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## Caring for a home-dwelling older parent with mental health problems: a narrative analysis of family caregivers' experiences

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### ABSTRACT

**Purpose:** To gain knowledge regarding family caregivers of home-dwelling older adults with mental health problems and the meaning-making of the caregiver's role.

**Design:** An explorative qualitative study involving narrative analysis.

**Methods:** Semi-structured individual interviews were conducted among eight adult children. Interview data were analysed using narrative analysis. The reporting adhered to consolidated criteria for reporting qualitative studies.

**Results:** Each participant narrated unique and nuanced stories of the caregiver role, but their stories also revealed prominent themes across participants' experiences and meaning-making. The analysis revealed three themes: family relationships through a long life, a demanding and difficult caregiver role, and reconstructing the caregiver's role by leaving the responsibility to healthcare services.

**Conclusion:** Family caregivers experienced the role as purposeful and demanding. Mostly, psychological reactions to behaviour symptoms and duration of caregiving were considered difficult and demanding. They described that they lacked knowledge of the illness and how to perform care. Sharing care responsibility with healthcare services had the potential to ease family caregivers' burden. However, based on a long life as caregivers, some experienced difficulties when reconstructing and adjusting the role to their life situation.

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### KEYWORDS

Caregivers; narrative analysis; home nursing; older adults; mental health problems



### Introduction


An increase in the ageing population leads to an increase in the prevalence of people with chronic illnesses or disabilities. Regarding older adults over 60 years, the empirical findings on the prevalence of mental health problems are heterogeneous, and are reportedly 15% (World Health Organization, 2017) to 23% (Andreas et al., 2017). Older adults with mental health problems are likely to experience physical comorbidities, and therefore, they may have complex needs (Soysal et al., 2017). The ageing population is a key policy issue worldwide owing to the expectations of increasing cost of care and limited availability of services (World Health Organization, 2015). In this context, family members play a significant role as caregivers, and their contribution is described as an essential care resource in the field of elderly care (Friedman et al., 2019) and for older adults with mental health problems (Wells et al., 2020). Family caregivers are considered a resource for healthcare services and have a central role in the lives of older care recipients. Demographical changes may also bring the family members' contribution as caregivers

to the forefront. Several studies have documented that caregiving may result in poor health of the caregiving family member (Behm et al., 2018; Pinquart & Sörensen, 2003; Schulz et al., 2020). This study aimed to explore family caregivers' experiences of caring for a home-dwelling older adult with mental health problems. Here, we have used the term family caregiver, which refers to an unpaid informal caregiver, most often a family member.

### Background

A variety of changing social forces that originated decades ago have helped shape the life-course of older adults with mental health problems and their families. The changes included the introduction of medication, community living, social politics facilitating social integration, and the civil rights movement (Cook et al., 1997). In addition, the policy of deinstitutionalization and the concept of ageing in place have led to a shift in the care patterns of older adults with mental health problems, where the intention is that older adults should live and receive support at

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home (World Health Organization, 2015). Consequently, older adults and their families have the opportunity to interact more closely with each other in the community. However, we must assume that a significant number of older adults with mental health problems were not institutionalized before the shift in care paradigms.

Family members' central role as caregivers has gained the attention of researchers for many decades. A major field of research has focused on the negative consequences of taking on the caring role for a family member (Jeon, 2003), referred to as the concept of burden. According to Bastawrous's (2013) critical discussion, the concept of burden is complex and multi-dimensional and therefore, no single definition exists. However, distinguishing between objective and subjective burden can help elucidate and capture the different aspects of the care burden (Bastawrous, 2013). The objective burden is often referred to as the physical or instrumental provision of aid to the care recipient, while the subjective burden is the family members' psychological reactions to the objective burden, such as frustration, guilt, and depression. Several predictors of stress or burden have been identified: the family caregiver's own health, the nature and intensity of care provided, and the extent of social and professional support (Lloyd et al., 2016; Pinguart & Sörensen, 2003; Schulz et al., 2020). Caring patterns and responses to caregiving may differ between men and women, and between spouses and other family members (Friedemann & Buckwalter, 2014; Pinguart & Sörensen, 2006). The older adults' illness trajectory may also affect family caregivers' experiences of the role. The results from a quantitative study have suggested that family caregivers of persons with mental health problems experience poorer health and mental health outcome compared to other caregiver groups (Broady & Stone, 2015). Especially family caregivers of older adults with multi-morbidity and a deteriorating mental state (such as depression and changed behaviour) are at a high risk of burden (Krevers et al., 2020).

The perspective of burden has been criticized for not offering a nuanced picture of the role of caregiving as it only focuses on the negative consequences. Contrarily, studies have revealed the meaningful and positive aspects of the caring role for family members, like companionship with the care recipient and a sense of purpose in life (Chung et al., 2017; Lloyd et al., 2016; Ratcliffe et al., 2013; van Campen et al., 2013).

Despite the extensive research in family caregiving, there has been a lack of consensus as to why caregiving is a difficult experience that has serious negative consequences for some family members while others who have the same responsibility are able to cope well (Montgomery & Kosloski, 2013). In

this context, healthcare professionals could play a significant role in providing support to family caregivers to help them cope and sustain in their caregiver role. Psychoeducation, emotional support, practical help, respite, and sharing responsibility are examples of interventions that have shown effect when supporting family caregivers (Anker-Hansen et al., 2018; Schulz et al., 2020). Notably, the majority of studies on caregivers' needs and studies on interventions have focused on dementia, while other conditions common in late life are under-represented (Young et al., 2020; Zygouri et al., 2021). However, it is to be noted that interventions are most effective when tailored to the specific needs of the individual (Montgomery & Kosloski, 2013; Schulz et al., 2020).

