involved coding each excerpt with a key term. Step two involved creating a hierarchical structure based on the coding that comprised 13 descriptive themes and 69 sub-themes. Based on the descriptive themes, step three entailed going “beyond the content of the original studies” (Thomas & Harden, 2008, p. 7) to generate analytical themes. To get a deeper understanding of the experiences of living together with a person suffering from dementia we created new descriptions representing the meaning embedded in each sub-theme. As a process of internal validation, these representative descriptions were continuously compared to the original excerpts to ensure that the meaning was not altered in a contradictive way. Getting deeper into the meaning of the descriptive themes, three analytical themes appeared across the descriptive themes, which will be presented in the findings below.

## Findings

Undertaking the role of family caregiver to a person with dementia often leads to a new, unexpected and unwanted life situation. Caregivers must adjust to new roles, tasks, and responsibilities as the dementia disease progresses. Adapting to this new situation is an act of becoming, which implies a quest to imagine a new kind of life for themselves as a family caregiver, i.e. to become a different kind of person due to the changed life situation. As shown in Figure 3, three analytical themes including seven sub-themes were extracted: (1) the family caregiver’s new roles and relationships, (2) caregiver burdens, and (3) information and support. In accordance with the aim of the study, each theme will be briefly followed by perspectives on challenges and needs.

### The Family Caregiver’s New Roles and Relationships

Being a family caregiver to a person with dementia implies undertaking new roles in relation to people within the caregiver’s inner social circle, primarily the person with dementia, family members and close friends,

whose well-known roles and relationships will change as the dementia disease progresses.

Many family caregivers can no longer understand how their relative experiences day-to-day life. This situation may lead to an inability to empathise with one another and thus, feelings of interpersonal distance and grief (Pini et al., 2018). This sense of distance in the relationship grows as the disease develops and as the personality of the demented person gradually erodes. Sometimes memory problems can cause difficulties in conversations and even lead to conflicts and family caregivers might miss the everyday talk and intimate conversations when the person with dementia is no longer able to go into an equal dialogue (Storjord & Lykkeslet, 2017).

### New Roles Towards the Person Living with Dementia

When the personality of the person living with dementia changes, also the perception of being a couple can gradually change and the role of the healthy spouse may be experienced more like a care provider rather than a spouse (Meyer et al., 2016). The literature describes a variety of new roles taken on by family caregivers, e.g. being a formal guardian (Landmark et al., 2013), handling the finances (Kuhn, 1998) or taking care of intimate tasks (Rayment et al., 2019). Some husbands struggle to improve their housekeeping skills and worry about providing healthy meals (Fjellström et al., 2010), while another study shows that many female spouses feel that the caregiver role “fell within their normative expectations of the spousal role” (Stirling et al., 2010, p. 7). In addition, family caregivers undertake various roles, e.g. as a supervisor, facilitator, or parent based on the situation at hand. Shifting between the assorted functions is described as becoming “full-time actors and for the play to end, the spouse or partner had to leave the common stage permanently, in some way or another” (Lövenmark et al., 2018, p. 4).

