

ARTICLE

Adjusting to dementia as part of life: an actantial analysis of agency reconstruction following diagnosis of young onset dementia

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Abstract

The agency of a person with young onset dementia (YOD) changes owing to individual symptoms, uncertainty about the speed of progression and the severity of YOD. Dementia usually greatly interrupts life and reduces agency. Previous studies show that some people and families integrate and cope with dementia better than others. This study aimed to find out how YOD changes the agency of the person who has it and what family members' role is in forming their agency. The data were collected in Finland in semi-structured interviews with 14 people with YOD and 15 family members, about a year after the diagnosis. These two data sets were analysed with a narrative method, actantial analysis. A wide variety of elements, both human and non-human factors, were found to promote and undermine agency. It was found that people with YOD need both integrity and flexibility to reconstruct their own agency. Resources support them in this process of reconstruction, and hinderers interrupt the process. This combination of integrity and flexibility, resources and hinderers, generates how people with YOD recount the future, the aims they set and how they reconstruct their agency. Other people, especially family members, are part of this dynamic process and when their relationship is cohesive, the agency of both parties increases. The participants used ideal and burdensome storylines to narrate factors that supported or interrupted their agency. Based on our findings, narrating one's situation is, for coping, not only a means but its very basis.

Keywords: actantial analysis; agency; narrative study; young onset dementia

Introduction

Dementia diagnosis before the age of 65 is called young onset dementia (YOD). Having YOD changes an expected lifecourse radically (Johannessen et al. 2018) because of its unexpected timing and rarity (Greenwood and Smith 2016). The global prevalence of YOD is 119 per 100,000 people aged 30 to 64 (Hendriks et al. 2021). In Finland,

the estimated number of people with YOD is 7,000–10,000, while the total number of people with a dementia diagnosis is above 150,000, in a population of 5.5 million (Memory Loss Diseases 2023). Young onset dementia differs from late onset dementia (LOD) owing to the high variability of aetiologies, symptoms (Millenaar et al. 2016), individual support needs and services design (Mayrhofer et al. 2021). Age-normative phases in the lifecourse are interrupted because of the dementia, which often has an impact on several areas of life including work, family relations, economic issues and interests. As the agency of the person changes, they might have to stop working, retire early or get support to raise children. Thus, YOD affects a person's whole life: their active roles and their future plans and hopes all need to be re-evaluated (Alzheimer's Disease International (ADI) 2015, 76; Spreadbury and Kipps 2019). These changes may be associated with transitions and the need to reconstruct one's own activity and agency (Roach and Dummond 2014) and recreate one's personal narrative (Bury 2001). The person with YOD is able to reconstruct their own agency based on their agentic abilities, and on how other people support these abilities. The impact of dementia on people with this diagnosis is understudied (Shoesmith et al. 2022), particularly for people with YOD who have been newly diagnosed.

Narrative reconstruction of a new life situation and agency

Chronic illnesses disrupt a person's life since they increase suffering and dependency, and also change social structures and the reciprocity of social relationships. These illnesses disrupt narratives of life and result in uncertain futures (Bury 1982). Adapting to illness as a part of life is a social, personal and unique process that the person with the illness, together with their family members and their social network, defines and lives through, using knowledge from other people's experiences, media and professionals. Narrative research tries to interpret this phenomenon by identifying individual remarks about meanings and 'voicing' the illness. Telling and retelling stories helps people to understand their experiences, so attempts to recall one's experiences are typical of illness-related stories (Gwyn 2001).

Living with a chronic illness may disrupt a person's sense of their own body, agency, self and surrounding world, all of which they need to reconsider. This process is called narrative reconstruction, a concept developed by Gareth Williams (1984) to describe the process that unfolds after a person is diagnosed with a chronic illness, which forces them to change their relation to the world and themselves. To renew these ruptures between the body, the self and the world, people use their own life stories to rearrange their present, their past, their future and themselves in society. Societal perceptions of illness affect this process. In the case of dementia, news and media discourses highlight the loss of agency and selfhood, while perceptions of living well with dementia are absent or rarely heard (Bailey et al. 2021). This study provides robust information about varying experiences, including positive ones, of adapting and coping in a new life situation with YOD.