Anker-Hansen et al. (2018) identified a gap in the current knowledge regarding what family caregivers of older adults living at home need from home care services. Notably, only a few qualitative studies explore the needs of family caregivers of older adults with mental health problems. Findings from the systematic review indicated that family caregivers primarily have the same needs for support, regardless of the older adults' health conditions (Anker-Hansen et al., 2018). However, it is argued that family caregiving must be placed within a historical context, because the bonds of affection and reciprocity that sustain caregiving are rooted in past relationships (Given et al., 2013). Family members' history of interaction may complicate the caregiving process. For example, adults, who as children had a parent with mental health problems, have described the relationship with their parent as being difficult because the illness negatively affected the parent's behaviour and parental role (Källquist & Salzman-Erikson, 2019; Murphy et al., 2011). The above studies showed that as children, they took on both practical and supporting aspects of the parenting role. Consequently, family caregivers of older adults with mental health problems may have lived most of their lives as caregivers. Knowledge of family caregivers' experiences of a long life as a caregiver can guide healthcare professionals in tailoring support to their specific needs.

Qualitative studies indicate that family caregivers of older persons with mental health problems experience the caregiver role as emotionally, physically, socially, and financially demanding (McCann et al., 2015). Furthermore, some family caregivers experienced their role as undesirable because it overshadowed the adult child-parent relationship (Anker-Hansen et al., 2019; McCann et al., 2015). Due to limited knowledge in the field, the present study used a qualitative approach to explore how family caregivers of home-dwelling older adults with mental health problems experience and make meaning of the caregiver role.

The knowledge gained from this study would provide healthcare professionals with a better understanding of how the dynamic nature of caring through a long life as a caregiver influences caregivers' experiences and needs. Furthermore, in-depth knowledge could guide further research, and the development and implementation of individual intervention to promote family caregivers of older adults with mental health problems well-being and facilitate family care.

## Methods

We conducted an explorative qualitative study involving narrative analysis. We chose a narrative approach to address the research question "How do family caregivers of home-dwelling older adults with mental health problems experience and make sense of the caregiving role?" A narrative approach was appraised to be appropriate because we wanted to tell stories of individual experiences embedded in personal, social, and historical contexts (Creswell & Poth, 2018). We defined narrative as an extended topic-centred and temporally ordered unit of speech (Riessman, 2008). Through storytelling, individuals can impose meaningful patterns on otherwise disconnected experiences and make sense of the past and the future (Bamberg, 2012; Riessman, 2008; Salmon & Riessman, 2008; Somers, 1994). In addition, the shaping of narratives serves the purpose of passing along culturally shared beliefs and values (Bamberg, 2012; Polkinghorne, 1988; Riessman, 2008). Broadly, this study was grounded in the constructionist perspective, which flows from the interpretive tradition (Creswell & Poth, 2018). The stories are understood as the participants' expression of their lived and told experiences, shaped by the social context within which they are expressed (Riessman, 2008). In sum, the narrative approach gave us the opportunity to explore the family caregiver's effort to understand, interpret, and begin to construct meaning of their complex experiences as a caregiver through their long life, in the context of their cultural values and beliefs.

## Setting

The present study was conducted in a rural region of western Norway, which is sparsely populated. In Norway, like the other Nordic countries, the welfare state is characterized by a universal and comprehensive public care service, where providing care for older adults is a public responsibility (Esping-Andersen, 2013; Montoro-Gurich & Garcia-Vivar, 2019). Home-dwelling older adults with mental health problems are provided for by community-based services, and many of the community-based services are

categorized as home care and mental healthcare. Due to somatic comorbidity, home-dwelling older adults with mental health problems are mainly cared for by home care services (McCormack & Skatvedt, 2017; Skatvedt et al., 2015).

Although providing care is a public responsibility in Norway, it is estimated that family caregivers provide almost as much care work as paid employees (Hjemås et al., 2019). Over the last few decades, family members' crucial contribution as caregivers has been politically recognized (Ministry of Health and Care Services, 2013). The focus has been on healthcare professionals facilitating family care by involving and supporting family caregivers. In addition, community-based services were given a legal responsibility to support family caregivers with burdensome care tasks in 2017 (The Municipal Health and Care Services Act, 2011).

## Study participants

The selection of participants for the interviews was guided by purposive sampling, and the inclusion criteria were as follows: (a) unpaid informal caregiver of a home-dwelling older adult (65+) with mental health problems and (b) the older adult receiving home care services or/and mental healthcare services. Caregiving included both instrumental and emotional assistance, and there were no criteria for the extent of assistance provided by the caregivers. This study included family caregivers of older adults with mental health problems such as depression, bipolar disorder, schizophrenia, and anxiety disorders. We excluded degenerative illnesses, such as Alzheimer's disease, Huntington's chorea, and Lewy body dementia.