Authors year	Aim/focus	Designs and methods	Population	Findings relevant for this review
Chan et al. (2010).	To assess caregivers' experiences and needs and to suggest interventions.	Qualitative. Focus group discussions.	27 spouses and grown up children.	Family caregivers experience of emotional burdens. They find it helpful to obtain information and advices from an accessible resource person and express the need for a one-stop service with the resource person as the contact point.
Pini et al. (2017).	To develop and present a needs-led framework for understanding how providing care impacts on carers' fulfilment of needs.	Qualitative. Semi-structured interviews.	48 family carers of a person with dementia.	Needs of feeling in control, time to relax or being spontaneous as well as relational needs for belongingness and love.
Meyer et al. (2016).	To describe spouses' experiences of living with a partner with dementia.	Qualitative. In-depth interviews.	7 spouses of persons affected with dementia	The study describes a shift from togetherness to loneliness, as well as a need for information and knowledge in the early phase of their partner's illness.
Torp et al. (2008).	To explore the use of information and communication technology (ICT) by informal carers of frail elderly people.	Quantitative and qualitative. Structured interview, self-administered questionnaire and focus group interviews.	19 dyads. Close relative to an elderly person with the diagnosis of dementia or stroke living together.	Information about the illness and the illness trajectory gave a better understanding of what was to expect and to better prepare for the future. Participants valued contact with and support from other carers with similar experiences.
Quinn et al. (2015).	To explore how meaning, motivation and relationship dynamics influence the caregivers' subjective experience of caregiving.	Qualitative. Semi-structured interviews.	12 family caregivers of relatives with dementia.	The study describes the caregivers' constant struggle to balance their own needs against those of their relative, and the caregivers' desire to preserve and maintain their relationship with their relative. Furthermore, some caregivers experience change in the reciprocal nature of the relationship and loss of a mutually supportive relationship.
Holthe et al. (2018).	To examine family caregivers' role and experiences when using assistive technology to support everyday life.	Qualitative. Semi-structured interviews.	13 family caregivers of people with young-onset dementia.	Assistive technologies have a potential to make the person with dementia more independent on the family caregiver, but if a device is too difficult to use it may enhance the caregiver burden.
Svendsboe et al. (2016).	To define challenges and impacts of caring for a person with Lewy Body.	Quantitative. Cross-sectional study.	186 persons with dementia together with their caregivers.	Caregivers experience burdens, which increase the risk of developing psychiatric disorders. The caregivers need effective support preferably specific for the type of dementia since there is a difference in caregiver distress related to different types of the disease.
Diehl-Schmid et al. (2013).	To identify problems of caregivers, their needs investigate how helpful support strategies are	Quantitative. Questionnaire.	100 caregivers.	Information is the most helpful intervention to meet caregivers' needs. They need a thorough explanation of the disease given by one who know about the disease and broader caregiver issues, so that they should not ask different people about different issues. They

**Table 1.** Matrix – Characteristics of Included Studies.

## Altered Relations to Family and Friends

Family caregivers also experience feelings of loneliness due to a reduced social network (Flynn & Mulcahy, 2013; Johannessen et al., 2017; Pini et al., 2018). Arranging and participating in social activities demand energy, and as friends and family can find it

difficult to deal with awkward situations due to conditions caused by the dementia, they often withdraw from the person living with dementia and thus the family caregiver might feel lonely (Shanley et al., 2011). In addition, the concerns about how the diseased relative might behave in public in general can

				need an all-inclusive packages tailored to their situation.
Kuhn (1998).	To study needs and perceptions of family members and patients in the early stage of Alzheimer's disease.	Qualitative. Interviews.	20 family members.	Caregivers describe a major shift in roles and responsibilities in relation to those with Alzheimer's disease. Getting accustomed to their relative's dependency can be a great challenge. Finding enough time away from their relative is another challenge.
O'Connell et al. (2014).	To describe the development of a novel use of telehealth videoconferencing to deliver a specialized support group for spousal caregivers of rural individuals with atypical and early-onset dementias.	Qualitative. Observations and audio recordings of telehealth sessions	10 spousal caregivers.	For group interventions for caregivers to be effective, they need to be specialized, and include family members caring for individuals with similar diagnosis.
Killin et al. (2018).	To establish the feasibility of the Digital Support Platform (DSP), an internet-based, postdiagnostic tool designed for families living with a diagnosis of dementia.	Qualitative. Semi-structured interviews.	10 dyads of people, with Alzheimer's, vascular or mixed dementia, and their family carers.	A Digital Support Forum may be of benefit to those experiencing later stages of dementia or with physical care needs. Carers stated a disinclination to prepare for or anticipate for future needs, rather than focus on those needs present. Tailoring this support to the exact needs and current arrangements of families is important.
Flynn & Mulcahy (2013).	To explore care giving for people with EOD from a family member's perspective.	Qualitative. Semi-structured interviews.	7 family carers.	The financial impact of caregiving is described as a major concern. Knowledge about what to expect with the illness and what to come, should be available from the time of the diagnosis. There is a need for psychological support.
Johannessen et al. (2017).	To examine the experiences and needs of spouses of persons with young-onset frontotemporal lobe dementia for assistance in daily life.	Qualitative. Interviews.	15 spouses and one cohabitant.	The spouses need assistance through all stages of dementia. They experience worries, loss of sleeping patterns and loss of working capacities. The constant considerations of the other's needs as mentally exhausting.
Wawrziczny et al. (2015).	To explore caregiver and patient experiences in the period between the initial signs and the years following diagnosis with a special focus on early-onset Alzheimer's disease.	Qualitative. Semi-structured interviews.	16 married couples in which one is diagnosed with Alzheimer.	The couples oscillated between the need to know and the need not to know more. The caregivers feel overloaded and being needed too much and too often and face challenges of balancing work commitments with the caregiving responsibilities.
Peeters et al. (2010).	To assess the need for professional support.	Quantitative. Questionnaire.	984 informal caregivers.	The need for professional support most often concerns advice about how to deal with behavior change. There is a need for information about the professional help and support available.
Steiner et al. (2015).	To identify family caregivers' information needs as perceived by home care workers and the caregivers	Quantitative. Survey.	33 unpaid family caregivers and 59 paid home	Information needs are mostly related to behavior changes. Furthermore, caregivers need information on managing their own stress.