People with cognitive impairment are at risk of reduced agency (Clemerson et al. 2014; Hedman et al. 2019) as physical, functioning and cognitive decline increases (Roach and Drummond 2014; Virkola 2014). Agency may be described as a person's own intentional influence on their function and living conditions. Core features of

human agency are intentionality, forethought, self-reactiveness and self-reflectiveness (Bandura 2001). From a socio-cultural viewpoint, human agency needs to be related to the structures and constraints of one's environment (Giddens 1984). Agency is often seen as goal oriented. Honkasalo (2009) introduces the concept of small agency, which is opposite to basic, active agency. Small agency is humble and minimal: it includes waiting, enduring one's own life situation and fulfilling demands. When people are less able to act independently, they may become less active in some areas, which affects their agency. The abilities of the person with YOD to reconstruct their own agency are based on that person's own notions about themselves, their abilities and restrictions, and the feeling that a purposeful life can be maintained by meaningful activity (Roach and Drummond 2014). People maintain their activity levels both by reacting and, proactively, by compensation (in organising their environment and routines, making notes, using a calendar and narrowing down everyday life) but also by keeping busy and doing memory exercises to maintain cognitive capacities (Beard et al. 2009; Pinkert et al. 2021; Virkola 2014). Focusing on meaningful things that the person with dementia can do to maintain their remaining abilities promotes positive perceptions of present and future agency (Hedman et al. 2019; Øksnebjerg et al. 2018).

Agency changes as the dementia progresses. When one's own abilities to act independently are reduced, support from other people is needed (Virkola 2014). Family members impact on how a person with YOD experiences their own agency because they provide them with the most support and care (Mayrhofer et al. 2021), and they strengthen or weaken the social inclusion of the person with YOD by their own attitudes and strategies (Pinkert et al. 2021). It is important to identify how a person with YOD and their family member(s) cope with the stressors of chronic medical conditions individually and as a unit (Bannon et al. 2021). Joint action is a dyadic phenomenon, which describes couples' attempts to manage a stressful life situation (Bannon et al. 2021; Falconier and Kuhn 2019). In YOD, stressors might include loss of employment and financial challenges (Roach and Drummond 2014), impaired functional capacity (Pesonen 2015), role transitions (Larochette et al. 2020), changes in communication (Wawrziczny et al. 2016) and changes in hobbies (Kilty et al. 2019). All of these include a social aspect; YOD causes ambiguous loss owing to changes in social networks for both the person with YOD and their family members (Harris and Keady 2009). When this happens, the relationships between the person with YOD and their family members become more important, for social, mental and cultural action (Gergen 2009, 75). Understanding the changes that YOD brings and effective communication strategies may help people with YOD to adapt to the illness in new life situations (Bannon et al. 2021; Larochette et al. 2020). The process of adapting might be time-consuming and require constant adjustment (Larochette et al. 2020; Wawrziczny et al. 2016).

The actantial model identifies and structures agency from stories

Narrative is a way to create and give meaning to our reality (Hydén 1997) by reproducing the purposeful events of the past in order to prepare for the future (Gwyn 2001) and by configuring oneself and others. A person makes sense of their life by narrating their

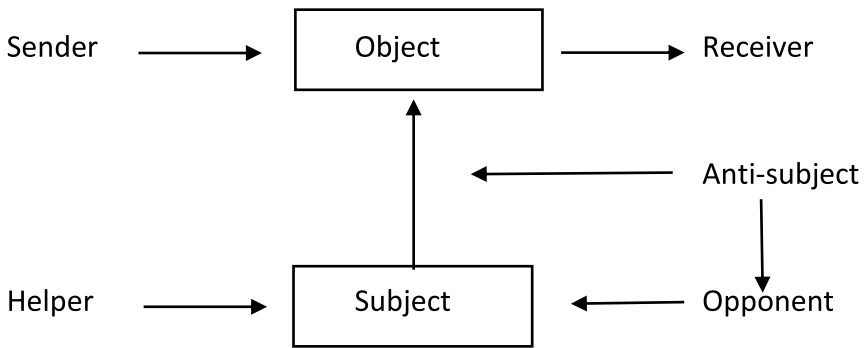


Figure 1. Actantial model by Greimas (1980).

own interpretations about events, and their emotional, causal and ethical meanings, to themselves or to others (Hänninen and Koski-Jännes 1999). A narrative is a story, told to oneself or others, consisting of events and actors chosen by the narrator, which the narrator connects in the narrative with the help of a plot (Hydén 1997). Narratives can be considered as cultural compasses used to navigate the person's actions and create social order (Wentzer and Bygholm 2013). Action manifests in social systems where actors operate under rules and resources in diverse contexts (Giddens 1984). According to Greimas (1980), scholars of culture use the actantial model to examine the structures of narratives, owing to its universal pattern. The actantial model can be used to find out what roles, relations and actions of participants are included in the story and what positions those participants (actors) get in the stories (Figure 1). In this model, agency, which is included in the narrative, emerges between the actants through their actions. Agency also extends beyond humans to non-human factors such as diseases, technological elements, animals and objects, all of which participate in action (Latour 2005). These actors (individual factors) form actants (actors performing the same task in the story), which occur and act in their own micro-universe or living context (Greimas 1980).