The health and social care service managers, who knew the older adults with mental health problems, assisted with identifying participants who met the inclusion criteria and with the recruitment process by distributing invitation letters to family caregivers. The recruitment of participants was challenging; consequently, we included two more municipalities, making it a total of five, and extended the period for data collection. An unknown number of family caregivers were contacted, but only a few agreed to participate. According to the managers who distributed the invitation letter, the reasons for not accepting were as follows: being too exhausted or did not define themselves as caregivers of an older adult with mental health problems. Eight adult children, five sons and three daughters, accepted the invitation. It is worth noting that spouses/partners also were invited to participate in the study, but no one accepted.

## Data collection

We collected data through single in-depth interviews and field notes with the intention of generating

detailed accounts as recommended in narrative inquiry literature (Creswell & Poth, 2018; Holstein & Gubrium, 2012; Riessman, 2008). Based on previous studies on family caregivers' experiences and needs, we developed a semi-structured interview guide with open-ended questions. Following Kallio et al. (2016) procedure, the interview guide was tested in a pilot interview with a woman who had cared for a parent with mental health problems for several years. After testing, we made minor changes to the interview guide's structure and formulated more open-ended questions to invite the participants to tell their personal stories. The questions in the interview guide were as follows: Can you tell me about yourself and your experiences of being a caregiver? How do you experience your situation today, have there been any changes? Can you tell me about episodes where you have experienced the caregiver role as positive/negative? Additionally, participants were asked about their age, marital status, relationship with the care recipient, care tasks, time spent on care tasks, and duration of caregiving. The first author conducted the interviews, in undisturbed surroundings, according to the participants' wishes (participant's home and workplace, interviewer's workplace). We collected data from August 2018 to March 2019, and each interview lasted between 1 to 2 hours. Field notes were documented during and after each interview. We started the systematic analysis when all interviews were completed.

## Analysis

We chose the analytic framework inspired by Riessman (2008) (dialogic/performance analysis) and Stephens and Breheny (2013) (integrated approach to interpreting stories). See Table I for a presentation of the analytical framework. This analytical framework was chosen to gain an understanding of the influences of past experiences, social life, and identity, which were assumed to be interesting dimensions of how participants experienced their caregiver role. Inspired by Riessman (2008), we identified the structural features of the stories and the thematic similarities in the stories told. Stephens and Breheny's (2013) integrated approach to interpreting stories

provided a framework for thinking about each level of the narratives in turn and then on how the levels worked together to understand how personal stories are situated within broader narrative structures in society.

The interviews were audio-taped, and the first author transcribed the interviews, reproducing all spoken words and sounds, including laughter, crying, hesitations, pauses, and strong emphases. In the presentation of findings, we removed words and sounds that were not essential for understanding the overall meaning of the quotes. First, we re-read the transcripts several times. Then the individual stories were analysed separately as a unit, starting with an inductive thematic narrative analysis focusing on determining the characteristic content within each story. We used the software program NVivo (NVivo, 2018) to organize and code the material relevant to the research question. In this coding process, we preserved sequences and details contained in long sequences. Themes and quotes were selected and woven into a descriptive narrative that represented each person's story.

In the next phases of the analysis, we analysed the data set as a whole, paying attention to similarities and differences in participants' stories. We identified common thematic elements across participants' stories and selected particular cases to illustrate general patterns and variations across all cases. Further, the analysis paid attention to form and organization (structural focus), how the narratives were organized, and how it was told to aid in the interpretation of how participants used the speech to construct themselves and their stories.

Further, the analysis focused on understanding the interview situation and the researcher's role as a co-constructor of the stories. All three authors are Norwegian females, with a background as nurses, as part of our framework of understanding in the interview setting and the analysis. The second and third authors are experienced, qualitative researchers. The first author has some experience in qualitative research, but no previous experience with the patient group. The first author performed the interviews, and the conversation drew upon shared cultural narratives about values and norms regarding family relationships

**Table I.** Analytical framework.

Levels of narrative	
Personal stories	What is this story about? What is distinctive in the story? How is the family caregiver's identity described? How are relationships described? How does the participant describe their position? Are there any conflicts or dilemmas? How are the stories told and put together?
Interpersonal	Who is the utterance directed to? And for what purpose? How do interviewer's questions enter the story production?
Public narratives	Have larger social structures influenced the participants individual consciousness and identity? What public narrative have participants drawn upon to provide subject position or moral identity? How are stories shaped to fit with or to justify contradictions with dominant narratives?

Inspired by Riessman (2008) (dialogic/performance analysis), and Stephens and Breheny (2013) (integrated approach to interpreting stories).

and caregiving. Field notes were incorporated into the analysis as to how the researcher, setting, and social circumstances had influenced the production of the narrative. During the interviews, participants expressed experiencing the interview as a safe setting. Nevertheless, some of the participants experienced dilemmas when sharing their own stories. The dilemma arose because participants' stories were closely related to their parents' and siblings' stories. The concern of sharing another family member's story may have had an influence on the stories told; for example, some used vague terms when talking about the difficult experiences in their lives.