Table 1. Continued.

be a reason for staying at home, causing further social isolation. Some family caregivers find ways to set up social interaction with friends (Pini et al., 2018); but even relationships with close family members can break if the family caregiver does not have the energy to maintain the relationships by visiting others or attending activities outside the home.

## New Relationships – Peers and Professional Caregivers

Family caregivers value contact with other people who are in a similar situation (Huis in het Veld et al., 2018; McKechnie et al., 2014; Rayment et al., 2019; Torp et al., 2008). In peer groups, family caregivers



	themselves.		care workers.	
Strandli et al. (2016).	To provide knowledge about family caregivers experiences of a daycare activity for persons with dementia.	Qualitative. Semi-structured interviews.	7 relatives.	Both persons with dementia and their relatives benefits from the Care Farm programme, which facilitates activities that promote identity.
Shanley et al. (2011).	To describe the experiences and needs of family carers of people with end-stage dementia.	Qualitative. Semi-structured interviews.	15 carers, who had been carers of a relative with dementia.	The carers describe a wide range of experiences. They need to maintain their own health as well as respite or 'time out' from caregiving responsibilities. They valued psychosocial support in the form of acknowledgement of their role, help with difficult decisions, or just having an empathetic person to talk to. A carers' support group is also a source of support.
Stirling et al. (2010).	To explore the relationship between different types of carer service.	Mixed methods. Questionnaire. In-dept interviews.	20 community-dwelling pairs of dementia carers and people with dementia.	Felt needs are an important indicator of service need by carers of people with dementia. Dementia severity and carer stress were not directly linked to out-of-home respite or practical assistance received – a wide range of concerns led to resistance to, or refusal of, services.
Olsson et al. (2011).	To describe relatives' reflections on ICT devices in the daily care of persons with dementia.	Qualitative. Semi-structured interviews.	14 spouses experienced with the use of ICT.	The study describes the need for safety and security and highlights that ICT devices with the right functionality and used at the right time, can be useful in solving everyday problems.
Bakker et al. (2010).	To explore the experiences of a caregiver of a patient with early onset dementia and the needs of patient and caregiver.	Qualitative. A single case study.	1 spouse of a young person with dementia.	Needs of both the patient and caregiver were subject to change as the disease progressed. The caregiver needs support from one person throughout the course of the disease. Furthermore, the study points at needs related to early-onset of dementia can be different from those related to older people.
Rosa et al. (2010).	To isolate the needs expressed by caregivers.	Quantitative. Questionnaire.	112 participants.	The article points out many different needs of caregivers ranging from the need for information, medical needs, educational needs, needs related to emotional reactions and the need of developing effective care-to-patient communications skills.
Vaingankar et al. (2013).	To explore the experiences and challenges of informal caregivers.	Qualitative. Semi-structured interviews and focus group discussions.	64 caregivers.	The study identifies need for emotional and social support, information, support on finances, and for accessible and appropriate facilities for people with dementia.
Huis in het Veld et al. (2018).	To discuss by whom family caregivers want to be supported in self-management when managing changes in behavior and mood of relatives with dementia and to	Qualitative. Focus groups.	32 family caregivers of individuals with dementia.	Family caregivers need information about dementia, and tips and advice on managing changes in behavior and mood. A personal approach is essential and eHealth cannot replace personal contact entirely.