The actant model can be used to analyse participants' roles, relations and actions in stories. French semiotician A. J. Greimas developed the actant model based on the model Vladimir Propp used to analyse Russian folk tales (Aarva and Pakarinen 2006; Czarniawska 2004). Greimas (1980) includes seven actants in his model (Figure 1): subject, object, helper, opponent, anti-subject, sender and receiver. The core of the model is the relationship between the subject and the object; other actants cluster around these two. The object is the goal of an action, considered significant and meaningful for the subject, which is the protagonist of the model. These actants constitute the desire axis. The helper supports the subject's embodiment, abilities and competencies, while the anti-subject hinders and complicates the subject's action and the opponent strives to prevent action by using obstacles and causing difficulties. These actants constitute the axis of power. The sender motivates and gives obligation for the action to the subject and the receiver benefits from the action. These actants constitute the axis

of knowledge. Actants are dynamic and have a certain power and energy (Aarva and Pakarinen 2006; Møller and Brøgger 2019; Törrönen 2000, 2014).

Aim

There is little knowledge about how YOD changes agency and how agency is reconstructed after receiving a diagnosis. At this initial stage, on diagnosis, the symptoms of YOD are often mild and action changes only in demanding tasks. Increased understanding of agency in the initial stage of YOD may challenge stereotypical assumptions about dementia and its impacts on people's lives (Virkola 2014). The aim of this article is to analyse how the onset of the illness impacts on the agency of the person with YOD and what family members' role is in this change in agency. In this article, we analyse (1) the interplay of human and non-human factors in supporting or restricting the agency of the person with YOD and (2) what actors may be identified and how those are connected in the initial stage of YOD.

Methodology

This article is based on narrative methodology. Human life involves telling stories, which is a universal way to form and sustain the structures of everyday life. Telling stories is also a way to maintain and repair meanings when those change, for instance owing to chronic illness (Bury 2001). When people experience major life changes, narrative reconstruction helps them to focus on important issues in their past and to consider their orientations for the future. Telling one's own story helps people to maintain a sense of continuity in the midst of changes (Hänninen and Koski-Jännes 1999). Analysing illness narratives helps researchers to understand how body, self and society, culture and contexts, are connected (Bury 2001). Actantial analysis is a helpful device in understanding narrative structures, actors, motivations and values (Sulkunen and Törrönen 1997). The actantial model was originally used in semiotics and literature studies but later extended to health and the social sciences (see Aarva and Pakarinen 2006; Hautsalo et al. 2023; Lejot 2017; Møller and Brøgger 2019; Wentzer and Bygholm 2013).

Data collection

The data were collected in 2020 in semi-structured interviews with 14 people with YOD and 15 family members (Table 1). The people with YOD and their family members were recruited from a neurological outpatient clinic with the help of nurses and a neurologist in two different regions of Finland, as part of the YOD diagnosis process. The participation criteria were: (1) the person with YOD received a diagnosis of generative memory loss disease before the age of 65; (2) the person with YOD was in weekly contact with a family member (over 18 years old) who wanted to participate in the study; (3) participants were able to give written, informed consent. The potential participants received verbal and written information on the research from the nurse or neurologist. If the person with YOD and their family member decided to participate, they both returned a signed informed consent form with their contact information by mail to

