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Veröffentlichungsversion / Published Version

Zeitschriftenartikel / journal article

#### Empfohlene Zitierung / Suggested Citation:

Hautsalo, K., Pirhonen, J., & Pietilä, I. (2023). Continuity, coping and finding meanings in everyday life: Storytelling by family members of people with young onset dementia. *JFR - Journal of Family Research*, 35, 574-594. <https://doi.org/10.20377/jfr-962>

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## Continuity, coping and finding meanings in everyday life: Storytelling by family members of people with young onset dementia

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### Abstract

**Objective:** This narrative study explores how family members readjust to young onset dementia (YOD) being a part of their everyday life during the first four years of their family member's illness.

**Background:** Young onset dementia affects family relationships and challenges their life situation from the onset of the illness. It is therefore important to recognise and understand the family members' supportive and resisting issues as well as their coping styles.

**Method:** The data was collected in Finland by conducting interviews with 16 family members of people with YOD and these were repeated once a year for four years (2019 to 2022). The actant model was used to carry out the analysis.

**Results:** Narrating the situation helps family members reconstruct their own story of their changed situation. Family members adjust their life situation at the beginning of the YOD diagnosis by retaining their daily continuity, coping, and by finding meanings. These require a recognition and an acceptance of the changes that YOD creates in relationships and daily living and may lead to a storyline that is broken, adaptive or alternative.

**Conclusion:** When family members engage in storytelling, this can result in an increased awareness of their situation and lead them to identify opportunities and problems and solve them. This also leads to their readjustment to dementia as a part of their own personal narrative.

**Key words:** young onset dementia, family carer, narrative reconstruction, actantial model, qualitative longitudinal research, dementia care



## 1. Introduction

When a person is diagnosed with dementia before the age of 65, this breaks an expected life course both for the person who receives the diagnosis and for that person's family. Dementia as a progressive, neurological, severe illness radically interrupts the age-normative phases of a person's life course (Johannessen et al., 2018). Being a family member of a person with dementia results in some type of challenges, such as confronting the symptoms of dementia, navigating healthcare systems and balancing life's other responsibilities (World Alzheimer Report 2022, 82–83). Families of a person with YOD have been reported to be more likely overwhelmed and carers experience distress, anger or depression compared to those who have older counterparts who have later onset dementia (Ryan et al., 2021). On the other hand, a carer may possess a strong sense of purpose, pride and gratification when living together with in mutual relationships through the ups and downs of life (World Alzheimer Report 2022, 82–83) and thus experience some positive consequences when helping a person with YOD (Werner et al., 2020). This study brings together knowledge about the changes that YOD requires in families and storytelling as a part of their readjustment to their new life situation. We particularly consider how the continuity of relationship and coping in a new situation forms and is narrated in the beginning of the illness. The family members of this study represent different kinship relationships and generations. We excluded the viewpoint of the carer of a family member and the focus on relationships and other aspects of this life situation.

### *1.1 The changes made by a YOD in the family's situation and attempts to manage them*

Families who have a member with YOD encounter other types of changes than those families who have a member with late onset dementia (LOD) because the life situations of middle-aged families is diverse (Milenaar et al., 2018). The common consequences of a YOD diagnosis include financial strains due to unemployment or early retirement (Roach & Drummond, 2014; Ryan et al 2021). Social relations also may decrease due to the changes in the person's social network as well as due to other people's attitude towards dementia and lack of knowledge (Lockeridge & Simpson, 2013). The persons with YOD may encounter different types of stigma which increases their emotional burden, isolation and future concerns (Werner et al., 2020). People with YOD retain the ability to function (IADL and ADL functions) better than persons with LOD and for this reason, the former rarely use normal services based on need, such as home care or meal services. A person with YOD and their family could benefit from support, but it should be treatment for neuropsychiatric symptoms, problematic behaviour (Ryan et al., 2021) or the provision of meaningful activities or suitable peer support (Giebel et al., 2020). Most family members of the person with YOD are actively engaged in working life and it is therefore important to consider their work-life balance (WLB). This involves interpreting the care partner's needs, the assistance the carer receives with the organisation of services and support as well as with providing affective support and coping during the unpredictable situations that arise. Some factors may negatively affect the work-life balance of family members, such as an increase in the carer's emotional difficulties, the adequacy of the public care services and the limited opportunities to offer concrete help and be with their loved one (Sihto, 2018).

The relationship between a person with dementia and their family member includes a wide range of emotions, changes, challenges, and opportunities and these all create a complex web that impact the well-being of all those involved (Hyden & Nilsson, 2015). Relational dynamics form the basis of coping in a new situation and a re-defining of the relationship (Wawrziczny et al., 2016). Family relationships normally provide a sense of continuity with familiar duties, security, the feeling of belonging, comfort and predictable company, but severe changes, such as dementia with uncertain outcomes threaten that continuity (Atchley, 1989). For dementia, issues of power, control and powerless arise in the relationship as well as the dynamism of those. However, the relationship is also affected by the context, culture and surrounding society. These factors all contribute to shaping the relationship and provide direction to the actions that each participant engages in (Dunham & Cannon, 2008).

The manner in which dementia progresses makes the situation special; the illness is a dynamic process due to the changes that occur and both the person with dementia and their family member have to respond to the challenges (Clemmensen et al., 2019). People with dementia as well as their family members need tailored measures and support to respond to their individual situations (Halonen, 2023). Studies report that the support of 'we-ness' and a dyadic relationship, helps both individuals in the management of stressors due to their dementia diagnosis as well as the progression of it (Bannon et al., 2022; Martin et al., 2009;

Wawrziczny et al., 2016). Role changes within the family arise when the abilities of the person with YOD deteriorate and the family member assume additional responsibilities or becomes a carer (Bannon et al., 2022). However, each family member balances between roles and take on a variety of roles, such as a service receiver, member of a network, or active citizen, etc. (Jolanki et al., 2023). Role reversal does not occur immediately, but instead involves battles of original roles and worry, reactions, needs, expectations, etc. (Dunham & Cannon, 2008). Studies have found that who care for people with YOD likely feel distress, anger, depression and that the care constitutes a burden (Hvidsten et al., 2019; Ryan et al., 2021). Dunham & Cannon (2008) also recall the dominant paradigm in the caregiving research that focuses on decline and the assumption that caregiving is a difficult and demanding task for the carer. The dyadic concept of coping, reciprocity and cohesion may increase our understanding of how some carers manage to maintain their wellbeing and health even when the illness progresses (Martin et al., 2009). When the family member of the person with dementia is able to identify positive aspects of caregiving, this is associated with better mental health, quality of life, satisfaction with life, and competence, but not with self-rated health or personal stress (Quinn & Toms, 2019). More studies are therefore needed on the positive aspects of families with YOD (Werner et al., 2020).