**Table 1.** Continued.

can experience a personal space that allows them to let off steam and to feel like they are not alone in recognising the experiences of other group members. Thus, peer groups are a source of social support that provides family caregivers with opportunities to learn new ways of coping (Melunsky et al., 2015). Similarities in age,

position in the family, disease progression and behavioural changes is considered important (McKechnie et al., 2014; O'Connell et al., 2014).

As the disease progresses, the need for professional support grows and professional caregivers enter the home and gradually establish joint responsibility

	consider eHealth a useful tool for self-management support.			
Lövenmark et al. (2018).	To describe spouse caregivers as subjects when living with and caring for their partners with dementia.	Qualitative. Semi-structured interviews.	Nine spouses whose partners suffered from dementia.	As spouses struggle with external and internal clashes as subjects, they therefore need to develop coping strategies. They also experience pronounced loneliness and a risk to their own health.
McKechnie et al. (2014).	To examine the impact of a UK based internet support forum.	Mixed methods. Questionnaire. Interview.	61 informal carers. Eight of the participants were interviewed.	The importance of similarity of participants in group forums is emphasized. A support forum can potentially reduce isolation and provide social support, and a possibility of learning to become a better carer, practical advice and information.
Melunsky et al. (2015).	To explore the experience of family carers attending the caring group, 'Remembering Yesterday Caring Today'.	Qualitative. Semi-structured interviews.	18 family carers.	Some carers experienced the intervention as entirely positive whereas others had more mixed feelings e.g. stress and guilt through not being able to implement newly acquired skills.
Macleod et al. (2017).	To examine the barriers and facilitators of service use among family caregivers of people with dementia.	Qualitative. Semi-structured interviews.	24 family caregivers.	The study reveals the need for ongoing information about available services and support, and some barriers for utilizing the in-home-care services are identified. Asking for help can be an embarrassing and an indication of not being capable of caring for the person with dementia. The study also describes poor quality or mistrust of the services.
Fjellström et al. (2010).	To examine how people living with persons with mild to moderate Alzheimer's disease perceived everyday life aspects of food choices, cooking and food-related work, and nutritional concerns.	Qualitative. Focus group interviews.	11 women and 6 men, living with a diagnosed partner.	Food related-work can be challenging for both experienced food providers and inexperienced food providers, and the caregivers feel the need to be good food providers as well as include food as part of the caring role.
Landmark et al. (2013).	To explore and describe relatives' experiences of people with dementia living at home and to reveal their needs for assistance and support.	Qualitative. Focus group interviews.	10 relatives who held the primary responsibility for a person with dementia.	The relatives experience a sense of powerlessness being in a situation that demands continuous presence. The burden of the relatives can be alleviated by proper assessment of the relatives' situation and individually tailored help.
Stokes et al. (2014).	To explore how caring partners understand and make sense of the diagnosis of dementia and how this affects their experiences of being caregivers.	Qualitative. Semi-structured interviews.	10 spouses of people with dementia.	The spouses need information about the disease and practical information about available health, social and financial support.
Ducharme et al. (2014).	To document the unmet support needs of family caregivers to persons with	Mixed methods. Structured interviews	32 spouses, sons or daughters who were	The caregivers had unmet support needs. They needed psycho-educational support to cope with the caregiver role. They

Table I. Continued.

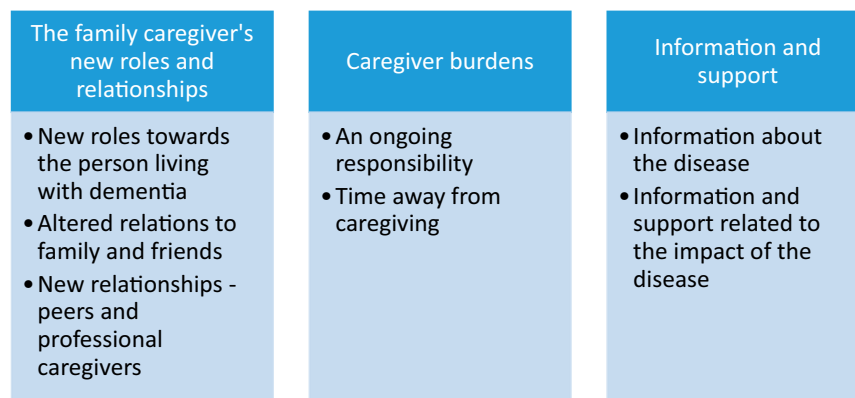
for taking care of the person with dementia. However, the professionals also need to be aware of the family caregiver's own needs (Storjord & Lykkeslet, 2017), and family caregivers value professionals who recognise the complexity of their responsibilities. It is emphasized that it is important for family caregivers to "feel they

