Meaning in family caregiving for people with dementia: a narrative study about relationships, values, and motivation, and how day care influences these factors

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Background: In addition to care-related burdens, most caregivers of a person with dementia perceive a variety of positive and satisfying experiences, such as feeling needed and useful in their family caregiving role. “Meaning-focused coping” describes both positive and negative emotions in periods with high levels of stress. Day care service may have the potential to increase caregivers’ positive experiences and meaning-focused coping, and positively influence interpersonal relationships between those giving care and those receiving care. The aim of this study was to gain knowledge about family caregivers’ experiences of meaning in their caring role. Additionally, the influence of day care services on caregivers’ experiences and motivation in their caregiving role is explored.

Methods: A qualitative design based on individual interviews was used. The interviews were analyzed using a narrative method and a case study approach.

Findings: Family caregivers’ roles and coping strategies were related to their relational ties. Caregivers had to make decisions about whether to enhance, maintain, or let go of emotional ties to find a good balance between meeting their own needs and the needs of the person with dementia. Family caregivers reported that day care positively influenced their “relationship-oriented coping” and experience of meaning.

Conclusion: Finding meaning in the role of a family caregiver for persons with dementia is closely connected to the caregivers’ own values and goals. Finding a balance between attending to their own needs and the needs of the person with dementia is crucial. Day care has the potential to increase family caregivers’ motivation to care by supporting their capacity to meet their own needs, cooperate and communicate with the person with dementia, and make competent and autonomous choices, thus increasing their feeling of mastery.

Keywords: dementia, family caregivers, day care, meaning, values, relationship-oriented coping

Introduction
Dementia is one of the most challenging age-related illnesses, not only for those diagnosed with dementia but also for their family caregivers and health care professionals. The burdens associated with caring for people with dementia, including physical, psychological, social, and financial aspects, are well known. However, most caregivers also perceive a variety of positive and satisfying experiences of feeling needed and useful in their role. Much can be gained by examining the positive dimensions of caregiving, including experiences, appraisals, and emotions, and the strengths and resources that caregivers can call upon in managing the challenges they face.
We identified similarities and dissimilarities with the other stories. In a narrative study, attention shifts to the details and conflicts, and stories are preserved and treated analytically as units, not points that create context or breaks in the story more than to identify similarities and dissimilarities with the other stories. This interview was therefore analyzed as a single unit, to highlight the conflicts and improve the quality of time caregivers spend together. Methods

This study has a qualitative design based on a narrative analysis using individual in-depth interviews. Based on the aim of this study, three research questions were formulated.

1. What motivates family caregivers to provide care?
2. How do family caregivers find meaning and develop a sense of coping in their role?
3. How does day care influence family caregivers’ sense of coping and motivation in their role?

Narrative analysis allowed us to gain deeper insight into the everyday lives of family caregivers according to these research questions. Narrative studies rely on extended accounts that are preserved and treated analytically as units, rather than as fragments divided into thematic categories, as is customary in other forms of qualitative analysis. Each interview was therefore analyzed as a single unit, to highlight points that create context or breaks in the story more than to identify similarities and dissimilarities with the other stories.
and why a particular event is recounted, or what a narrator accomplishes by developing the story that way. In this study, narrative analysis provided greater scope for including and emphasizing past experiences and self-representation in the analysis, which was assumed to be an interesting dimension of how family caregivers experience their role.

According to Riessman, in a narrative inquiry, the analyst “is interested in how a speaker or writer assembles and sequences events and uses language and/or visual images to communicate meaning, that is, make particular points to an audience.” Additionally, Riessman does not simply emphasize the content of the story, but also interrogates the storyteller’s intentions: how do people choose to tell their stories and why. A narrative method with a performative analysis focuses on the identity or the character of the person who tells the story. In this study, we paid special attention to how the caregivers positioned themselves in relation to the person with dementia.