### Ethical considerations

The research project was approved by the Norwegian Centre for Research Data (approval number 58,265). Ethical considerations consistently followed the principles of the Declaration of Helsinki (WMA, 2018). We obtained written informed consent from each participant and informed them that they could withdraw at any time. We also intended to obtain written consent from care recipients if the circumstances allowed it; however, this was not possible because we did not meet with any of the older care recipients. Confidentiality regarding the collected data was safeguarded through storage on a computer in double password-protected files. While reporting the findings, all data were anonymized to protect the personal details of the participants or persons not present, such as the care recipients and other family members. In addition, the interviews focused on the story of the

family caregiver and did not ask for information about persons not present. In reporting the study, consolidated criteria for reporting qualitative studies (Tong, Sainsbury, & Craig, 2007) served as a guideline to promote transparency (See File 1).

### Results

The participants in this study were five adult sons and three daughters caring for a home-dwelling older parent with a mental health problem (age 65–85). Characteristics of the family caregivers and their relationship to the older adult are provided in Table II. The participants provided various care tasks throughout their caregiving career, and the extent of their contribution varied according to the older adults fluctuating needs. Their care currently included social and emotional support, daily telephone check-up calls, practical help, managing finances, and organized support from healthcare services when the older parent's health situation had deteriorated (see Table III). Only the women described that they rarely helped with activities of daily living, such as bathing and dressing. All the participants were in full-time or part-time employment. Six participants were married, seven had children, and four also had grandchildren. Four participants reported that they received support from siblings in their caregiver role. All participants stated that they had family, especially spouses, and friends, who gave them emotional and practical support, which sustained them in the role. All participants were Norwegian.

**Table II.** Characteristic of participants.

Number of family caregivers by the given characteristic	Participants = 8
<b>Relationship to the older adult</b>	
Daughters	3
Sons	5
<b>Age</b>	
40–50	2
51–60	3
61–65	3
<b>Life situation</b>	
With spouse	6
Alone	2
<b>Duration of caregiving</b>	
10–20 years	4
20–30 years	2
> 30 years	2

**Table III.** Description of caregiving tasks.

Number of participants who provide the given care	Participants = 8
Social and emotional support	8
Organizing and coordinating professional care	8
Practical help in the home	6
Managing finances	6
Telephone check-up calls	6
Transportation to medical appointments	7
Personal care tasks (bathing, dressing)	3

Although participants cared for older parents with various mental health problems, their unique and nuanced stories had common themes. The prominent themes across participants' experiences and meaning-making in the caregiver role were family relationships through a long life, the difficult and demanding role of a caregiver, and reconstructing the caregiver's role by leaving the responsibility to healthcare services.

### Family relationships through a long life

Four of the adult children grew up with a mother experiencing mental health problems, whereas other participants' parents fell ill 10 to 15 years ago. Participants' different experiences related to the length of their caregiver trajectory contributed to different stories about growing up and their relationship with their parents. However, all participants revealed common challenges in the demanding caregiving role and reconstruction of the role. Common to participants' narratives of being a family caregiver were stories of a long life together with their parents. They organized their narratives in two storylines, one being the story of the child-parent relationship and the other regarding their experiences as caregivers to their parents with mental health problems. In the narratives of their relationship with their mother or father, all participants emphasized that they felt affection and attachment towards their parents, and a long life together entailed good memories. The participants were concerned about presenting their parents as caring, kind, helpful, and resourceful. The interviewer's research interests and questions contributed to participants paying the most attention to their storyline as a caregiver, which we will account for further in the result section.

Woven throughout all participants' narratives were stories of feeling sorry for their parents and having a desire to help them, which they linked to the child-parent relationship. Jacob, a man in his forties, cared for his father who experienced mental health problems in old age. Jacob described how he wanted to help his father, like how his father had cared for him when he was little. He believed that owing to his role as a son, he had a responsibility to provide care. Jacob described, "The care tasks I provide or the things I do to improve my father's everyday life are tasks I want to do. It is your role as a son or a family member, so you have a responsibility. I would almost say that the role has reversed, he made sure I had a good childhood, and now it is my responsibility."

John narrated a different story of his childhood and the child-parent relationship. He grew up with a mother experiencing mental health problems, and during times when his mother's mental health was worse, he experienced a lack of parental support and

insecurity regarding his relationship with his parents. When looking back on life in his twenties, he recalls the experiences of worrying about his parents' well-being, especially his father's, because he was aware that they were both struggling and needed his help. To be able to support them, John chose to live close to his parents. He explained his choice of being a caregiver by referring to the child-parent relationship, "but of course, she is my mother anyway. So I try to help as best I can." John is now in his sixties and has been a caregiver most of his life. He expressed that providing care has been valuable for himself and his parents through statements such as "I'm sure they would have been worse off without my help."

Participants who grew up with a mother experiencing mental health problems told stories of how a long life together had affected them over the course of their life. George is now in his forties, and he said that learning about his mother's illness was a turning point in his life. As a young man, he was insecure about whether his mother's behaviour was a result of something he had done wrong. George described that the feeling of insecurity negatively affected his view of himself and his relationship with his mother. After learning about the illness, he was able to distinguish between his mother's actual self and when she experienced delusions. George noted, "When I got knowledge of the diagnosis, it helped a lot in terms of distancing myself mentally because then I knew it was the disease, every time there was something ... vicious words and insulting comments. It was not my mother who spoke, but it was the disease that had taken over my mother, so when she was done with that part and came back to the part of being a mother, it was fine." Although George described that knowing about the illness was essential for him to take on the role as caregiver, he emphasized that mental health problems affect the whole family, and those experiences had made him vulnerable.