were still seen as the primary caregiver and genuinely involved in decisions about care of the person with dementia" (Shanley et al., 2011, p. 332).

Family caregivers find it important that professionals relate to the person with dementia on a personal level and focus on the same goals as preferred by the

	early-onset dementia or a related cognitive disorder.	including open-ended questions.	primary caregivers for a person with dementia.	underscored the importance of timely support and interventions tailored to their needs instead of one-size-fits-all.
Rayment et al. (2019).	To explore the lived experience of informal caregivers supporting a person with dementia.	Qualitative study Photo-elicitation and in-depth semi-structured interviews.	Six individuals with lived experiences of being a caregiver of a person with dementia.	The caregiver's individual needs are often compromised due to their role as caregivers, and they are in need of focusing on activities for their own enjoyment. Having a place to meet and talk with other caregivers in a similar position provides emotional support.
Storjord & Lykkeslet (2017).	To explore the experience by spouses to persons living with dementia.	Qualitative study, in-depth interviews.	4 spouses living together with a person with dementia	The caregivers need care for the person with dementia who gradually becomes dependent. They also need care for themselves and they worry that the caregiving responsibilities will be too much one day, and that they have to give up.

**Table 1.** Continued.



**Figure 3.** The Thematic Structure.

person with dementia and the family caregiver. In this regard, trusting relationships are important for family caregivers to allow professionals to meet the needs of the person with dementia and of the family caregiver. They might worry whether the professionals can deliver the needed care to their relative (Macleod et al., 2017; Shanley et al., 2011). In addition to this, it also appears to have an impact on the family caregiver's relationship with the professionals, that there is a continuity within the staff, as they are concerned about frequent changes, which can be upsetting for the person with dementia (Macleod et al., 2017).

### Challenges and Needs Related to New Roles and Relationships

As the reciprocal relationship between the family caregiver and the person living with dementia gradually diminishes, the family caregiver needs to have social contacts outside the home. When living with a person with

dementia the family caregiver needs to be prepared for the challenges that will arise. They need to learn how to perform new, unknown care activities and how to handle difficult, somewhat awkward situations. When professional caregivers enter the home family caregivers need to be acknowledged in their efforts to do the best for their loved one, and they need to be actively involved in decisions about the person with dementia.

### Caregiver Burdens

#### *An Ongoing Responsibility*

Taking care of a person with dementia implies a full-time responsibility. The burden implies constant fear for safety and security of the person with dementia if, for example the person attempts to leave the home unaccompanied (Olsson et al., 2012). To relieve the ongoing dependency on the family caregiver, a study shows that "Assistive technology that enabled the person with dementia to become more independent and undertake



meaningful activities during the day, like mastering the TV remote control, was considered important” (Holthe et al., 2018, p. 758).

Family caregivers experience an overwhelming sense of responsibility in terms of dealing with e.g. medication (Rayment et al., 2019), feeding, and cooking, which for inexperienced food providers can be a major challenge (Fjellström et al., 2010). Also the financial costs of caregiving e.g. due to the loss of income can be of major concern (Flynn & Mulcahy, 2013) as well as an uncontrolled spending money by the person with dementia which can be challenging for the family caregiver to deal with (Johannessen et al., 2017).