Family members differ in their attempts to manage in the new life situation and they readjust in individual ways. Early narrative research on illness-related experiences have reported cultural storylines (Frank, 1995; Freeman, 2008; Hautsalo et al., 2021) and strategies to manage in difficult situations (Baltes & Rudolph, 2012; Frankl, 1979). Independent stories are always individual and may consist of features from different storylines that vary according to the related context and changes in the narrator's life situation. Frank (1995) presents three illness stories: the quest story experience in which suffering changes life but the person finds a purpose for that change; the restitution story in which illness produces a temporary interruption and there is an attempt to fix it quickly; and the chaos story in which incessant problematic issues arise and the situation becomes overwhelming. Freeman (2008) writes that an overwhelming situation may lead to "narrative foreclosure", which is a narrative of inexorable decline at the end of one's life. A person's vision of the future is based on thoughts that "the story is over" and this excludes vitality and abilities (Freeman, 2008). The meaning of life disappears in narrative foreclosure. An alternative to narrative foreclosure is Frankl's (1959/1979) theory of logotherapy, which is based on existentialism and the view that it is possible to find the meaning of life in every situation, even in despondent circumstances. Human beings have free will which enables them to choose their responses to all types of circumstances and when a person realises the meaning of life, they have the capability to withstand pain or a burden for a meaningful cause (Frankl, 1979; 2005). This existential perspective has been studied with respect to the carer's of people with dementia and the literature reveals that some family members are able to find and create meanings from a changed life situation. Difficult situations encourage those experiencing them to embrace an exploration of the deeper meanings of life (Farran, 1997, McLennon et al., 2011). Studying meanings may result in a broader perspective than the studies that explore the stress or coping in the caring situation (Farran, 1997). By finding meaning in their demanding care situations, family members may decrease their burden and support their mental health. (McLennon et al., 2011).

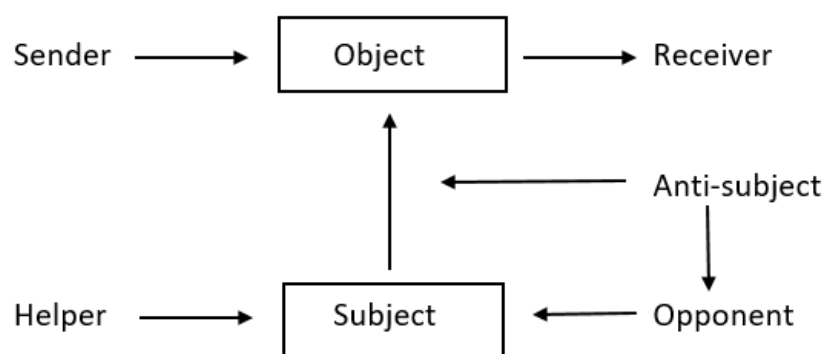
Another orientation to adapting and managing challenging life situations is the SOC model (Selection, Optimization and Compensation). This model can be used to readjust developmental opportunities or losses. The selection involves identifying, setting and redefining goals, and acting towards them by using one's own internal or external resources, which are often limited. Optimisation means acquiring, renewing and using means to achieve goals, such as by practicing, modeling others behaviour or by investing extra time and energy. The purpose of compensation is to prevent losses and to maintain progress towards goals. When there is a reduction in resources, alternative means are devised to maintain the desired level of action either through the help of others or by redefining the relevancy of the action or goals. (Baltes & Rudolph, 2012.) DiLauro et al. (2017) analysed how spouses perceived and advanced the participation of a person with dementia and reported many reflections on the action to the SOC model components. Family members may find it difficult to redefine goals when considering the YOD situation and SOC, and this may be due to many changing factors in the life situation of the person with YOD, the unknown progression of their illness and their broken future dreams (Millenaar et al., 2018). In the new situation, optimisation may be the solution to the problem by identifying the needs of the person with YOD and offering help in matters such as using technology or by emotionally responding (Lockeridge & Simpson, 2013). Compensation in YOD families can be focused on opportunities, positive matters and adjusting expectations to a new situation. This has been observed to promote the well-being of a family member (Millenaar et al., 2018).

## 1.2 Actant analysis of illness-related narratives disclose actors, emotions and structures of action

The human life experiences related to a person's own positioning in life as well as to determining that relationship to others are based on language and discourses. Narrative 'storifies' language of bodies, health, sickness and provides an understanding of these (Gwyn, 2001). This study combines knowledge of the powerful act of storytelling in the middle of changes that YOD creates in families. Through self-narratives, the interviewees can disclose essential events and issues which are important to them particularly during the changes in their life and when they consider the future while they attempt to preserve a sense of continuity (Hänninen & Koski-Jännes, 2010). Stories are always individual and connected to a person's overall life situation, but a better understanding of some specific experiences and these life situations may be achieved by analysing family members' story structures, actors and action. Törrönen (2000, 2021) describes pending narrative as a future-oriented form of story, which raises specific goals and threats that endanger the continuity of life. The macrostructure of a story reveals the unknown and threatening future and it is more predictable by recognising the disorder of the story, disclosing the responsible actors and emotions that drives them and by noticing the values. The macrostructure also helps in interpreting an uncertain situation, an interrupted story and in proposing a solution to the problem and this may help the subject take action and eliminate the threat (Törrönen, 2021). Families with a member with YOD face extensive changes and recognising them enhances the understanding of the situation, adaption and the re-forming of their own story. In dementia studies, the narrative approach has been shown to enable comprehension of the impact that emotional and spiritual personal means have on the illness, future expectations and attempts at coping. As a participant in a study, recounting one's personal story expresses an understanding of the events and means of living with dementia but also shapes the wider discourse on dementia. We need wider-ranging discussions on dementia, that is, other alternatives to a story of inevitable decline and defeat, such as understanding what it means to live well with dementia (Hautsalo et al., 2021; Hillman et al., 2018). Storytelling may also be beneficial at the individual level by facilitating the meaning-making in one's own situation or by helping listeners to understand how even in exasperating situations, there is an opportunity to find meaning (Butcher & Buckwalter, 2002). Storytelling may also help the person to maintain a sense of continuity between the past and present (Hillman et al., 2018).

The structures of stories and their meaning systems may be analysed by applying the actantial model created by Vladimir Propp and developed by A. J. Greimas (1980). According to this model, participant roles, in other words actant positions, obtain their meaning in relation to each other. The actantial model (Figure 1) has actants (seven roles in the figure) and actions (between actants, arrows in the figure) from the story and helps to realise the social and cultural elements of narration. Action is performed by both human and non-human actors (Törrönen, 2014).

Figure 1: Actantial model of Greimas (1980)



Source: Greimas (1980); Törrönen (2014)

The actantial model includes seven actants (Figure 1). These are the subject, object, helper, opponent, anti-subject, sender and receiver. The object is a goal of the action, which is considered significant for the subject, who is the protagonist of the story. The interrelation between the subject and object is the core of

model and the tension of the story arises from the subject's will and motivation towards the object. The helper supports the subject's abilities and competencies, whereas the opponent creates resistance that the subject must overcome. The anti-subject hinders and complicates the subject's action. The sender motivates and creates obligation for the action. The receiver benefits from the action of story (Aarva & Pakarinen, 2006; Törrönen, 2000; 2014). The actantial model has been used in health and social science studies to conduct a structural narrative analysis (for example, see Aarva & Pakarinen 2006; Kalalahti & Varjo, 2022; Møller & Brøgger, 2019; Törrönen, 2014). This study combines the knowledge of the major changes that YOD makes in families and the powerful act of storytelling as a part family member's readjustment to the new life situation.