The study is a part of the research project “Effects and costs of a day care centre program designed for people with dementia – a 24-month controlled study (ECOD).” This study has been accepted by the Regional Committee for Medical and Health Research Ethics for South East Norway, and the participants gave written informed consent. The participants in the current study were recruited from the intervention group in the ECOD study and selected to participate in this study based on the themes that were exposed during interviews, for example, their descriptions of their experience of meaning and other positive aspects of the caregiving role.

To go into even more depth with these themes, these family caregivers described, in the past and the present, 1) themselves, their values and goals, and the position they placed themselves into in the caregiving role, 2) their relationship to the person with dementia, and 3) how day care influenced their situation. The interview guide is presented in Table 2.

Inspired by Riessman’s understanding of the performative narrative method, we performed a systematic seven-step analysis of each interview. These steps are described in Box 1, and an example of the analysis process (step 5) is described in Box 2 in greater detail.

To ensure the quality of this process, the analysis model was designed under the guidance of two experienced researchers. These two were also involved in the process of selecting key utterances that were descriptive of global, local, and thematic contexts.

During the analysis, themes and quotes were selected and interwoven into a descriptive narrative representing the person’s story as a whole. Descriptions of identity, relations, sense of belonging, and so forth were compiled into an overall picture and a descriptive plot based on the researcher’s interpretation. These condensed stories were then seen in light of a greater whole, for example, the values of society or attitudes toward dementia or the role of family caregiver.

The interviews were conducted and analyzed in Norwegian and then the quotations were translated to English by the research group.

Based on the narrative analyses, the five interviews were transformed into five short narratives summarizing the stories’ plots (theme). Each story was given a name. We present the findings as spots on each story’s uniqueness and the variation between the stories.

### Table 1 Characteristics of the participants and the persons with dementia

<table>
<thead>
<tr>
<th>Family caregiver's role</th>
<th>Age of the family caregiver</th>
<th>Living together with the person with dementia</th>
<th>Working</th>
<th>Relationship of the person with dementia</th>
<th>Severity of dementia (CDR)</th>
<th>Age of the person with dementia</th>
<th>Days at day care (per week)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Case 1, daughter</td>
<td>61</td>
<td>No</td>
<td>Part time</td>
<td>Mother</td>
<td>Mild</td>
<td>82</td>
<td>5</td>
</tr>
<tr>
<td>Case 2, son</td>
<td>54</td>
<td>No</td>
<td>No</td>
<td>Father</td>
<td>Severe</td>
<td>76</td>
<td>4</td>
</tr>
<tr>
<td>Case 3, wife</td>
<td>76</td>
<td>Yes</td>
<td>No</td>
<td>Husband</td>
<td>Moderate</td>
<td>79</td>
<td>4</td>
</tr>
<tr>
<td>Case 4, husband</td>
<td>79</td>
<td>Yes</td>
<td>No</td>
<td>Wife</td>
<td>Moderate</td>
<td>79</td>
<td>3</td>
</tr>
<tr>
<td>Case 5, wife</td>
<td>87</td>
<td>Yes</td>
<td>No</td>
<td>Husband</td>
<td>Severe</td>
<td>93</td>
<td>3</td>
</tr>
</tbody>
</table>

**Abbreviation:** CDR, Clinical Dementia Rating Scale.
Findings

The findings are presented through five narratives describing the family caregivers’ individual experiences of meaning in their caring role and how the day care services influenced their experience and motivation in their role.

The condensed narratives are presented and outlined under the following headings:

1. The counselor – from support to emotional closeness.
2. The project leader – from occasional to regular contact.
Narrative 1: the counselor – from support to emotional closeness

Mom has always asked me for good advice. When I was in my 20s, she called me daily for support in her difficult relationship with my dad. After my mom got dementia, I found that she became more like a “real mom” for me. Before she got sick, she was concerned only about her own problems, but our relationship has now changed and our closeness has increased; she is more concerned about how I feel. I feel like I understand Mom very well, it is probably because of my education and my strong interest to be with her. Once we lay in the double bed chatting; I felt so close to her – I felt she was a “real mom” for me, interested in my life. Mom likes to participate in day care, it gives her something to do with her days. On those days, I do not need to visit her because her social needs have been met and she has had healthy meals. I think Mom enjoys day care, but there should have been more activities there. When I was on long-term sick leave, I had plenty of time to spend with Mom. Now I am more tired, and therefore, I must give her less priority because I also want to spend time with my boyfriend.