Emma's narrative of living with a mother experiencing mental health problems entailed stories of keeping the illness a secret and close family ties. Emma told stories about how the family protected and supported each other and how they mostly managed the situation alone. She placed her father as the hero in her story and gave him credit for the fact that she and her siblings had a good life. Emma expressed how her mother's illness and the family's suffering had been kept a secret. "It has become evident in recent years that my father, until he died, had been a huge support for Mum. He helped and protected her. Very few knew how mentally ill my mum had been. It has been kept a secret." Later in the interview, Emma reflected on her own role as a caregiver and realized that she had taken over her father's role. "We have been there all the time to clean the house because we wanted to protect her. The neighbours could not see how dirty it

was. It bothers me a lot that I have to go home to clean the kitchen because maybe the neighbours will come to visit. So, in a way, I continued where my father had left off. He has cleaned and hidden, and I have continued."

### The difficult and demanding role of a caregiver

Common to all participants' stories were the experiences of a difficult and demanding role of a caregiver. In unique ways, the experiences of burden were linked to the duration of the caregiver's responsibility, their psychological reactions to behaviour caused by the mental health problems, and their lack of knowledge regarding mental health problems and how to give care.

Anna has been caring for her mother for nearly 30 years by providing practical and emotional support. She described being a caregiver as both meaningful and demanding. The caregiver's role has given her joy, but in other periods it has been a burden. Anna described, "I feel that when I am not exhausted, it is very nice to be able to give care. I feel that I do not do everything out of conscience. I do it because I want to give. When I get tired, I forget, but it (caregiving) can give me a lot of joy, or it feels good to give." When Anna reflected on why she thought the caregiver's role to be demanding, she referred to many years spending time worrying over her mother's situation, planning for how she could help and processing her own psychological reactions. Especially when her mother's mental health worsened, she recalled the time and energy required to deal with her own feelings of anger, frustration, and despair associated with her mother's personality changes. For many years she had to deal with what she experienced as unreasonable demands from her mother while fulfilling her role as a caregiver, something she described as "pressure."

Researcher: "Can you tell me about your experience when you are exposed to such pressure?" Anna: "I can feel really bad. I feel that I tolerated it less and less. It can take a whole day before I feel completely at ease again, so to speak. It is very tiring."

Caregiver's role was particularly demanding when taking on an unwanted care responsibility. While Anna experienced unreasonable demands, Sara told the story of how an unwanted care responsibility arose when her mother did not consent to the treatment provided by formal healthcare services. Sara noted, "Had she given her consent to receiving treatment. then it would have been okay, a little easier. But when she did not want to, the doctors were powerless, and we, as a family, were just as powerless. We wanted the best for her." When compulsory admission for treatment was not a possibility, Sara took on an unwanted care responsibility involving motivating,

persuading, and pressuring her mother to receive treatment and take her medication. Although Sara viewed herself as an important contributor to the recovery of her mother's mental health, she felt guilty because she was so hard on her mother in situations where her mother refused treatment. Sara believed that her guilt had led her to take on a greater care responsibility than she perceived she should. Especially when care responsibilities had taken precedence over responsibilities as an employee, a mother, grandmother, and friend.

Furthermore, the participants described that they experienced a one-sided relationship. Owing to the illness, the parent could not contribute much to the relationship with their adult children. David provided social and practical support to his father. He experienced the caregiving role as demanding at times when his father gave little in return. David referred to the caregiver role as a "job," and he described the one-sided relationship as follows: "Sometimes, it is difficult to be a family caregiver, when I visit, and I have to keep the conversation going, and there is no response or just 'yes' and 'no.' So, it is a demanding task when you give and do not get anything in return." Later in the interview, David told the story of how his father's behaviour had changed to be more positive and responsive in the relationship. David noted how these changes had influenced his perception of the caregiver's role "So, it is a bit easier to be a caregiver when you receive more feedback."

On the contrary, Emma recounted her ambivalent feelings when her mother changed her behaviour in recent years and started to show affection and gratitude towards her. In her childhood, Emma experienced a mother who did not provide her with emotional or physical care. Therefore, she did not know how to interpret the changes in their relationship, and she became uncertain of what the changes meant. "Why is she doing this? Is it because I should have a bad conscience? Or is it because she wants to give me a signal that she needs me more than ever before? I thought it was tough when my mom suddenly started to tell me that she loved me and started to hug me."

Another aspect of participants' narratives of a difficult and demanding caregiver role were stories about not having the necessary knowledge about the illness and how to perform care tasks. Lack of knowledge led to feelings of insecurity in the caregiver role; specifically, they were afraid of doing or saying something wrong that could potentially worsen the parents' condition. Jacob described a sense of insecurity in the caregiver's role because he had no previous experiences or professional background that helped him understand his father's situation. He expressed his lack of knowledge of mental health problems and treatment and his insecurity in how to support his father with statements such as, "I do not know



how to talk to a person who wants to die.” Jacob said that his lack of knowledge had contributed to him reacting with irritation to his father’s symptoms, and he believed his irritation had led to his father becoming increasingly frustrated. Another family caregiver told a similar story. Peter described how he and his mother experienced situations differently, resulting in him setting boundaries for his contribution as a caregiver. However, he was also afraid of saying something which could deteriorate his mother’s mental health. Peter expressed his insecurity, “There was a time I was uncertain of what was right and wrong. I was so strict. Had I made it (his mother’s mental health) worse? Had I said too much? Had I destroyed something that the others had built up?”