### *Time Away From Caregiving*

In addition to the above mentioned burdens household chores and practical tasks, such as shopping or paperwork, can take up their extra time, leaving little time left for the family caregivers themselves (Pini et al., 2018; Shanley et al., 2011). Formal respite services or support from friends and family can generate valuable time away from caregiving responsibility and are by some seen as an opportunity to maintain their social network (Shanley et al., 2011; Strandli et al., 2016). However, the quality of respite services and the feeling that the person with dementia is safe and taken good care of can be of great importance in allowing the family caregivers to feel relaxed (Macleod et al., 2017; Pini et al., 2018; Shanley et al., 2011; Strandli et al., 2016). Lack of time away from caregiving affects the family caregiver’s well-being, stress level, and ability to care for the person with dementia (Ducharme et al., 2014; Macleod et al., 2017; Meyer et al., 2016; Rayment et al., 2019). Furthermore, they might find that asking for help is embarrassing or that it is an indication of them not being capable of caring for the person with dementia on their own (Macleod et al., 2017, p. 770).

Coping with the limbo of not knowing how one’s life situation will turn out in the long run can be tough as concerns about an unpredictable and unknown future are ongoing, just knowing that it will get worse (Storjord & Lykkeslet, 2017). Caregiver burdens may vary in form and intensity, but a common issue for family caregivers is that they feel full responsibility for carrying every kind of burden, regardless of the efforts of the professionals, and this responsibility will remain throughout the course of the disease. They do not have the option to refrain from caregiving, they are constantly in a position where they must balance between their own needs, and those of their relatives, which in general are prioritized (Quinn et al., 2015).

### *Challenges and Needs Related to Caregiver Burdens*

Because of the constant responsibility and pressure, family caregivers need to be aware of their own health and well-being. Therefore, they need respite time to manage stress and pursue their own interests in life. Nevertheless, spending time away from caregiving can be a great challenge. Paradoxically, it seems that arranging respite time might add to the amounts of burdens instead of relieving the burdens the family caregivers need a break from. In other words, burdens may obstruct having time away from burdens.

## **Information and Support**

### *Information About the Disease*

When a dementia disease enters the daily living, the family caregivers need a variety of information (Flynn & Mulcahy, 2013; Huis in het Veld et al., 2018; Peeters et al., 2010; Rosa et al., 2010; Steiner et al., 2016; Torp et al., 2008; Vaingankar et al., 2013). Many family caregivers feel unprepared and in great need of knowledge about the dementia disease and illness trajectory. They need to know what to expect at present and in the future. A study reveals that information about the “illness and the illness trajectory was of particular interest as it gave them a greater understanding of what they could reasonably expect of their spouse and they were also better prepared for what was likely to occur in the future” (Torp et al., 2008, p. 79).

Although the need for information about the disease is predominant, some studies also mention family caregivers who experienced an overload of information about the disease at times when they were not yet ready to receive it (Holthe et al., 2018; Huis in het Veld et al., 2018; Rayment et al., 2019). This indicates that the individual timing, of when information is delivered, is important and that family caregivers often prefer to get the specific information, when they need it (Huis in het Veld et al., 2018; Wawrziczny et al., 2016). Some caregivers explained that they preferred to only get information about the initial stages of the disease at the beginning of the disease trajectory and then wait with information about the final stages until their loved one faced the last stages (Killin et al., 2018). Meyer et al. (2016), on the other hand, indicate that some family caregivers consider that information about dementia should be provided at an early stage.

Overall, the needs of family caregivers concerning when to receive which kind of information seems best met using an individual approach, since the families are in different situations. Furthermore, some studies mention that family caregivers think that it is important to have one person providing the information as independently searching all over for information can be difficult

and confusing (Chan et al., 2010; Diehl-Schmid et al., 2013; Shanley et al., 2011).

### **Information and Support Related to the Impact of the Disease**

Apart from information about the dementia disease itself, family caregivers need support to develop effective carer-to-patient communication skills (Rosa et al., 2010) and to learn how to act towards and communicate patiently with the person with dementia (Kuhn, 1998). A key factor for benefiting from the information appears to be that it is provided in a way that helps the family caregiver feeling competent and in control of the situation. Consequently, providing the information and supporting new skills in a caring and non-judgmental way appears to be essential since dealing with an array of opinions and judgements may make caregivers feel unsettled (Huis in het Veld et al., 2018; Pini et al., 2018; Shanley et al., 2011).