Table 1. Participant information

Person with dementia	Age at the time of diagnosis	CDR scores at interview	Family member, age and relationship	Living arrangements
Ritva	65	Moderate dementia, 15	Matti, 63, spouse	Home, with spouse; respite care from 1/2020
Anja	64	Moderate dementia, 10	Reino, 64, spouse	Home, with spouse; informal care began 4/2020
Mikko	64	Questionable impairment, 1	Leena, 65, spouse & Marja, 38, daughter	Home, with spouse
Sylvi	60	Questionable impairment, 1	Teuvo, 61, spouse	Home, with spouse
Raili	65	Questionable impairment, 2.5	Juha, 33, son	Home, alone
Salme	62	Mild dementia, 5	Seppo, 62, spouse	Home, with spouse
Hanna	55	Questionable impairment, 1	Kalervo, 57, spouse	Home, with spouse
Merja	51	Questionable impairment, 0.5	Janne, 58, spouse	Home, with spouse
Taina	57	Normal, 0	Pirjo, 78, mother	Home, with spouse
Riitta	52	Normal, 0	Osmo, 49, spouse	Home, with spouse
Irmeli	52	Normal, 0	Mauno, 63, spouse	Home, with spouse
Sari	55	Normal, 0	Irma, 75, mother	Home, with spouse
Martta	64	Questionable impairment, 2.5	Hannu, 33, son	Home, alone
Hilkka	57	Questionable impairment, 1	Petri, 57, spouse	Home, alone

the first author. This author then contacted the participants to make an appointment for the first research interviews.

The first interviews were conducted within six months of the person with YOD receiving the diagnosis and the follow-up interviews were carried out about a year after that. In this article, we report on findings from the follow-up interviews, which were conducted about 18 months after the diagnosis (2020). The first author, who has extensive experience in communicating with and caring for people with dementia, conducted all the interviews. Interviews were mostly carried out at the participants' homes. Owing to the Covid-19 pandemic, some interviews were carried out by video-call or phone. Semi-structured interview was a suitable method for this research, which involves studying people's perceptions of complex and sensitive issues and topics that participants are not used to narrating as values and intentions. Moreover, this method enables reciprocity between the participant and the interviewer, who can improvise detailed follow-up questions (Kallio et al. 2016). The topics of the interviews were: cognitive symptoms; how the illness has changed the daily living, needs and desires of the parties; social relationships and attitudes towards illness; future plans and any other

things the interviewee wanted to talk about. Since dementia disturbs cognition, and everyone's situation is unique, semi-structured interviews were an appropriate method for gathering data about variable experiences.

Background variables were age, gender, relationship with the family member, type of dementia and Clinical Dementia Rating (CDR). The CDR is a dementia staging instrument used to assess performance in six areas: memory, orientation, judgement and problem-solving, community activities, home and hobbies, and personal care. The measurement is used to characterise and track a patient's level of impairment owing to dementia. In this study, a CDR worksheet was used to calculate the current level of impairment. The CDR values are classified as follows: 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). The CDR score provides general information with which to track the type and severity of the changes that dementia has made in the person's current life situation. The interviewer conducted the CDR assessment together with the person with YOD and their family member, if both participants were available. This required discussion and reaching consensus. In other cases the person with YOD and their family member did the CDR separately and the mean of the scores was noted.

Analysis

The analysis began by listening to the interviews and transcribing them verbatim: the total duration was 28.5 hours and the amount of transcribed text was 439 pages (1,800 characters per page). The actors in the stories were identified using questions about their core mission. The extracted texts were condensed and coded for actors. Actors include all those participating in action, including non-human actors such as disease, technological elements, animals and objects. The same actor also got different roles in different stories.

To get an overview of the actors in the stories told by the people with YOD and their family members, we first constructed a matrix of actors, which created the actants of each story. After that, we grouped these common instances and related expressions for each actant into themes to identify contents, tensions and similarities. This stage of analysis gave us an overview of two data sets: people with YOD and family members. The next step was to put the story of each person with YOD side by side with the story of their family member and to look at each pair of stories together. After that, we identified what storylines were included in the stories, and identified three storylines, one ideal storyline and two non-ideal storylines. In the last stage of the narrative analysis, we used the actant model to formulate the figures of all storylines, named the actants included in them and selected direct quotes that described them.

In this analysis, the ideal story is used as a reference point and other storylines are approached through this. Reference point is defined as 'a fact forming the basis of an evaluation or assessment' (Educalingo n.d. n.p.). Each actant is analysed separately and notions about variation of actors inside the actant are reported. The results section starts from the ideal storyline; then the different actants and actors are considered to outline the variation of agency; after that, two non-ideal storylines are presented. Each storyline is also modified as a figure, where the main actors are presented inside

actant boxes and the action in the storyline is demonstrated using arrows. The CDR scores of participants are included in [Table 1](#) to give general information about the progress of the YOD, which varied between participants. We did not include progress of YOD in the analysis; rather, we considered all the stories and the descriptions they contained to be qualitatively equal regardless of the severity of the person's dementia. We demonstrate the variation and implementation of analysis through direct quotations.