## 2. Aim

The aim of this article is to discover how the family members readjust to YOD being a part of their everyday life during the first four years from the onset of the illness. Due to the various effects of YOD, it is necessary to first analyse the types of storylines they narrate of their everyday life and how those storylines relate to either other cultural illness stories or to their strategies for managing their challenging life situation. The second part of the analysis is to determine which types of human and non-human actors generate readjustment in everyday life.

## 3. Method

### 3.1 Data collection

The data were collected between 2019–2022 by conducting thematic interviews with 16 people who were family members of 14 YOD people. While people with YOD were interviewed, this paper presents an analysis of family members interviews. The participants were recruited from a neurological outpatient clinic in two different regions of Finland. The first interviews were conducted within six months after the person with YOD received the diagnosis and the follow-up interviews were subsequently organised once a year. One participant dropped out during the follow-up interviews and two family members joined in the study during the follow-up interviews. The interviews were conducted individually for the YOD person and the family member. Most of the interviews were held in the participant's homes. Due to the Covid-19 pandemic, some of the interviews were conducted by videocall or phone. The themes of the interviews were the symptoms of cognitive problems, how the illness affected their daily living, needs and desires of the parties, social relationships and other people's attitudes towards the illness, future plans as well as other matters that the interviewee wished to discuss. The interviewees were asked to provide background variables such as their age, gender, relationship with the family member, type of dementia and the CDR-measurement. The CDR (The Clinical Dementia Rating) is the Dementia Staging Instrument and it was used to characterise and track a patient's level of impairment due to dementia.

### 3.2 Participants

The kinship relations of the family members were spouses (10), children (4) and parents (2) and the family members' ages ranged from 33 to 78. Out of the people with YOD, twelve were women and one was a man. At the beginning of the study, their ages ranged from 51 to 65 years. The diagnosed memory disorders were Alzheimer's disease (12), Lewy body dementia (1) and frontotemporal dementia (1). The progression of YOD during the data collection (2019–2022) was individual: some participants continued working after their diagnosis while five participants moved to a nursing home during the study. The values of CDR demonstrates progression, the variation of values was between 0–7 in the first interviews and 0–17 in the fourth interviews. The individual changes in values are shown in Table 1. Concerning the classification of the CDR values used: 0 is for normal; 0.5–2.5 for questionable impairment; 3–4 for very mild dementia; 4.5–9 for mild dementia; 9.5–15.5 for moderate dementia; and 16–18 for severe dementia (O'Bryant et al., 2008).

Table 1: Participant and interview information

Family member and the relationship	type of high/medium/low skill or work: entrepreneur	Person with dementia	with CDR rates, annual: 2019–2020–2021–2022	Significant changes in the family situation
Matti, spouse	retired, medium	Ritva	4–15 - -	respite care from 1/20, moved to nursing home 9/20, death 10/20
Reino, spouse	retired, entrepreneur	Anja	4.5–10 to 8–14	informal care began 4/20, moved to nursing home 4/22
Leena, spouse & Marja, daughter	medium	Mikko	1– 0.75 to 1.5–4	
Teuvo, spouse	low	Sylvi	0.5–1 to 0.5–1.5	
Juha, son	medium	Raili	2–2.5 to 9–17	home care from 3/21, moved to nursing home 1/22
Seppo, spouse	entrepreneur	Salme	7–5 to 16–17	moved to nursing home 10/21
Kalervo, spouse	entrepreneur	Hanna	1–1 to 1.25–1.5	
Janne, spouse	unemployed, medium	Merja	0–0.5 to 0.5–1.5	quit working life 10/19
Pirjo, mother	retired, low	Taina	0–0 to 0.5–0.5	
Osmo, spouse	high	Riitta	0–0 to 0.5–0.5	in working life, changed workplace 8/22
Mauno, spouse	medium	Irmeli	0–0 to 0.5–0.5	
Irma, mother	retired	Sari	0.5–0 to 0–2.5	
Hannu, son & Tarja, daughter	high	Martta	3.5–2.5 to 5–11.5	home care started 2/22, moved to nursing home 11/22
Petri, spouse	entrepreneur	Hilkka	1.5–1 to 0.5–2.5	

Note: The classification of the CDR values used: 0 is for normal; 0.5–2.5 for questionable impairment; 3–4 for very mild dementia; 4.5–9 for mild dementia; 9.5–15.5 for moderate dementia; and 16–18 for severe dementia (O'Bryant et al., 2008)

### 3.3 Analysis

The analysis of this study consists of a total of 58 interviews with family members. The analysis began by listening to interviews and transcribing them verbatim for a total of 558 pages of data on family members. The actors of the actant model were recognised and coded from the story of each family member, as were the actions between the different actants. The actors had diverse issues and some actors also assumed different roles in different stories. The questions from the pending narrative analysis were utilised (see Törrönen, 2021) in the analysis to increase finding tension in the story, the responsible actors and emotions that drives them as well as noticing the values and motivations. After this, the analyses continued horizontally by mirroring findings from an individual story to the entire group of stories by combining similarities of actants and those actions between stories and identifying different storylines. The actants of different storylines were collected for the table. The analysis is illustrated in the results section by showing actants of each storyline in Table 2, and subsequently describing the essential actants of each storyline and the action between them through direct quotes and examples. The analysis is summarised by looking at how the storylines varied in terms of continuity, coping in difficulties and finding meaning.

### 3.4 Ethical consideration

This sensitive subject belongs to human sciences and is associated with persons' experiences of chronic illness as well as the changes that dementia causes in the family and the ethical considerations that are need-

ed (see Simpson, 2010). The ethical review was accepted in March, 2019 by Tampere University Hospital's Ethics Committee. The participants received verbal and written information on the study and they signed a written, informed consent before the first interview. The information was repeated verbally before each interview. The names and other identification information are anonymised in this article. The direct quotes were translated by the first author.

## 4. Results

Recounting a story about the changes caused by YOD altered their life situation and their relationship with the YOD person. This process is referred to as narrative reconstruction (Williams, 1984). Three different storylines were distinguished from the family members' stories: broken, adaptive and alternative. The positioning of dementia and the burden of it varied among the storylines, as did the embodiment of the subject and objects. The subjects of the stories displayed different abilities to share and maintain continuity from the pre-dementia period and to carry on coping. Let us now turn to introduce the storylines by showing the actants of each storyline in Table 2, and then describing the storylines with quotes and this provides examples regarding the actors as well as the action of the stories.