### **Reconstructing the caregiver’s role by leaving the responsibility to healthcare services**

Based on participants’ narratives of a demanding caregiver role and changes in their older parents’ health condition, including somatic comorbidity, they all wanted less care responsibility. With time, as the parents grew older, the elderly health service became available, which gave the participants an opportunity to share responsibility and change their caring role. Leaving more care responsibility to healthcare services required reconstruction of the caregiver role. Even though participants wanted less care responsibility, they experienced transitioning to a new role as a long-lasting and challenging process.

John had been caring for his mother for almost forty years. Recently, his parents moved into a care home with increased support from home nursing, which has given John the opportunity to put aside the feeling of care responsibility.

John: “I am happy with the way things are. I actually do not want to be called (from the home nursing). My mother had fallen down some time ago, but we did not know until a week later, it was perfectly fine. I think it was perfectly fine. It is awful to say.”

Interviewer: “No, you have left the responsibility.”

John: “Yes, but if this had been some time ago, I would have worried about it. I have come to the point that I have left the responsibility to them (home care nursing), and I think it is all right.”

John described how he reconstructed the caregiver role by distancing himself from the care responsibility and trying to go back to his role as a son. He noted,

“Now I have chosen not to ask questions because it is the responsibility of home care nursing. Now I am more of a son who comes to visit and helps if there are things they need, for example, shopping. I try not to get involved in anything else, but still, I see things and hear, but I try to keep a distance, and I think I can make it work.” The time perspective was a key factor in John’s case regarding his transition to a new caregiver role with less care responsibility. The time perspective emerged through descriptions of how past experiences through a long life as a caregiver had enabled John to develop the new role he had at present.

The time perspective is also evident in Jacob’s story of his process of accepting his own prerequisite for being a caregiver and finding a balance between caring for his father and caring for himself. In the past, Jacob experienced guilt because he gave little of his time to his father as he lived at a great distance. Feelings of guilt led to him sleeping badly at night, which negatively impacted his health. Now, Jacob is satisfied with his contribution as a caregiver. He explained, “I think the answer for me is that I have been cynical, I have learned to accept the facts, I have learned to accept my own possibilities and limitations, how I can contribute and what I cannot do.”

Not all the participants had reconstructed the caregiver role in such a way that they experienced practical and emotional relief. Anna described feeling exhausted, and the caregiver role was too consuming, with little time for other activities. She wanted to reduce the time spent on caregiving tasks but found it difficult. Anna described herself as a conscientious person, and she experienced a strong commitment to her mother. “I feel responsible for her well-being. Then it comes to this bond between my mother and me, a feeling of great responsibility for her well-being. It has to do with her illness, because I cannot understand ... I do not feel such a great responsibility for anyone else, not even my kids.” Furthermore, Anna explained that it was difficult to leave care responsibility to healthcare service, even though her mother had moved to a care home, because her mother did not want her to be less involved. According to Anna, her mother had been dependent on her support for 30 years, and now she preferred help from the family instead of healthcare services. Anna expressed, “It is not just now, it is not just these last two years, or let us say the last eight years, but it is about many years, and that may be the reason why it is a little harder to let go, because she does not want me to let go. She does not want me to let go, so I have to make that decision.”

Emma also perceived herself as a caring person with a central role in her mother’s life. She wanted to be less involved in caregiving, but she did not know how. Even though her mother received help

from home care nursing, she kept asking for Emma's attention and contribution. She noted, "Maybe we could stay at a distance and leave the care responsibility to home care nursing. But as long as she can use the phone and call us for everything, it does not work, then we have to take away her phone, and that is the only joy she has in her everyday life."

## Discussion

This study aimed to explore the narratives of family caregivers of home-dwelling older adults with mental health problems. Our analysis showed that all participants wanted to provide care to their parents owing to the family relationship; additionally, the caring made them feel more satisfied. In their stories, the participants position themselves as important care providers in their parents' lives, describing that their old parents were dependent on their support and often preferred the support of family members. However, participants experienced the role of caregiving as difficult and demanding, which was related to their psychological reactions to mood and behaviour symptoms and the length of the course of their parent's illness. Some participants explained that their experiences through a long life together with a parent with mental health problems made them vulnerable. Additionally, the lack of knowledge regarding the illness made the participants insecure in the caregiver role. Leaving care responsibility to healthcare services had given them the opportunity to reconstruct and adjust the caregiver role to their life situation. However, the transition to a new role was challenging if participants experienced that the older parent did not accept adult children's withdrawal from care responsibilities.

The main contribution of this narrative analysis is the unique insight into adult children's perception of how the long trajectory of the illness had affected their experiences as a caregiver. During the long course of care, the social context for family care changed. For example, the children lived through changing views on mental health problems. Our analysis revealed that negative views on mental health problems were not a prominent theme in participants' narratives, although previous studies have shown that stigma associated with mental health problems influences families' experiences (Reupert et al., 2021). However, we interpreted Emma's story of keeping the illness a secret as an illustration of the stigma her family experienced, which in turn influenced her performance as a caregiver today.