Ethical considerations

This subject is sensitive and ethical review was necessary as the topic is in human sciences and is associated with patient experiences of dementia. People with dementia may lose the ability to make decisions, so ethics must be considered carefully (Simpson 2010). The ethical review was accepted in March 2019 by Tampere University Hospital Ethics Committee (R19023). As advised in the ethical review, every participant received verbal and written information about the research and gave written informed consent before the first interview. Information about the research and voluntary participation was repeated verbally before follow-up interview. Dementia affects participants' cognitive skills, so special attention was paid to giving the information clearly. Furthermore, process or ongoing content was used in the situations when limited capacity was suspected (Dewing 2007). One interviewee's illness had progressed so that her communication skills were weakened and memory problems were severe, so there was a need for process content. She had given written informed consent to participation a year before, at the beginning of study. In the follow-up interview situation, she could not answer verbally the question 'Do you want to participate in a research interview and talk about your situation?', but she expressed her will by answering some simple questions and was showing wellbeing in the conversation situation. This behaviour confirmed ongoing consent. All the names of the participants in this article are pseudonyms. Direct quotes were translated by the first author.

Results

Altogether there were 29 participants in this study, 14 people with YOD and 15 family members. Thirteen of the people with YOD were women and one was a man; all were aged between 51 and 65. The diagnoses of YOD were Alzheimer's disease (12), Lewy body dementia (1) and frontotemporal dementia (1). Ten of the family members were spouses, three were adult children and two were parents; all of the family members were aged between 33 and 78. Two family members (the wife and the daughter) of one person with YOD participated. Two of the people with YOD continued working after diagnosis and the other 12 were retired or on sick leave; two of them received regular support in the form of respite care and informal care. The participants' CDR values demonstrate progression of the illness; the values ranged from 0 to 15 (see [Table 1](#)).

Next, we describe the results of the narrative analysis. We start this from the ideal story, which is used as a reference point to describe how the agency of the person with YOD and their family member changed, but they managed to respond to the disruptions, maintain earlier agency as much as possible and find a balance in their life

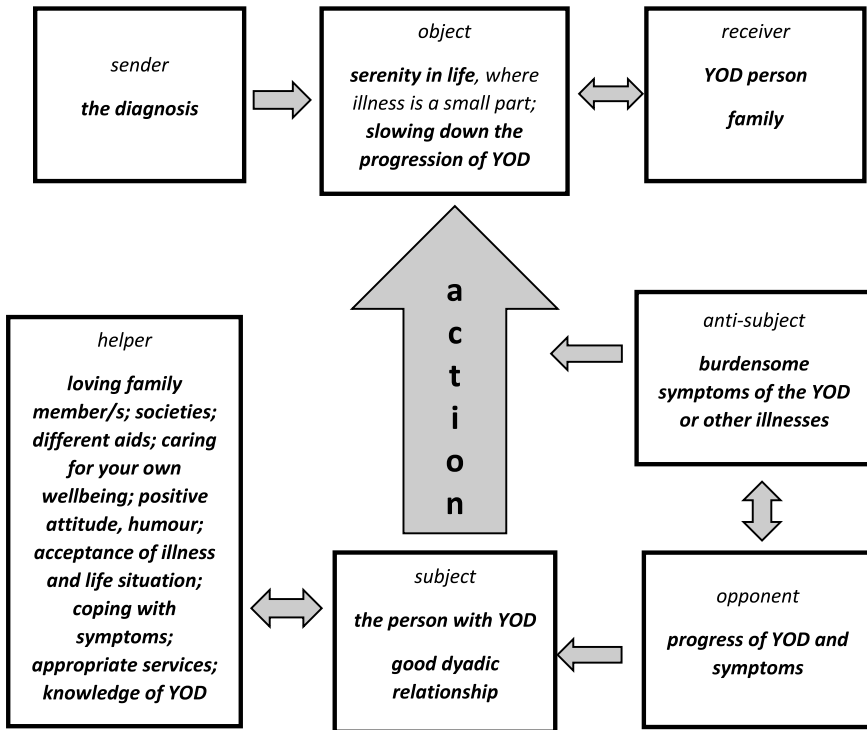


Figure 2. The ideal storyline: action (arrows) and actors (in actant boxes).

situation. This storyline was named ideal because it follows the original actant model: all actants of the model exist and the flow of action between actants is the same as in the model. This story is gathered as a combination from several participants' stories. The actors and the action of this ideal narrative are described in [Figure 2](#).