### 4.1 Broken story

The key factor in a broken storyline was dementia and its impact. The burden of the illness extended throughout the story. The diagnosis of dementia interrupted the continuity of the previous living and relationships, and the diagnosis served as catalyst for a new stage in life. As a result of the dementia, the roles inside a family switched and a family member had to foresee situations, assume responsibilities and in some stories, also act sacrificially for the sake of the person with YOD. For example, the daughter of a person with YOD, Tarja, tells about the unbearable weight of her responsibilities for the past years:

*...it was my mother's illness that made me think that... uuuh..... I'm not ready to consider having my own family, I just don't have the resources for it. And then again, I wonder if it's right that my mother takes from me my chance to have my own family. But it's been so hard to cope with and I haven't even been able to think about my own family (cries)...*

Supporting her mother and responding to her needs drained the daughter's energy as well as her abilities to plan her future and to have her own family. The family member's position in a broken story was overloaded and due to conflicts, symptoms of dementia and disturbing situations, the feeling of togetherness with the person with YOD was also absent or weak. The continuity of mutuality and support from their early years was gone or there was no means to carry it out in the changed situation. There were some examples of how distance arose in the relationship with the YOD person. For example, Leena (wife), spoke of her closeness to her spouse:

*A gap has grown (between us). There is no closeness at all like it was before. Well, he gives me a kiss if I take the initiative, but he doesn't initiate anything.*

As Leena recounted, this type of one-way interaction and the loss of initiative caused by YOD increased the distance and feelings of loneliness in their relationship. The aim of the broken story was to somehow find a means to survive in disturbed everyday life and to at least somehow maintain one's own wellbeing. The actions by the family member to attain that goal arose primarily from external issues because the person with dementia recounted personal problem or the health care staff requesting a family member's help or someone else remind the family member about taking care of their own wellbeing. Being together primarily meant surviving from one situation to another. Irma (Sari's mother) told about an accidental fall that her daughter had while walking the dog and Sari's mother continued envisioning other difficulties immediately thereafter:



Table 2: The actants of the family member's storylines

Actants of story	broken story	adaptive story	alternative story
Subject	Family member as a burdened and overloaded actor, experiencing weak or absent togetherness with the person with YOD.	Family member as an active actor who pays extra attention to the needs of the person with YOD and adjusts their own action to this.	<b>The dyadic unit of a person with YOD and a family member. The YOD illness is part of this dyadic subject.</b>
Object	To survive in an everyday life that is disturbed and to somehow maintain at least one's own wellbeing.	<b>Maintain a shared life, preserving the continuity and living a normal and serene life as is possible. A balance of wellbeing and demands as determined by the YOD.</b>	To take life as it comes day by day and integrate the illness and other matters as all part of it. Maintain togetherness, accept and adjust changes as a part of life.
Helper	Narrow selection of helpers. Modified attitudes and actions, external help, distance and one's own time.	Many individual helpers embodies abilities and feeling of coping in disturbed daily living. The person with YOD is also a helper.	Versatile and variable network of helpers exist, supporting the family member, the person with YOD and the whole family.
Opponent	Disturbing illnesses (or behaviour such as alcohol abuse) are part of family's everyday life, breaking the continuity of their earlier living and creating an unknown future.	Disturbing illnesses effects in the background and these cause concerns. Continuity is interrupted, but some balance exists between helpers and resistances.	The effects of dementia, which threatens we-ness or the personality of the person with YOD are opponents. The opponent could also be absent due to the attitude/mild effects of dementia.
Anti-subject	Symptoms of the YOD that create negativity and are burdensome to the family member's daily living, as constant blaming, complaining, unpredictability, disregard or apathy.	Symptoms of the YOD that threaten common daily living, such as the variability of the condition, tiredness or irritation.	External hinderances related to everyday life, as unsuitable services for a person with YOD or impossible paperwork when a family member is a trustee of the person with YOD.
Sender	<b>Dementia as a sender can create the switching of roles, as a carrier of the responsibilities or create a need to act sacrificially for the sake of the person with YOD.</b>	Dementia as a sender forces one to rethink and rearrange matters and pay attention to the dementia, to notice it and to understand the effects.	YOD of family member forced to pause and assess the meaningful aspects of life, which may lead to some positive notions and changes – the situation introduces a new dimension to one's own and shared life.
Receiver	Only the person with YOD	The person with YOD and both family member and the person with YOD as partners in a shared life situation.	The person with YOD, family member and both together as a dyadic unit. Also, all close people due to increased togetherness and sharing.
The most important action	Reactions to dementia: illness as an instigator of action and fights with resistances, which breaks the continuity and creates a burden.	Active action of a family member to support the person with dementia and to promote maintaining their relationship and shared life.	We-ness of action and attitudes towards the illness, objects and continuity in daily living. Finding and creating meanings and acting according to them.

Note: The key actant of the storyline is in bold

*Another time, a mug of boiling water fell over and burned her. Of course, it was the weekend, the health centre wasn't open, so I got those things from the chemist and then went back to the health centre for her wound care.... I said that how can one person have all these things.... now I just have to think that we'll get through this day, too, and not make any plans for the future.*

Irma found herself in a situation where the only option was to merely live a day at a time. This means that Sari's situation and incidents changed Irma's plans for her own daily living. Her worry concerning Sari's difficult home situation was also a burden for Irma. Her daughter did not want outsiders to visit her home, even though she was not able to do the housework herself. As a consequence, Sari's home had become cluttered and it was obvious that she needed help:

*...I have been in contact with client guidance and everything is open. I've tried to talk to Sari about the extra help, but no (she doesn't want it).... so now we (the mother herself with her other daughter) went to client guidance to talk about what we should do and they advised to (give) the notification of concern again. The previous one was deleted, and I don't know why such a concern notification is deleted when nothing is done about it. And they said again, do it, do it again. Sari's sister said that she would not do it again because the previous one did not lead to anything.*

Due to these ongoing changes, one means of coping for Irma was for her to live and react in the moment; her story was a mixed collection of incidents. In this storyline, the subject found it difficult and stressful to reconcile her giving support with her other areas of life, such as her work or personal interests. Those who recounted broken storylines generally had a more narrow selection of helpers and abilities than in the other family members' storylines. While the stories with broken storylines did include supportive factors, such as the availability of public services, home care or visits in hospital related to treating some illness, these events were nonetheless described by the carers with mixed feelings. If the service did not fulfil the family member's needs or the needs of the person with YOD and the family member noticed it, these factors could alone contribute to their increased emotional difficulties. Similar experiences could arise from informal help if a person with YOD refused to accept the help offered or if there were obstacles for the person with YOD to overcome in requesting help from other close people. In the broken storyline, the family member attempted to modify their own attitudes and actions and they tried to request help when potential situations arose. However, if these actions did not provide sufficient support, then the burden and fragmentation of the situation continued. The family member distanced themselves and made certain they had their own time and this temporarily relieved their stress. The resisting issues, such as dementia and other disturbing illnesses (or behaviour such as alcohol abuse), dominated the situation and no balance was achieved between the supporting and hindering issues. The dementia and symptoms of it were pervasive in the family's everyday life. The stories of some family members consisted of constant blaming and complaining as well conveying unpredictability, disregard and apathy and these negatively impacted their everyday living and their relationship. For example, Tarja (daughter) states:

*...Mother is really negative; she complains about everything all the time and it gets really hard for me. It startled me, at one point, when I saw that my mother was calling and my first thought was, oh no, what's going on there... when you knew that every time she calls, she has some worries or problems. And she just complains about everything. It's just been like that, and I couldn't always handle it. And it's a real shame...(cries)...if you think about your own mother that you can't go to see her. Although I know that this illness does that, but still.*

As Tarja observes, negativity was a part of all her communication with her mother and their action had become one-way and was related to the daughter's fulfillment of her duties. Due to many burdening issues, daily living was disturbed and owing to a lack of abilities and support, the continuity of their previous manner of living was abandoned and the family member harboured fears about the unknown future. In other words, daily living consisted predominantly of surviving from one situation to another with or without the exceedingly rare experiences of coping and receiving supportive help and services.