Further, participant stories showed how a lack of knowledge about mental health problems had affected them throughout their lifespan. George's story illustrated how the lack of knowledge had negatively affected his self-understanding early in life. In

addition, his story showed how gaining knowledge of the illness made it possible to change perspective and understanding of the situation, functioning as a relieving experience. Although some participants had gained more knowledge, others still experienced a lack of knowledge in their current situation. They described lack of knowledge as leading to feelings of insecurity in the caregiver role, mainly because they were afraid of saying or doing something that could deteriorate their parents' mental health. Participants' descriptions of insecurity in the caregiver role emphasize the need for healthcare professionals to support family caregivers by providing knowledge of the illness and how to perform the caregiver tasks. This result is worth noting. A previous qualitative study has shown that when caring for older adults' with complex healthcare needs, home care services focus on particular care tasks related to physical health. It can prevent healthcare professionals from recognizing the older care recipients' mental health needs and the needs of family caregivers (McCormack & Skatvedt, 2017).

Although the social context for family care has changed through their long caregiving career, our results showed that participants' motivation to take on and sustain as a caregiver had been stable throughout their careers. Participants described affection and experiences of duty as motivation to provide care, which has been reported in previous research as motivators for both women and men across different cultures (Zygouri et al., 2021). Furthermore, our narrative analysis revealed that adult children position themselves as important care providers for their home-dwelling older parents with mental health problems. This result is in line with previous research documenting family members' essential role as caregivers (Friedman et al., 2019; Schulz et al., 2020; Wells et al., 2020).

The findings from this study confirmed that participants experienced the caregiver's role as difficult and demanding, which is consistent with results from a qualitative study exploring the perspective of family caregivers of older adults with mental health problems (McCann et al., 2015). Our analysis revealed that features of the older care recipient's mental health problems had negatively influenced their experiences of caring, especially symptoms of the mental health problems, such as personality changes and how the illness affected their interaction. Challenging behavioural symptoms in the care recipient are documented as a predictor of negative psychological effects of caregiving in previous studies (Lindt et al., 2020; Schulz et al., 2020).

Furthermore, the findings from our narrative analysis indicate that the risk of experiencing psychological distress may increase when care lasts for many years, independent of the changes in the older

person's needs. Anna's story illustrated how a long course of caregiving is a central dimension of the demanding role *per se*. She described how 30 years of caring had made her tolerate less and react more negatively to her mother's symptoms than before. This is indeed a noteworthy result because participants' experiences of the duration of caring provide nuances and depth to findings from quantitative research aiming to identify who is at risk of burden and in need of support from healthcare professionals. Lindt et al. (2020) identified the duration of caregiving as a strong determination of burden. However, their systematic review gave no clear answer as to why duration was a strong predictor, whether it was the length of the care itself or the care recipients' need for care increased. According to Given et al. (2013), most families can respond to care needs for a shorter duration, such as four to six weeks. However, once care provision extends beyond this time, distress is more likely to occur.

Based on our findings, we assume that the family caregivers' reaction to the caregiver role and their needs for support depend on the duration of care. Our analysis showed that adult children felt sorry for their parents. They could express empathy and understanding for their parent, despite the major negative consequences the disease had for them. However, their stories did not include mourning their own loss. In contrast, findings from McCann et al. (2015) qualitative study showed that family caregivers who have had the role of caregiver for less than three years experienced grief about a significant loss in their lives when realizing that their older parent was no longer the independent person they once knew. These findings indicate that the duration of a caregiving career changes caregivers' experiences, and their needs will vary. Furthermore, the time perspective, comprising participants' experiences throughout a long life with a parent experiencing mental health problems, may have positively impacted adult children's acceptance and reconciliation with their situation.

Participants' narratives of being a caregiver gave examples of how the changing social context shaped their caring role, and in some situations, it has become an unwanted care responsibility. Sara's story demonstrates how care recipient's right to co-determination resulted in an experience of having no choice but to assume responsibility for care. Healthcare based on voluntary consent is an important legal right to safeguard the older care recipients' right to co-determination. However, these results suggest that even in Norway, with universal and comprehensive public care services (Esping-Andersen, 2013), family members can experience a lack of choice when the older care recipient does not consent to treatment. We expect that caregivers experiencing a lack of choice will be an even more prominent issue

worldwide, owing to the variations in the development of community mental healthcare services (Thornicroft et al., 2016). Participants experiencing a lack of choice is a notable finding because previous research has reported that a lack of choice about caregiving can lead to reduced psychological and physical health and lower life satisfaction (Schulz et al., 2020).

Furthermore, when the parents grew older and were included in the public elderly healthcare system, the participants got the opportunity to reconstruct and adjust the role to their life situation. Some participants were able to reconstruct their role towards their parents, but for others, it was difficult. For John, the public health service created room to take on a new role *vis-à-vis* the parent. Leaving on the responsibility to home healthcare enabled him to restore his identity as a son. In contrast, other participants experienced the transition to a new caregiver role as challenging, especially if their parents did not accept it. Adjustment of the caregiver role has been described as an important course of action to alleviate stress, where family caregivers change their behaviour to bring them in line with their identity standard (Montgomery & Kosloski, 2013). However, the authors note that changing behaviour could create stress as it undermines the ability to comply with personal identity standards. In our study, it was expectations and demands from the care recipient that created difficulties in taking on a new role. Our findings indicate that this can be even more difficult for daughters, which might mirror how the traditional gender role expectations influence the meaning of caregiving and the consequences of performing the caregiving role. The same has also been pointed out by others (Gonyea, 2013; Zygouri et al., 2021). However, the difference in our results between sons and daughters may also reflect that each caregiver is currently at a different point in their caregiving career.