I am Maria, and I received an Alzheimer diagnosis when I was 55 years old, a bit over a year ago. I have two grown-up children; both have moved away from home. We got divorced when the children were teenagers. Three years ago, I met a wonderful man, Pete, and we moved in together and got married last year. I don't work anymore. Before this diagnosis, I had some periods of sick leave. After diagnosis I started to work half-time and that was alright for me; working as a nurse wasn't too burdensome that way. But after this year's summer holiday, I noticed that work was too much for me, busy and stressful, so now I'm on sick leave and waiting for a pension decision.

After diagnosis I have started to take better care of my wellbeing. I try to avoid stress and do meaningful things, which I enjoy. In fact, my object is to focus on the most important things for my wellbeing. I have always taken care of others, but now I must look after myself. The time for that is now or never and nobody else is able to do it for me. This diagnosis made me understand that I need to live my life;

it is not worth it to freeze and mourn. I don't want to shout [about my illness] or make a big fuss about it. However, I am me, and not my illness. It's like a secondary thing. I agree with my husband: this illness is just one small part of our life; we have accepted it and we can live in serenity with it. Pete reminds me if I'm overloading myself. Nowadays we do more things together than earlier. We often go biking or for outdoor walks, meet friends, make sure we sleep and rest enough and eat good food. We have plans for travelling and developing our home, too. I have changed my way of thinking; I keep to positive thoughts, concentrate on the moment and have a simple lifestyle. Routines make life easier: I have an alarm in my phone for taking medicine and I use an e-calendar; I store my important things in the same places; I have discarded my unnecessary clothes and belongings.

Diagnosis cut down something, I can't be my old parents' legal guardian or drive a bus or a truck. But those don't matter so much. The most difficult thing is the unknown future because of this Alzheimer. But that's the way the cookie crumbles, and I do manage with it. This illness doesn't stop me from living a full life, it has just brought a new tone to some situations. Like I don't trust my memory very much, so I write notes, use a calendar and take time to learn/practise things. I try to listen to myself and my feelings carefully; if I'm tired, in a low mood or angry I take time for myself and let it be; it will pass like that. I have learned to know and understand myself. I am interested in many things and I have possibilities to choose and do things I like, and also time to use because I don't work anymore. My intense eagerness for life and my loved ones around me are my greatest resources.

Pete: We are very close to each other, and we value living together a lot. We have shared housework according to both strengths and interests, and we do many things together. Maintaining good wellbeing is important for both of us. Well, my own chronic illness needs that too. We have similar values and views about life and also about this Alzheimer. We don't talk a lot about it nowadays, just to make sure that it won't take too big a role in our life. I'm used to some symptoms that Maria has, and I have noticed that I support her sometimes too easily, like saying a word she can't remember. We do challenge our brains in different ways, but I also encourage her to notice her stress level and small things like that. My current ideology is: 'Don't waste time worrying. Do the things you can influence and do them well.'

The ideal storyline is about adapting and renewing agency in the YOD situation. In this story resources are used well, there is enough support, agency is maintained and the illness is accepted as a small part of life. The subjects of the story, the person with YOD and their family member, both parties in a dyadic relationship, are very strong. They strive determinedly together to achieve the object, which is serenity in life and slowing down the progression of YOD. Another objective in the story is to reduce the role of the illness to a small part of life. The main action in the story is the effort to achieve the aim of the story. The action is performed in joint agency, by Maria and Pete together. Other actants cluster around these two actants and give ideal support to the main action of the story. The variation of helpers is wide and the subject has the will to increase their number and active use, owing to the subject's orientation towards

adapting and coping. One example of this, in Maria's story, was the need for simple living and routines, which she implemented by discarding unnecessary belongings and using a calendar and reminders. The opponent is the illness, its symptoms and other illnesses, all of which hinder the action. Disruptions caused by the illness are noted and action is balanced with support from helpers. Awareness of the diagnosis acts as a sender to help the subject notice their own and their dyadic wellbeing, which helps to maintain the agency of the person with YOD. Receivers are highlighted; the new situation has brought some good things for the person with YOD and their family.

However, experiences of changing agency varied, and most of the stories included lots of actors and action that did not fit the ideal story. Actors could change places, or stories did not include some actants at all. Moreover, the role of certain actants was emphasised, which changed the relationships between the actants, the flow and the action in the story. Next, we consider different actants and variation of actors to outline the variation of agency. We use the ideal story as a reference point and mention first the elements of actants that supported agency and then the elements of actants that reduced agency.