## 4.2 Adaptive story

This storyline was based on the object of the story, which was to maintain a shared life, preserve the continuity and living as normal and as serene a life as possible. Janne (husband) tells about these aims during the early stages of YOD and how the adaption to the situation is an ongoing process:

*There are no such (future plans) – you just have to look at what will come. You can't really plan immediately. In a way, the world is getting narrower all the time. But now you have to try to make sure it doesn't become too narrow.*

The changing of the future prospects was accepted and one's own possibilities to act towards maintaining the balance in a situation were achieved. The basis for the action in this story was a family member's action and the carer's uncompromising effort to work for the benefit of the person with YOD and their shared life situation. This type of approach towards coping applied to many areas of the carer's life, such as how to reconcile the carer's situation with work as well as to how to manage other family and personal interests. The family member continued their action when the dementia progressed and this led to their adaption. Matti (Ritva's husband) describes his own objective, which is to do as much as he can do to preserve the continuity of their shared life.

*Matti: We live according to Ritva's needs now. Ritva is the most important thing, I follow her... she always talks about how we must do this and that, but she can't. She can't even make coffee, although we practice it every day...but she participates in everything. She stands by and watches. Frankly, she doesn't do anything anymore. And it doesn't matter, I'll do everything as long as I can.*

*Researcher: Exactly. How are you coping?*

*Matti: Good. I've made it clear to myself that I have to be the one to cope with this. And yes, I do sleep... I can take care of that... back then it was difficult when during the nights I was kept awake due to Ritva's restless sleep. Nowadays, we have such restless nights sometimes. But she doesn't stay awake, she just wakes up sometimes, then I go talk to her again and she falls asleep again. It's great (when you sleep), those nights began to be a strain when you had to stay awake.*

The couple's daily living included shared duties, even though the spouse was the only active actor and his wife watched from the side and only talked about duties. Matti had also realised the importance of sleeping and that earlier nights spent watching her had been exhausting and now when sleeping was better, it was easier to achieve his own objective – to help wife so that living together at home became possible.

Furthermore, in this storyline, as in the broken story, the dementia diagnosis served as a catalyst to enter a new stage in life. The particular aspect of this story was that it described the change as neutral or even mildly positive. In other words, the change in life circumstances acted to motivate a new type of conduct that the family member wanted to carry out and believed it was worth undertaking. Change thus forced them to rethink and rearrange matters and to pay attention, notice and understand the changes the dementia caused. Reino (the husband of Anja) tells about information he had imparted about his wife's condition in the nursing home and what he has done to ensure Anja's well-being:

*Well, I have given feedback. Just last week, in that care meeting, I said that you have to stop giving those drugs (Anja's walking position had changed to one of leaning). And I said frankly that her hair has been crap at times. They said that her hair is washed twice a week... previously those nurses avoided me. I have given direct feedback.*

During the same interview, Reino also described how they were able to make small daytrips together: “we have two grandchildren who play floorball, and we go to see their games at the weekends if those are in cities nearby”. These examples reflect the family member’s will to promote the well-being of his wife, and also reveals an understanding of the situation and adaptation. Both the family member and the person with YOD benefitted from the action towards the aims of the story but it also strengthened them as partners as they continued to share their life as much as possible in their situation.

For the adaptive storyline, a family member was the active and understanding subject, someone who paid extra attention to the needs of person with YOD and adapted their own behaviour to this. The family member’s will to promote their togetherness in the relationship was intense, as evidenced by the previous quote by Reino. However, the balance between wellbeing and demands as determined by the YOD are also recognised and taken into account. During the following excerpt, Marja (daughter) remarks how she shares some duties with her brother:

*...we agreed with my brother, we are two siblings, that he will take care of more of these practical things...and since dad is still very busy, he uses the phone, the internet and e-mail... and we have to constantly put out small fires, because there are always offers messages and offers calls, sometimes the post brings vitamins home and we try to cancel those orders. I have asked my brother to take care of these things, so that I could take care of the illness and nursing matters. I am trying to have my own load shared.... and I also have to anticipate my own ability to cope, so that I don't get to the point where I lose out on the important things in my life... my ability to work or cope, or do hobbies and then it's all about taking care of my father. I have to take care of myself, too. You can't take care of others if you're not well yourself.*

One means to help during a person’s disturbed daily living was to both recognise the problems that arise in the situation as well as the opportunities to resolve them. The stories included many of these type of individual helpers who guaranteed support and enhanced the feeling of coping. Kalervo (husband) speaks of his supportive issues:

*...During the winter and spring, we went to the same gym group. And we go to the same body care groups twice a week, and then Hanna has been going to that hot yoga for several years... I was there in the autumn, too, but when I fell asleep there every time. I realised that there's no point for me going there... and we managed to get her the food service, lunch is organised on weekdays. And the cleaning services have been in use here for a good year now. Those have made everyday life a little easier... and luckily she uses that diary, it maintains a rhythm during the days, everything is written in it. Hanna always checks in the morning to see what the day's program is.... and I have a good group of friends, I can share my worries with them and receive good advice or bad advice, but it's good that I have people like that... I talk a lot and I'm such an open person, so it's quite easy and normal for me.*

This storyline has a wide variation of issues that relate to the abilities of a family member, and those included human and non-human issues, as well as formal and informal support. In addition, the number of helpers usually increased in follow-up interviews. It was important for the carer to notice the needs that the illness created and the resultant changes. This led to requesting and receiving information and to experiences regarding the services that helped family and individuals cope. This made it possible to select and receive help according to their specific needs. Furthermore, the person with dementia or the relationship of parties could also be a helper if those assured the well-being of both. Examples of this were provided by Teuvo (Sylvi’s husband): “I think Sylvi has been very nice and easy-going this past year” and Pirjo (mother): “we go for a walk, often we walk to the library and I wait outside and Taina borrows the books. I read them, too. And we go to the theatre together”. For Pirjo, their relationship and action helped an otherwise lonely family member and she found the situation to be comfortable.