This daughter appreciates the experience shift in the relationship with her mother. As the dementia has progressed, her mother has changed from being a selfish and suffering person to being more interested in her daughter’s life. New roles have emerged in the mother–daughter relationship and a new intimacy has developed between them, which the daughter missed earlier. Nevertheless, the daughter still wants to play her old role as her mother’s supportive partner. She wants to influence her sisters’ caregiving and give them advice, but she feels that they are not particularly receptive to it. Day care keeps the mother active, and this helps the daughter maintain her role without a bad conscience, even though she spends less time with her.

Narrative 2: the project leader – from occasional to regular contact

Although I am not fond of my father, I feel it is my duty to help him in his current difficult situation. He left our family when I was a teenager; since then, contact has been sporadic. In spite of this, I have no reason to avenge myself on him for what happened to us. I have good relationships with my siblings, and we cooperate well as family caregivers. Dad has given us different roles. He calls me the project leader – it is really a poor job, but I help him when it suits me, so it is fine. Participating in day care gives my father...
This wife struggles with her new role and her new relationship with her husband. They are still a couple, but the relationship has become asymmetric and demanding. To manage, she must change her behavior and stick to strict routines. She is tired of the situation, but she feels she can handle it, largely because of the day care service. Without day care, she is not able to keep the two of them together the way she wants.

Narrative 4: the adaptor – from teamwork to solo

My wife and I have moved several times because of my job. Hence, we have always been close and quick in adapting to new places and making new friends. Because of my wife’s sickness, now I have to adapt our social life to her needs. That is ok, because I am a good cook, so we still often invite family and friends for dinner or coffee. If we are invited to friends’ homes, I have to make sure that she gets rest, and I give her an extra tablet so she can stand it a little bit longer. However, when she has her anxiety attacks, it is hard to handle. We are coping with our everyday life, but when she starts with her meaningless activities, for example, washing the floors repeatedly, we often end up arguing. When I ask her to stop, it provokes confrontations and I feel helpless.

This husband works hard to adapt to their new situation and maintain their social network. Even though he thinks dementia is challenging, their friends and their social life provide links to their “normal life”: a life which this husband is trying to hold on to. The activities he describes as meaningless irritate him and make him feel out of control and angry. This is hard for both of them. On day care days, they spend several hours apart, and this makes him more patient in the relationship.

Narrative 5: the supportive wife – from hanging on to letting go

We have been married for over 60 years, and we have always been together. I was in charge of his company and he was very dependent on me. Now his dementia is severe, so I have to look after him constantly. God helps me, but now it is very hard because of my own health problems. It is
like looking after a baby; the roles are completely changed, and he speaks very little. When my husband is at day care, I can go shopping or for a cup of coffee with my nieces. I really enjoy these moments. In addition to day care, I have regular respite when he is in the nursing home. Then, I can sleep during the whole night and I do not have to rush. I relax when he is away, but I also feel guilty because I have “sent him away”. When he is at day care, I feel no guilt the way I do when he stays at the nursing home. Our sons are supporting me; they say it is too hard for me to care for him at home. The staff at the day care service also tell me so. I know I will be fine if he moves to a nursing home, but I am afraid that he will feel abandoned.

This wife struggles with two conflicting feelings. On one hand, she wants her husband to stay at home, but on the other hand, she has to accept letting him go. This is a difficult process for her, and she seeks arguments and support to justify her feelings and her choices. Living separately seems to make life easier, but the risk that her husband will feel abandoned makes her insecure and vulnerable in this decision-making process. The husband’s participation in day care gives the wife less feelings of guilt than when she “sent him” to the nursing home for relief. Although using day care as a respite service is the best option for her, she is extremely tired and is in need of more respite than the day care can offer.