Different positions of the subject

The subject and the object are the core of the actantial model and make up its desire axis (Törrönen 2000, 2014); the main agency of the story is built around these actors. The subject in the story of the person with YOD was how their own position with the YOD diagnosis was described, including attributes of their illness. In the ideal story, the subject's sense of agency was strong. In the non-ideal story, the subject's sense of agency was described as variable and unpredictable. In these stories, illness had different impacts in different situations. Those changes felt like a burden, as Martta tells:

Martta: Well, I live alone, and I've never adapted to it. I'm aware that there was something I had been meaning to do, but I can't even remember what I was supposed to do. Then, aaah, if I plan to go to the store or even for a walk, then I prolong leaving so much and check the time and I think that I won't even bother to go there.

Martta felt loneliness and isolation. Furthermore, symptoms of YOD made it difficult for her to go out alone. These changes undermined her sense of agency. She could not act independently but needed support, such as company for a walk or shopping, to be able to use her potential agency. Weakening sense of agency was also described as uncertainty, a sense of diminishing abilities and distancing from previous ways of doing things. Some participants described withdrawing and freezing in some situations. The unpredictability of their own abilities made situations difficult: sometimes the person with YOD felt that their own agency was normal, but in general their agency varied.

In family members' stories, an important part of the subject was how the family member experienced the relationship with the person with YOD. In the ideal story, both saw the illness's role in their life as similarly small, the relationship with the family member was equal and they could give each other mutual support. The family members' stories included non-ideal storylines. It was stressful if the relationship made them too dependent on each other, or changing roles were very demanding for family

members. Conflicts caused by changes due to YOD changed how they acted together, as family members Juha and Hannu describe:

Juha: My mother thinks I have become distant because she constantly insists that no one visits her... She feels like she's been left all alone here. Of course, that's not true, but she forgets our visits. And when I visit her, she vents her feelings about how I just sit here and no one comes ... I don't want to be mean to my mother and remind her about earlier visits or tell [her] that I don't see my friends every day or week, either. My attitude toward my mother has perhaps matured as I understand that she has that illness, and that's why I need to be more patient.

Hannu: There was a conflict because she has certain blocks in her thoughts. She keeps saying that I waste her money when I buy something for her that she herself wanted a little while ago. This conflict was related to buying a coffee maker (explains the flow of events in detail). I told her directly my thoughts, there must be some limit in how you treat others. She might have a misunderstanding, and then a ridiculously small matter blows up into something big ... My sister also called me and asked if I could come with mum and asked can I forgive to her. I told to her that I am okay with this, I have accepted this. But it would be such a huge plus if my mother could get rid of the idea that I have any bad intentions. I always think solely about what's best for her. It's incredibly tiresome from a relative's perspective when you give your all, and the other person just complains.

Both these quotes from family members describe the changing action of parties and the changing relationships. The family member had to take more responsibility and support the person with YOD even when their behaviour was negative and burdensome and changes happened one after another. Ongoing changes forced the family member to reconsider their attitude many times, as both Juha and Hannu describe. Juha accepted the situation, while Hannu described a conflict when he responded to his mother's accusations. These situations had an impact on the cohesion of the relationship. Family members also balanced their own agency so that the person with YOD was able to retain some of their agency. Changes in family roles have been found to cause stress in the early stages of YOD (Bannon et al. 2021; Harris and Keady 2009).

Objects of wellbeing and conflicts of objects

In the ideal story the object was to fight against progression of the illness and to improve or maintain as much wellbeing as possible. In some narratives, the main object did not include an attempt to improve one's own wellbeing, but was more about retaining the meaningful parts of the previous lifestyle and seeing how the illness would develop. In these stories the dementia was seen as unavoidable and one's own opportunities to influence the situation were seen as minimal. This weakened the person's own agency: the lack of a goal decreased action and the desire to achieve it.

Raili: this illness has now slowed me down and there are many things that have to be accepted and nothing you can do about it. That is how it is now, at the moment.

Reconciling oneself in this way may lead to narrative foreclosure, if the person experiences that the productive part of life is ended and ageing with progressive illness has taken over (Freeman 2000).