### Methodological rigor

The interviews provided a rich source of material, and we considered narrative analysis as appropriate to explore family caregivers' experiences and meaning-making. Our narrative analysis provided in-depth knowledge of family caregivers' experiences in the role. Trustworthiness was considered throughout all steps of the research process, as recommended by Riessman (2008). The validation of this study was ensured by consciously and strategically considering the trustworthiness of the stories collected and the analytical stories we developed. All three authors participated in discussions regarding the emergent analysis to increase the creativity and thoughtfulness of

data analysis. Furthermore, in the analytical stories, we have provided a presentation of quotations and focused on contextualized narratives in time, place, and storyteller.

### Limitations

This study has a few limitations. Only one interview was carried out with each participant, although the narrative approach entails that considerable time be spent with the participants (Creswell & Poth, 2018). However, owing to expectations that family caregivers would be already burdened, the design did not include multiple interviews. Instead, during the interview, we asked participants to clarify and confirm the interpretations of their statements to ensure the validity of the findings. Clarifying questions also gave participants an opportunity to reflect on their meaning-making.

Another notable limitation is that we recruited participants via managers in community-based services, which meant that only participants who were defined as caregivers by healthcare professionals participated in the study. Consequently, this study has no information on family caregivers managing the care responsibility alone or caregivers who had withdrawn from the role, where both groups are expected to have different experiences. The sample included family caregivers of persons with various mental health problems. Different mental health problems can cause different challenges for older adults and those closest to them. For example, caring for an older person with schizophrenia may be an experience different from caring for a person with depression. The interviews provided a basis for highlighting aspects of family caregivers' situations common to participants. However, the heterogeneity in the group of older adults with mental health problems and their family caregivers will be significant. The needs and experiences described by participants in this study are not necessarily common to other family caregivers of older adults with mental health problems. We designed this study so family caregivers could participate without the older person's consent and did not collect personal or health information about the older adult. Consequently, describing family caregivers' experiences related to diagnosis was beyond the scope of this study.

This study had eight participants, which might seem like a limited number. However, we considered that their detailed stories provided rich material and a solid foundation for this study, in line with recommendations for narrative approaches (Creswell & Poth, 2018; Malterud et al., 2015). Although the small number of family caregivers limits the transferability of findings, case-centred approaches, with detailed stories of experiences, can generate theoretical concepts and observations about general processes that can be transferred (Riessman, 2008).

### Conclusion and implications

The findings from this narrative analysis show that caregivers have unique experiences through their long life, influenced by the history of interaction and the care context. Through a long course of caring, adult children experienced caregivers' role as both purposeful and difficult and demanding. Participants perceived the symptoms of mental health problems and long-term caregiving as difficult and demanding. Furthermore, a lack of knowledge of the illness and how to perform the care tasks made them insecure in the caregiver role. Our findings indicate that sharing care responsibility with healthcare services has the potential to ease family caregivers' burden. However, based on a long life as caregivers, adult children may need support in the process of reconstructing the caregiver role to adjust the role to their life situation.

This study extends knowledge about the caregiving experiences of adult children with in-depth knowledge gained through long-term caregiving. In-depth knowledge, as presented in this study, can prepare healthcare professionals so that they can be attentive to the diversity in family caregivers and their individual needs. Additionally, findings from this study provide a basis for healthcare professionals to understand why leaving the responsibility to healthcare services can be challenging for family caregivers. The Norwegian Directorate of Health [Helsedirektoratet] (2017) proposes respite to support caregivers in their general recommendation on family involvement and support. Our findings indicate that increased support for older adults by healthcare services does not necessarily provide relief to family members. We recommend that interventions targeting family caregivers' respite include healthcare professionals supporting caregivers in reconstructing their caregiver role to adapt the role to their life situation. There is a growing recognition of inclusive and integrated health services. This study indicated a need for interventions to promote knowledge about mental health problems and models for integrated services for older adults with mental health problems and their family caregivers.

The narrative approach provides in-depth knowledge regarding family caregivers' unique experiences gained through a long life as a caregiver. In future studies, researchers should explore the experiences of the spouses/partner of older adults with mental health problems, owing to the expectations of different caring patterns and responses to caregiving between the spouse and other family members.

Diagnoses are an important part of the clinical assessment, but the diagnosis alone cannot provide a comprehensive understanding of a person's unique need for help. A person's cultural and social background, life experiences, and other individual characteristics will influence a person's needs. We recommend

more studies, with both qualitative and quantitative approaches, to bring out variations in burden and help needs among family caregivers according to the older adults' specific mental disorders. Furthermore, we recommend investigations with a broader sample, including variations of diagnosis groups, considering whether there is a common feature of family caregivers' situation.

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## Author contribution

O.S.S. and S.Y. contributed to the design of the work. O. S.S., J.A., and S.Y. contributed to analysis and interpretation of data. O.S.S. performed the data collection and drafted the manuscript. All three authors made critical revisions to the article and approved the final manuscript.

## Data availability statement

Research data is not shared.

## Ethical approval

Permission was obtained from the Norwegian Centre for Research Data, approval number 58,265.

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