The topic of resisting issues was mentioned, but those were adapted as part of the story. The main opponents were dementia and the other disturbing illnesses, but those existed in the background and did not dominate the story. Issues that hindered them achieving their aim included the symptoms and effects of dementia, the variability of the condition (such as more tiredness or irritation than previously) or conflicts between family member and the person with dementia. The following quotes are from Teuvo’s (husband) in the second and fourth interview regarding the conflicts that were caused by forgetting:

*Her memory sometimes fails...if we talk about something in the morning, then after a while it's forgotten, and I have to repeat it several times and she still doesn't (remember). Some things are forgotten very quickly...and when the same thing is repeated enough, I get irritated, and she says don't shout at me and I reply that I don't shout... I just repeat the thing. However, that's where you might start to tighten up and get nervous... forgetfulness is daily, but major nervous breakdowns are less frequent...it was two or three weeks ago, when she last got nervous and was depressed and blamed me for many things and even her illness was my fault.*

This type of situation interfered with their daily action and was a burden for the family member, but in the follow-up interviews, that load was decreased due to adaptation, as expressed in Teuvo's later interview:

*You have to be understanding and patient and try to understand what the reason is. And nothing helps if the other person is in a bad mood or something. You just have to understand the illness. It's so every day that when the other person decides something, you just let it go in one ear and out the other, and don't always react, at least not negatively. It will only become an argument if you start to debate about something small.*

These resisting issues altogether did cause concern, created an unknown future and disrupted the continuity of everyday life, but the adaptive storyline had a balance of abilities, supportive issues and resisting matters.

### 4.3 Alternative story

The alternative storyline was based on a strong feeling of we-ness, a close, two-way relationship and a devotion that existed between the person with YOD and family member. We-ness was present in daily living, concerning interests, actions but also attitudes towards the YOD illness and role of it in the life situation. For example, Seppo (husband) recounts the following:

*In a way, this long relationship shows that no matter what situation we get in, it stays, and there are no pre-conditions... we are in the same jumble and then we just learn to live with this (dementia).*

In this alternative storyline, changes, even dementia, was taken as a natural part of life. The family member and the person with YOD were a dyadic unit in the story, a unified subject. This is reflected by the use of the pronoun "we" and by the description of togetherness and reciprocity in their relationship. The aims of the story were connected to the situation, as to accept all of the life as it comes day by day and this included the illness. This storyline mentioned in different ways an intention to remain together, and an attempt to accept and adjust changes as a part of an enjoyable and demanding life. The action towards aims was based on one's own will and the resolution to achieve it and verbalised the meanings of the situation. The actions included continuity from the pre-dementia time, as Janne (husband) observes:

*Our relationship is pretty much the same as before. I don't think it has (changed). Maybe it's getting a little closer all the time. We're making a certain kind of journey here, such a common journey...and there's always a certain kind of basic trust in life. Life always carries us and it's the basis of everything, even if anything comes up, it's still nothing cause in any case, life endures everything that comes our way.*

Janne's story expresses his value of trusting in greater powers in life and his account conveys a level of spirituality. He also thinks of difficulties as meaningful aspects of life. The abilities of the family member and the person with YOD were supported with a versatile and variable network of helpers, and more supportive factors were recognised and recruited. Resources and helpers created a type of network which had mutual connections and this was a special feature of the alternative storyline. The actions between helpers and the subject of the story were mutual and it benefited all human participants. The increased togetherness and sharing of various issues were experienced as beneficial for the person with YOD, the family member and other close people who were participating in the daily living of the person with YOD.

The main resisting factors in this storyline were the issues that threatened we-ness or the personality of the person with YOD. These are evident in Seppo's (husband of Salme) story. He told about their relationship during Salme's illness when her dementia had progressed to a severe stage:

*I think we have a very good relationship. I have understood how difficult it is to separate the illness and the person. At a bad moment it won't work.... But then later, always after that situation, we also had some of those arguments earlier, so I always realised that you have to be able to separate them... Salme is not the easiest person in the world and me, neither. We both have some fire in our souls. But we have managed well.*

What helped adaptation during the demanding situations was an understanding of one's own behaviour as well as that of a loved one and the effect that the dementia had on it. It was important to maintain the balance between supportive and resisting matters and this helped to normalise living. In some stories, the opponent was absent due to attitudes and the mild effects of dementia. Some external issues also made new demands on the family member's everyday life, such as unsuitable services for the YOD or impossible paperwork for someone serving as a trustee. When these matters were perceived as meaningful, performing them was a matter of effort and subjects of the story noticed their potential to transform those into a resource or supportive matter.

In the alternative storyline, dementia did not serve as a catalyst for a new stage of life. Instead, it merely constituted one change among many others that steered their life in some direction. Family members noticed that the situation had introduced some new dimensions to their own and shared life and their story also had positive aspects and benefits that were mentioned. The illness forced them to pause and assess the meaningful issues in life, and this could lead to formulating some positive perspectives and changes. For example, a new direction for an entrepreneur would be to decrease the overall workload and to work more remotely from home; in one story, a new direction meant being more aware of their common welfare and to negotiate that with the person with YOD. Furthermore, the meaningful issues and attitudes that affected their own situation were noticed, as evidenced by Osmo's (husband) comments below:

*Things progress individually. You can come up with all kinds of tricks and ways to keep your thinking fresh. Use everything possible, like mobile phone applications, which can foster your own thinking. It doesn't help to be afraid of changes; changes are part of life, they bring strength to one's thinking. At least I consider it as a motivator because appropriate changes are needed. People like to stay in a familiar routine, it's built into us, we enjoy security and it no longer challenges us. And above all, it doesn't strain the brain. It's not a good idea to slack off; It's better to accept everything in order to get challenges.*

Osmo (husband) had a strong will to find meanings and solve challenges, which motivated him. For this storyline, life was experienced as an adventure with inevitable ups and downs.

#### 4.4 Summary of results

The results of this study can be viewed as a summary by looking at the storylines through continuity, observing the interviewee's account of coping in difficult situations and the named meanings in the story (Table 3).

A broken storyline lacked continuity and there were no named meanings in the story. A family member acted reactively to fulfilling responsibilities and to being a carer for the person with YOD. For the adaptive storyline, the essential meaning of the story was a need to preserve the continuity of their shared life. The family members in this storyline possessed a strong inner will and motivation to live as normally as possible and to notice the needs of their loved ones to adapt their own action toward these ends. The alternative storyline conveyed the continuity of a shared life as self-evident and this included dementia. The meaning of life included placing one's trust in higher powers and considering suffering to be a part of life. Action was proactive in an effort to understand one's own behaviour and that of a loved one, recognizing the impact of the illness and this helped them cope in all situations.