The family caregivers also need information about legal and financial issues, as well as advice on how to submit applications for service (Ducharme et al., 2014; Johannessen et al., 2017; Macleod et al., 2017; Stokes et al., 2014). Furthermore, they need information about the transition to a nursing home and how to gain access to respite care (Shanley et al., 2011; Vaingankar et al., 2013) as well as how to manage their own stress (Steiner et al., 2016).

As social and emotional support is imperative for family caregivers, relatives, experienced professionals, and peers are important sources of emotional support (McKechnie et al., 2014; Rayment et al., 2019; Shanley et al., 2011; Torp et al., 2008). Some of the benefits of support are not to feel alone and the feeling of being understood through shared experience (McKechnie et al., 2014).

Technological solutions can represent another source of support, which some caregivers find helpful while others experience it as challenging. A study concludes that support “can be provided to some extent through eHealth, but this cannot replace personal contact entirely. Support must always be geared to the personal situation” (Huit in het Veld et al., 2018, p. 158).

The availability of an accessible resource person with knowledge about the dementia combined with experience to understand the family caregiver’s situation, and who can help them to navigate through available information, can be helpful (Shanley et al., 2011). The family caregivers want to have just one person who can provide all kinds of information and they need what Diehl-Schmid et al. (2013) call all-inclusive information packages. However, all-inclusive information packages do not mean one-size-fits-all standard information, as non-specific information can be perceived as unhelpful (Ducharme et al., 2014; Macleod et al., 2017).

### **Challenges and Needs Related to Information and Support**

Family caregivers need to learn new skills and knowledge to be able to manage to adapt to their new situation. They have an extensive need for information about dementia and about what kinds of support is available, as well as a need to receive various kinds of support. There is a need for information that is individually tailored that takes into account the circumstances within each family to ensure proper information and support without overloading the family caregiver.

### **Discussion**

Our study shows that the family caregivers’ burdens and subsequent needs are overwhelming, and they have to adapt to their circumstances and learn new skills in an extremely strained situation. An overall look at the findings in our review brings two perspectives for further discussion into focus. Firstly, the similarities and differences in the needs of family caregivers will be discussed in relation to other studies. Secondly, the study reveals that the family is placed in a key role as caregivers for people living with dementia, which entails an apparent imbalance between the family caregiver’s burdens and needs and society’s general expectations toward caregivers. This discrepancy between the needs of family caregivers and existing dementia care policies will be discussed in the light of Tönnies’ (2002) concepts of *Gemeinschaft* and *Gesellschaft*.

### **Similarities and Differences in the Needs of Family Caregivers**

At first glance, the lives of family caregivers appear to be similar but with a closer look, individual differences become important regarding how to understand and support family caregivers. People living with dementia go through all-encompassing changes in cognitive skills, psychological state and behaviour that permeate the lives of family caregivers in many similar ways. Relationships are broken and the family caregivers have overwhelming burdens with almost no time to spend on themselves. They neglect their own needs and they have lost a beloved person they once knew. In that light, it could be tempting to perceive family caregivers as a homogenous group with the same needs for support.

However, family caregivers comprise of many different kinds of individuals, each living in distinctive contexts. People living with dementia also differ from one another, as dementia is an umbrella term for many diseases developing individually (World Health Organization, 2020). Consequently, although family caregivers at first may appear to look alike, understanding each caregiver’s

individual needs and grasping how to support those needs on an individual basis is crucial (Bangerter et al., 2019; Brodaty & Donkin, 2009; Kaschowitz & Brandt, 2017). The apparent sameness and underlying differences between family caregivers spans the themes in the review, and their individual differences prepare the ground for a discussion of how to support them individually. A study of family caregivers' use of services made available for them implied that "caregiver service use is related to caregiver characteristics" (Martindale-Adams et al., 2016, p. 1053), which supports the notion of adapting the support to each individual caregiver. A review of the effects of social support interventions shows that the effects are inconsistent, i.e. what works for some of the caregivers, does not work for others (Dam et al., 2016). Another review (Farina et al., 2017) emphasises that supporting the caregivers' own health, their independence, and their possibilities to pursue their own interests is the most important factor in sustaining their quality of life. A study on developing online support for family caregivers (Davies et al., 2019) underlines the need to feel in control of the care situation. The above mentioned studies indicate that not all family caregivers benefit from the same kind of support, which is why the support should be customised to meet the individual needs of caregivers.