**Discussion**

The aim of this study was to gain knowledge about meaning in the family caring role, and how day care services may influence family caregivers’ experience and motivation in this role. According to Folkman, meaning-focused coping creates the opportunity for a person to act in accordance with their values and goals. The five narratives present a picture of how family caregivers cope with their new situation in different meaningful ways. These results are discussed in relation to three main themes:

1. enhancing, maintaining, or letting go of relational ties;
2. finding a balance between caring for one’s own and another’s needs;
3. increasing family caregivers’ motivation to care with the help of day care.

**Enhancing, maintaining, or letting go of relational ties**

The family caregivers’ descriptions incorporate a variety of strategies they use to cope with their relational ties. Should they maintain and strengthen their emotional relationship with the person with dementia or let it go? They describe different relational and emotional coping strategies ranging from a desire for emotional closeness and a need to hold on to the connection to the need for distance and acknowledging the need to gradually let the relationship go.

According to the daughter in narrative 1, the new situation gives her an opportunity to fulfill her need for emotional closeness to her mother. She likes her position as her mother’s closest daughter and she seeks appreciation from her mother – as she always has done. The new intimacy motivates her to act in accordance with her values, which include being a good caregiver for her mother. By doing so, she simultaneously satisfies her own need for emotional closeness.

The son in narrative 2 feels a sense of duty to provide care for his father despite the emotional distance between them – a distance he describes as expedient and rational in his role as caregiver. This duty includes supporting and helping his father without taking revenge for the betrayal by his father he experienced earlier in his life. The emotional distance makes it easier to limit his involvement while at the same time do his duty in accordance with his own values. This son meets his obligations as expected by the community and receives gratitude from his father.

The spouses in this study describe different relational changes. The wife in narrative 3 struggles to maintain emotional closeness to her husband. Her primary goal is to stay together with her husband in the marriage. This goal motivates her to care for him even if she is stressed and tired. She describes a potential situation without this caregiving role as empty, lonely, and meaningless. The wife wants to fight for her strong relationship with her husband. She still values this relationship highly, even though it has significantly changed because of her husband’s dementia. To handle her challenges, she implements a daily schedule to fulfill her need for predictability and control. That schedule helps her in her role as family caregiver and brings their life under control. Similarly, the husband in narrative 4 introduces stricter routines and control for the purpose of maintaining the relationship. By doing so, he intends to maintain their social network. He fulfills his need for a social network by taking responsibility for the housekeeping and invitations to social events.

Regarding the wife in narrative 5, the relational emotional challenge is connected to the hard process of “letting go.” She knows that she must loosen her emotional ties to her husband. This is painful because “staying together” is one of the things she values most. This process brings forth ambivalent feelings: she wants to remain close to her husband,
but she is very tired and longs for freedom and time to meet her own needs. In this process, she becomes sad when she dwells on the possibility that their long cohabitation could end. When she has to entrust her husband to professional health care workers, her relational focus changes from “staying together” to “fixing their lives separately.” In this process, she needs acceptance and support from family members and health care workers at the day care center. According to Molyneaux et al, this shift in focus is expedient in reducing the family caregiver’s burden.13 However, this wife describes this experience as painful.

These five narratives demonstrate in various ways how meaningful relationships motivate family caregivers to act in accordance with their own values and goals. These results confirm the “relationship-oriented coping” theory11 and previous research describing how family caregivers find meaning in their role.5,10

All the family caregivers feel that the day care center positively influences the relationship between themselves and the person with dementia. Attendance at day care provides individuals with dementia with topics to discuss later with the family caregiver, and they are calmer and more satisfied on the days they attend day care. This leads to less nagging and conflicts between them and their caregivers. Hence, day care has a positive influence on the ability of family caregivers to cope in the caregiving role.

Finding a good balance between caring for one’s own and another’s needs
The family caregivers describe challenges connected to finding a balance between maintaining the needs of the person with dementia and taking care of their own needs. This dilemma can be elucidated by the ideal of altruistic care that influences the community and affects the family caregiver’s own expectations and demands in their role as caregivers.