5. *Table 3: Variation in continuity, coping and named meanings in the different storylines*

	<b>broken storyline</b>	<b>adaptive storyline</b>	<b>alternative storyline</b>
<b>Continuity</b>	continuity was lost due to losses and the effects of the YOD; roles had changed and benefit from relationship was turned one-way, family member carries PwD.	The aim of this story was to maintain the continuity. The family member's motivation of action was to live as normal and serene a life as possible with PwD.	To take all of life as it comes day by day and include the illness and all other matters as a part of it. Dementia was a self-evident part of the current common story.
<b>Coping in difficulties</b>	The situations forces them to act reactively: as being a carrier of the responsibilities or making sacrifices for the sake of a person with YOD	Coping is an attempt to maintain the balance of wellbeing and demands. The YOD determines situations and the family member adapts their own action to the needs of the person with YOD. The action starts and proceeds mainly in one-direction.	Proactivity is part of daily living. Coping in all situation is helped by understanding one's own behaviour and that of a loved one and the impact of the dementia. The action is mutual and both parties are active actors in accordance with their own abilities.
<b>Named meanings</b>	no meanings narrated	Live together and help the person with dementia and these arise from family member's own inner will	Trusting in greater forces in life as well as a level of spirituality, and finding meaning in suffering as a part of this; life is an adventure with ups and downs, as it has always been.

*Note:* These results are based on the data of the follow-up interviews

## Discussion

This article contributes to the existing scientific discourse by analysing information on the varying and individual coping styles of YOD families and how storifying their personal circumstances may encourage these storytellers to accept their changed situations. Telling a story is a powerful act that can facilitate meaning-making (Butcher & Buckwalter, 2002), formulate a more conscious reorientation and help to adapt to a new situation along with unfolding life (Hänninen & Koski-Jännes, 2010). Furthermore, hearing a story may help others understand that even those that are exasperating offer an opportunity to find meaning (Butcher & Buckwalter, 2002). The aim of this article was to discover how the family members readjust to YOD as being a part of their everyday life during the first four years from the onset of the illness. By narrating their own situation, talking about their relationship with the person with YODs and the impact on their daily living, the family members were able to reconstruct their own story about their relationship as well as their own coping, abilities and burdens (see Frank, 1995; Hautsalo et al., 2021). The analysis uncovered broken, adaptive or alternative storylines. These differed in terms of the actants and their actions but also in relation to how the people maintain continuity, coping, and finding meaning. An individual participant's story could contain features from different storylines and it often underwent changes in the follow-up interviews, mirroring the changes in their life situation.

To consider the overall storylines, the previous knowledge of the differences between the YOD and LOD families situation was confirmed. The YOD family's life phase is more active than in LOD families. The YOD families have heightened expectations for the future, therefore the diagnosis and effects of it do change their life situation more radically than in LOD families (Millenaar et al., 2016). YOD families may struggle with a feeling of being overwhelmed, distressed, financial strained and having unmet needs (Millenaar et al., 2018; Ryan et al., 2021). In our study, the examples we cited of struggle arose as unexpected events and accidents that happened to the person with YOD and this required a family member to always be vigilant, act reactively and to help even at the expense of their own wellbeing. Furthermore, feelings of be-

ing overwhelmed arose when the participants' pervasive mode of communication became negative or when the changing roles necessitated one family member to become the one to bear the burden of the responsibilities. This type of struggle was primarily related to stories in which the participants' entire life situation was characterised by the illness. Some narratives conveyed coping and adapting to the illness as all being a part of life. These stories included similar types of action that Millenaar et al (2018) observed to be beneficial for YOD families. These included the need to pay special attention and conduct interventions to promote an acceptance of the diagnosis, to adjust aims and objectives in the changing situation, but also to notice resources and acknowledge the positive aspects of their variable life situations. Our analysis uncovered storylines that help explore more detailed actions by family members during their readjustment to dementia as a part of their everyday life.

The broken storyline told of disturbed daily living, of the gradual increase in the burden, losses and the sacrifices that the storyteller experienced. The continuity and togetherness from the era of pre-dementia ceased to exist and the present involved struggling, reactive action, attempts to survive and an awareness of a future that was to become bleaker. The services and support in the new situation did not correspond to the participants' needs. As the sense of continuity was connected to the perceived experiences of the past, and for the person with YOD, the predictability of their former daily living was replaced by disturbed or strange settings, characters and action (Atchley, 1989). Taking into consideration that context, then an uneven and fragmented story is reasonable. This narration has connections to Freeman's narrative foreclosure (2008) and to Frank's chaos narrative (1995). The future is envisioned as an inevitable repetition of present suffering and the person is stuck in reoccurring difficult situations (Frank, 1995). This scenario offers no opportunities to depart from the pre-scripted ending and if the societal context also fails to support the renewal of the story and promotes a premature end, the subject of the story results in an apparent ending (Freeman 2000, 2008). Dementia may cause a family member to experience negative reactions, hopelessness and feelings of powerless in their daily life as well as force them to face repetitive, confusing situations that are related to issues of power in relationships and role reversals. Moreover, the context, culture and expectations of society may increase a sense of obligation, leading family member to battle between responsibilities, control, burden and guilt (Dunham & Cannon, 2008). This type of workload and emotional toll was present in the broken storyline and the narration of this storyline led to a dead end, a narrative foreclosure. As Freeman (2000) warns about telling a story of narrative foreclosure, as it is unlike other storytelling, this may be a harming narrative itself. Internalising this type of storyline may be ubiquitous in the areas of life and promote the shutting down of possibilities, resulting in a dead end. To prevent this, one may seek help to rewrite the past and the future of the story differently. Identifying societal, cultural and other constrict issues may enable the person's hope of creating different endings for their own story and then reopen that story of the present circumstances. (Freeman, 2000.) For YOD and for family members who are in demanding situations, experiencing high mental stress and lack of support, the opportunity to rewrite the future may be possible with external help. In addition to focusing on the capacity and needs of a person with dementia, family members likewise benefit when their needs are assessed. Family members need tailored support, such as knowledge of the illness and its effects, guidance on how to cope in difficult situations, and on which available support and services are offered especially in the initial stages of dementia (Halonen, 2023).

For the adaptive storyline, the most important issue was the objective of the story and the active action undertaken by the family member to attain it. Family members invested a great deal of effort and action into achieving objectives such as maintaining a shared life, preserving continuity and living as normally and as serene a life as possible. The restitution narrative (Frank, 1995) has similarities regarding the narrator needing to invest in restoring as many matters as possible to normality. Moreover, experiences of external continuity (Atchley, 1989) are significant and they are maintained with predictability, familiarity of activities, dependability for mutual aid and a sense of belonging in relationships. Reflecting on the SOC-theory, Baltes and Rudolph (2012) link this to optimisation and selection, because the story included redefining and selecting the most valued aims and considering proper activities to promote both the wellbeing of the person with YOD or shared participation. This storyline also included the use of a variety of abilities which aided in action, and compensation was achieved by constantly considering the needs of a loved one by adapting to different situations. This supports the notions by Jolanki et al. (2023) of some couples who address dementia by enlisting the support of a variety of helpers from different sectors, such as from their own social network or public services. In the adaptive storyline, resisting issues are mentioned, such as the interruption to the daily life of a family due to the symptoms of dementia or living with the thought of an unknown



future due to the progression of the YOD. Yet these problems were expressed as predominantly being tolerable. Similar observations have been made in the study by DiLauro et al., (2017): some spouses have a strong will to increase their engagement of the person with dementia and they adapt to preserve continuity as well as previously enjoyed activities in their lifestyle. Furthermore, it is important to support family members: professionals need to provide tailored strategies to help and support family member identify the needs and abilities of a person with dementia (DiLauro et al., 2017) so that a family member could also feel certain of the well-being and safety of their loved one (Sihto, 2018). Peer support can offer valuable discussion opportunities and advice for adaptation. (DiLauro et al., 2017.) Regarding the storyline of the adaptation, these types of behaviors would truly benefit family members by directing their strongly motivated actions to helpful issues.