### *The Discrepancy Between Needs and Care Policies*

Expecting family caregivers to lift their burdens without buckling under to become the next in line for help is almost unrealistic. Accordingly, Martindale-Adams et al. (2016) suggested that the costs society incurs should cover the services family caregivers use for themselves as receiving support from society appears to be crucial for their well-being. The unclear mixture of societal and family obligations is a well-known topic in many areas, where society, together with the family, is supposed to take care of family members in need of support. Our review shows that the two perspectives mix in modern society, with society gradually taking over some traditional family obligations, only to draw back again in some cases, leaving more responsibilities to the family.

The principles of *Gemeinschaft* and *Gesellschaft* that Tönnies (2002) introduced in 1887 may contribute to understand the upheaval family caregivers' experience. Tönnies defined *Gemeinschaft* as the way in which relationships functioned in a traditional family-based society, where the individual was subordinate to the family and had unlimited obligations to help other family members. *Gesellschaft* described the sense of belonging to a new, industrial society, where relationships between people are temporary, serve the rational pursuit of self-interest, and are based on contracts, laws, and specific regulations, with the obligations of the involved parties clearly described. Tönnies' concepts still apply in

modern society (Asplund, 1991) and are intertwined in present-day society. This is the case, for instance, when society places older people in professional 24-hour care, the spirit of *Gemeinschaft* underlying society's assumption of the familial role of providing care, love, and support. The 24-hour care setting, however, is pure *Gesellschaft*, with professionals exchanging their services for money under explicit conditions regulated by rules and laws, resulting in *Gemeinschaft* content in a *Gesellschaft* setting (Bulmer, 2015).

Family caregivers likewise try to meet *Gemeinschaft* qualities, but the *Gesellschaft* settings of modern society leave family caregivers with inadequate conditions for meeting the boundless *Gemeinschaft* obligations, as people live separately minding their own businesses at the same time as people live longer and as more people live with dementia. For family caregivers to carry their burden without buckling under, an extensive, official *Gesellschaft* system is required that provides support from society, but this is where problems arise. The rules and regulations that support *Gesellschaft* involve treating everyone in the same way, but as our review has indicated, family caregivers should not be treated as a homogenous group in a standardised way. Each caregiver is different, operating under the unique conditions of their family's *Gemeinschaft*, which means it is not easy to provide tailored *Gemeinschaft* support in standardised *Gesellschaft* settings.

### **Conclusion**

Becoming a family caregiver to a person living with dementia involves entering unknown territory. The family caregiver faces a range of new tasks and challenges as the dementia disease progresses. Taking a full-time responsibility to care for a person living with dementia is a burdensome task. Gradually, the family situation changes, often leaving the family caregiver more and more socially isolated, coupled with the sorrow of losing perhaps the person they are closest to in life. Managing this situation alone can be overwhelming. Having full-time responsibility for the person living with dementia often leaves caregivers with no energy to take care of their own needs, which has implications for their own health and well-being. The process of becoming a family caregiver to a person with dementia entails a range of needs. It spans from the need for social contact with people in a similar situation, for knowledge about the dementia disease and its consequences, to a need for support in daily life in terms of care activities and in receiving help to provide some respite for caregivers to allow them to pursue self-care. Since social norms and political policies are often embedded with the expectation that the family is the primary caregiver to people living with dementia, society must also support family caregivers in successfully executing that care.



## Implications for Practice

The revealed problems in modern society's unclear mixing of *Gemeinschaft* and *Gesellschaft* obligations need to be addressed in their own context to find the right balance between the family caregivers' obligations and those of society. Thus, the study points to this essential challenge for both social workers, health care professionals and politicians to deal with in the future. The study focuses on family caregivers who live together with a person with dementia. Relatives to a person living with dementia who lives alone or in a nursing home may encounter different challenges and needs which call for further research. We recommend further research on challenges and needs experienced by family caregivers seen in a broader societal context with the consideration of how the societal context intersects or implies the well-being and situation of family caregivers and people living with dementia.

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