The Norwegian philosopher Pettersen criticizes the ideal of the altruistic, compassionate caregiver,26 which has been the prevailing caregiving ideal throughout human history. Altruistic care is meant to be selfless and should be unconditionally based on spontaneous compassion and sacrifice. The altruistic care ideal can disallow caregivers’ needs, including the need for support and relief. In altruistic care philosophy, the caregivers’ feeling of doing the “right thing” is both their reward and their motivation for caring or doing their duty. This means putting their own needs aside in favor of another persons’ needs.26

Duty is a prominent motivator for family caregivers. However, how this value is expressed and justified varies. The wives’ stories reflect their feelings of marital duty based on their own expectations of being supportive and the desire to preserve the emotional closeness in their relationships with their husbands. The son justifies his sense of duty based on values from his childhood inherited from his mother and grandparents. The emotional distance that he has from his father helps him balance his own needs with those of his father in an expedient way. Placing emotional limits on caregiving helps the son provide so-called mature care. Mature care is a care philosophy meant to conceptualize care as a rational, not a monodirectional activity. In this conception of care, self-care is not by definition unethical, but a prerequisite part of ethical care.26

The daughter in narrative 1 is motivated by her own needs for intimacy with her mother. The combination of her own and her mother’s needs must be made visible and reflected in the caregiving role. According to mature care philosophy, regular reflection about the situation can increase the caregiver’s understanding of their role as caregiver and the care recipient’s needs. Reflection might lead to new understanding and help the caregiver balance his or her needs with those of the care recipient. If the caregiver’s primary need is intimacy, the caregiver might take advantage of the situation. If meeting the needs of the caregiver is the main option, the person with dementia could suffer because of their total dependency on the caregiver and their limited ability to leave the relationship. However, the mutual need for satisfaction could balance the relationship.

According to mature care philosophy, the caregiver and the care receiver’s needs, interests, and values are equivalent. Hence, this philosophy violates the traditional altruistic care ideal, as it is based on communication between equal partners, information, expertise, and continuous reflection. According to mature care philosophy, it is immoral to put one’s own values and needs as caregiver aside, at least over time.26

The mature care philosophy criticizes the altruistic care ideal based on the risk of negative consequences for both the caregiver and the care recipient. The family caregivers, particularly the spouses, describe how they prioritize the needs of the person with dementia over their own. They try to balance their own needs and the needs of the person with dementia, and hence maintain equal roles.

According to Pozzebon et al, the process of losing a partner with dementia can be broken down into four phases: 1) acknowledging change, 2) being in crisis, 3) adapting and adjusting, and 4) accepting and moving forward.27 The wives in the current study describe their situation according to
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These phases. They alternate between adapting the situation by following strict routines and trying to accept more help from professional health workers. Their shifting emotions include thankfulness, love, happiness, anger, powerlessness, and despair. Both women try to spare their husbands from experiencing their negative feelings. Being angry or sad gives them both a bad conscience. To cope with everyday life, regular morning and afternoon routines are crucial for the wife in narrative 3. Having these routines fulfills her need for control and mastery of the situation.

This study reveals that family caregivers have more time to attend to their own needs when the person with dementia attends day care. According to the mature care philosophy, day care increases family caregivers’ opportunities to maintain a balanced relationship with the person with dementia. In all stages of dementia, support from day care staff is important to relieve family caregivers from feelings of bad conscience as they seek to meet their own needs. This is especially important in situations where they have to consider the need for home care or institutional services. In these situations, family caregivers need to be supported to be able to redefine their values and goals and to adapt to a new or adjusted “meaning focus” in their caregiving role.

**Increasing family caregivers’ motivation to care with the help of day care**

The family caregivers describe the relationships with the person with dementia as essential in their motivation for caregiving. According to the mature care philosophy, we are guided by our motivation when acting and making choices. Motivation is linked to the extent to which our actions will lead us to our desired outcomes and goals. Additionally, it refers to the processes that lead to the achievement of the goal.