The alternative storyline included an awareness of meaning and creating it, which was more than merely responding to the demands of the illness or the environmental issues that were raised. For this type of storyline, the described action was proactive, and the early pros and cons were taken into account and utilised in their present action. Life was seen as an adventure with ups and downs and the meanings that were recounted related to the dyadic subject of the story (a family member and a person with dementia), maintaining their togetherness, how the adjustment in a changing situation was achieved and by noticing the beneficial issues of the situation. The name of the storyline “alternative” conveys the attitudes and values of the protagonists of the story. They made the conscious decision to accept the YOD as a part of their life and this choice rejected the common perception of the inevitable decline and loss related to a diagnosis of dementia (for example, see Freeman, 2008). This narration has overlaps with cultural storylines, such as existentialism (Frankl, 2005) as well as the quest narrative (Frank, 1995). These narrative express that the suffering and changes in life are necessary, which help the narrators live a purposeful way of life. The alternative storyline is supported by early dementia studies: some people are able to explore the deeper meanings of life when confronting changed and difficult situations. This offers a broader perspective than merely managing with stress or coping in the situation (Farran, 1997; McLennon, et al., 2011). This perspective also leads to the prospect of living well with dementia even when the illness progresses. Martin et al. (2009) represents a dyadic exchange which promotes the wellbeing of both partners and requires a variation in strategies to respond to the losses related to dementia as well as to understand that dyads differ in the degree of resources available in changing requirements. Living well depends on both individual and dyadic factors but is also related to the living context and the network of helpers. The participants of this study who recounted a story featuring an alternative storyline were grateful for many things. An example of this was that they also experienced the interview as being particularly beneficial for them. This reinforces the previously mentioned observation from the research by Martin (et al., 2009): narrating one’s own story helps to establish resources for oneself for the dyadic relation. This narrative activity also fosters coping strategies, finding meanings from changing and demanding situations and enhances empowerment.

The actantial model is used to analyse narratives to determine the actors of the story and the relationships between them and their actions. By combining and applying tools from the pending narrative analysis (Törrönen, 2000; 2021) various threads were highlighted, the responsible actors and their interaction were identified as were the values that guide their actions. This type of storytelling and knowledge can make the future more predictable and controllable, highlight the will and motivation that supports the action and even encourage action. This study focused on families with a YOD member who conveyed their views and this brought out their abilities and capacities to adapt to their situation. The vast array of stories, life situations and longitudinal setting with follow-up interviews enabled us to determine the variation in the storylines as well as to detect their progress in reconstructing their own story.

## 6. Conclusion

After a person is diagnosed with YOD, as the disease progresses, a family can preserve the continuity as well as the we-ness of their relationship, but there is also a threat of being overwhelmed by the intolerable burden. This study argues that family members readjust to their new life situation at the beginning of YOD by retaining continuity, coping, and by finding meanings in the new circumstances. These requires that a family recognize and accept the changes that YOD creates in their relationship. This disturbance in their daily living may lead to a broken, adaptive or alternative storyline. The act of telling one’s own story may

promote one to perceive the feelings and meanings of the situation and to focus on one's own and dyadic actions related to valuable and empowering issues. Narrating may also encourage one to identify problems and needs that arise in a situation as well as to recognize opportunities for solving them and in this manner, address dementia as a meaningful part of their own life story. In addition, the social networks of the family can promote and support family members to achieve well-being. Professionals should also assess the needs and resources of the whole family and respond to the individual needs. In this manner, they could contribute to enhancing the cohesion of the story that involves a changed life circumstance as well as the actions that the story conveys.

## Acknowledgments

We are very grateful to the individuals who volunteered and participated in our study. We also appreciate the collaboration of staff member who helped with recruiting participants for this study. This study was supported by the Finnish Brain Foundation (20210021). The financial sponsor was not involved in the design or execution of the study. This study has received a favourable opinion by the Tampere University Hospital Ethics Committee (R19023). The authors declare no conflicts of interest.

## Data availability statement

The research data is not publicly available.

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## Information in German

### Deutscher Titel

Kontinuität, Bewältigung und Sinnfindung im Alltag: Storytelling der Angehörigen von Patienten mit früh einsetzender Demenz

### Zusammenfassung

**Fragestellung:** Diese narrative Studie untersucht, welche Anpassungen Angehörige von Patienten mit früh einsetzender Demenz (*young onset dementia*, YOD) in den ersten vier Jahren der Krankheit vornehmen, um diese in ihren Lebensalltag zu integrieren.

**Hintergrund:** Früh einsetzende Demenz hat von Anfang an Auswirkungen auf die Beziehungen innerhalb von Familien und stellt eine Herausforderung an ihre Lebenssituation dar. Daher ist es wichtig, die Fragen, die sich für die Angehörigen bezüglich Unterstützung und Resistenz auf tun, sowie ihre Bewältigungsmechanismen zu erkennen und zu verstehen.

**Methode:** Die Daten wurden in Finnland anhand von Interviews mit 16 Familienmitgliedern von YOD-Patienten erhoben; die Befragungen fanden vier Jahre lang (2019 bis 2022) einmal jährlich statt. Zur Analyse wurde das Aktantenmodell verwendet.

**Ergebnisse:** Die Situation narrativ darzustellen, hilft Familienmitgliedern, ihre eigene Geschichte in der veränderten Situation zu rekonstruieren. Zum Zeitpunkt der YOD-Diagnose passen die Angehörigen ihre Lebenssituation an, indem sie die Kontinuität im Alltag aufrechterhalten, Bewältigungsstrategien entwickeln und Sinn suchen. Dies erfordert eine Anerkennung und Akzeptanz der Veränderungen, die die YOD in Beziehungen und im Alltagsleben mit sich bringt, und kann zu einem Narrativ voller Brüche, Adaptationen oder Alternativen führen.

**Schlussfolgerung:** Storytelling kann das Bewusstsein der Angehörigen für ihre Situation erweitern und zur Identifizierung von Chancen und Problemen sowie zu deren Lösung führen. Hierdurch entsteht auch eine Anpassung an die Demenz als Teil ihres eigenen, persönlichen Narrativs.

**Schlagwörter:** Früh einsetzende Demenz, pflegende Angehörige, narrative Konstruktion, Aktantenmodell, qualitative Längsschnittstudie, Demenzpflege

JFR – Journal of Family Research, 2023, vol. 35, pp. 574–594.

doi: <https://doi.org/10.20377/jfr-962>

Submitted: June 14, 2023

Accepted: November 10, 2023

Published online: November 21, 2023

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