The motivation to act can be intrinsic and/or extrinsic. Intrinsic motivation refers to initiating an activity for its own sake because it is interesting and satisfying in itself, as opposed to doing an activity to obtain an external goal (extrinsic motivation). In their theory of self-determination (SDT), Deci and Ryan focus on the differences between intrinsic and extrinsic motivation and describe three psychological needs that motivate the self to initiate behaviors that are essential for psychological health and well-being. Competence refers to the perception that one’s behavior results in the intended outcomes and effects. Relatedness refers to feeling connected to others and the capacity to receive feedback from them. Autonomy refers to being able to choose activities, make decisions, and regulate behavior in accordance with one’s goals.

According to this theory, support and relief from day care have the potential to enhance family caregivers’ motivation to care. The family caregivers’ competence is important. It is important for them to be able to choose the actions that are necessary to achieve their value-based goals of caregiving. As previously described, respite gives family caregivers more energy and patience in their complex caregiver role. They become more competent as caregivers. In addition to providing respite, the day care staff has the possibility to offer support and guidance to family caregivers, assuming that the staff has knowledge about the caregivers’ values and their goals for caregiving. In Norway, the municipalities offer classes for family caregivers where they receive information about the health care system and their rights and learn about dementia and communications skills. Additionally, caregivers are offered support groups run by trained health professionals. Individual guidance from day care staff could be a complementary supplement to the classes for family caregivers. The staff’s competence in dementia care makes them especially skilled to give individual support and advice to family caregivers.

According to the mature care philosophy, using day care as a respite and support service can increase family caregivers’ autonomy and ability to meet their own needs; this was described by the participants in the study. The support from day care staff is central to caregivers’ ability to make autonomous choices and maintain these choices. The staff has to respect family caregivers’ various choices in their care provision and empower them to act in accordance with their own values.

According to SDT, the relationship between the person who provides support and the person who receives support is an essential effective factor. Therefore, the staff must be empathic and know the family caregivers’ individual situations when offering them support.

The family caregivers describe how their feeling of duty affects their actions in different ways and with varying strength. This feeling of duty is related not only to their personal values but also to the values and expectations of society. Through this feeling of duty, the family caregivers describe how the aim of the action motivates them to care (extrinsic motivation) more than the action itself (intrinsic motivation). As per the SDT, the activities motivated by intrinsic motivation are activities or situations in which the activities themselves are the primary motivating factor. The family caregivers describe how day care enhances their chances of having several good moments together with the person with dementia, for example, having a pleasant telephone call, a
nice meal, or emotional intimacy. Based on the family caregivers’ descriptions, day care, as a support and relief service, can contribute to facilitating intrinsic motivation in family caregivers. Activities based on intrinsic motivation are more rooted in the integrity of the person than are activities based on extrinsic motivation. Furthermore, activities rooted in a person’s integrity have a higher potential to increase that person’s psychological health and well-being.30

Methodological considerations
The in-depth semi-structured interviews provided a rich source of material with personal descriptions related to the aim of this study. The participants were diverse with respect to gender, age, and caregiver roles (spouses or children living together or separately), and the sample included caregivers of people with various degrees of dementia. Considering the aim of the study, the narrative method was appropriate because it provides relevant knowledge about the participants’ experiences of meaning based on their values, goals, and relationships.

This study has some limitations. Only one interview was carried out with each participant, and hence, it was not possible to verify the researchers’ interpretations of the data or for the participants to add further information. Had we used a longitudinal approach with repeated interviews, the study could have provided greater insight into how the caregiver role changes as the disease progresses. Although the results cannot be generalized to other groups of caregivers, they can elucidate the situations of similar groups of family caregivers and how their needs for support and respite can be met.

Conclusion
This study reveals that finding meaning in the role of family caregiver for persons with dementia is closely connected to the caregivers’ own values and goals. Finding a balance between attending to their own needs and the needs of the person with dementia is crucial. To accomplish this, individual support can be useful, for example, individual tutorials with day care staff who know the person with dementia well. Day care has the potential to increase family caregivers’ motivation to care by supporting their capacity to meet their own needs, cooperate and communicate with the person with dementia, and make competent and autonomous choices, thus increasing their sense of mastery.

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Disclosure
The authors report no conflicts of interest in this work.

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