Examining the objectives from a dyadic perspective brought out variability of action. If the aim of the person with YOD and that of the family member were different, this affected their actions. Kalervo talks about how he experiences Hanna's daily action and his thoughts about the need for rehabilitation:

Kalervo: Things are quite up and down here. We can't get her activated, and she has no interest in rehabilitating herself or her memory. She doesn't have any desire for it. We've been trying to motivate her for a year now, but it's not working.

Interviewer: What kind of activity does Hanna engage in?

Kalervo: Well, it's close to zero if you consider a normal person in this situation – being at home without the need to work. She attends the mandatory appointments, participates in a fitness group 2–3 times a week, but that's about it. She doesn't go grocery shopping or cook when she is at home. There's no normal daily activity.

In this situation, Kalervo's aim was to support Hanna to improve her wellbeing and brain health and to help her get more active. Hanna did not agree; her aim and interest were different. The situation was burdensome for both of them in the dyadic relationship and drove them apart. When the person with YOD felt that their agency was reduced and aimed to disengage, and the family member agreed this aim, the family member's agency concentrated mostly on modifying the living environment to best support the agency of the person with YOD. This meant arrangement of services (meals delivered to the person's home, support person's visits, house cleaning) or aids (GPS on the person's phone, a medicine dispenser, etc.) but also planning leisure events, like travelling together with a child's help, or shared hobbies. In these stories services, aids, trips and hobbies became helpers. This mutual action with helpers supported the wellbeing and agency of the person with YOD, and often also the dyadic wellbeing and adapting to the changed situation.

Helpers empower and support agency

In the actantial model, tension between the actants of helper, opponent and anti-subject gives power in the story: helpers give positive power to the subject's agency while opponents or anti-subjects impair the subject's power (Törrönen 2000, 2014). Helpers were positive resources that supported the subject's agency. Each story included some helpers, but each helper was different and they were used differently. We describe this variation next. In the ideal story, the subject described a great variety of smaller and bigger helpers. In non-ideal stories, the subject described hinderers and burdensome changes, and had fewer or scattered helpers who did not support the agency of the subject.

In the stories of people with YOD, individual factors that helped them to adapt in their new situation were important helpers. These storytellers said that it is important to be open about your illness, to have positive perceptions about yourself and your

skills, to be able to change your own action and use routines in daily living, to rest and sleep well, and to notice good things in life. Furthermore, a positive attitude towards YOD helped. Riitta describes how she experiences Alzheimer's:

Riitta: I don't find it (dementia) a burden because I don't think of it that way. I think it's also a matter of attitude. I think that this is the same thing as joint pain. I had painful joints and got artificial joints and then I was moving forward again. Okay, Alzheimer came, I got pills and I started to take care of myself and again I'm moving forward.

Riitta's attitude helped her to accept the changes that came with YOD and encouraged her to take care of her own wellbeing. Other people, like siblings, parents, friends and neighbours, are important and they act as helpers if the subject experiences them as supportive and their relationship is maintained despite the YOD. Helpers were often connected to social relationships and narration of those included emotional issues and values. Helpers also had a strong connection to the prior life, to the interests and aspects of the person's individual lifestyle. Mikko describes his favourite hobby:

Mikko: I always look forward to autumn (hunting), it's always like life starts again when I get there. I go there (to the forest) as long as I can and enjoy hunting as long as possible.

Mikko had previously participated in moose hunting for decades, and the people in the hunting group were his friends. He enjoyed being part of that group, going to the forest and getting venison for his family. Hobbies were an important part of life: they promoted wellbeing, belonging to a meaningful group and interesting activity.

Non-human resources needed to support agency included a driving licence, which enabled independent mobility; appropriate services; and daily living aids like GPS in the phone, an e-calendar, alarms, a medicine dispenser, notes and daily structure.

Family members' stories included similar helpers, support and routines. All of these were important, as Matti, husband of Ritva, tells us in his interview:

Matti: We have two adult sons. The younger one lives just ten minutes' walk away; he visits us often. The older son lives a little further away, and he comes every Sunday and he cooks for us for the next week. He comes with our dog; he has it nowadays.

This kind of help brought rhythm to the week, maintained social relationships and enabled family members to share responsibilities. Matti was not used to cooking, so his son's help enabled him to concentrate on caring for Ritva, whose YOD had progressed and thus she needed lots of help.

Family members needed resources to support the person with YOD and to care for their own wellbeing. Peer meetings were an example of this kind of support; they helped family members to understand YOD and its symptoms, and to reflect on their own situation with other people who had similar experiences. Family members said that future planning was beneficial and it helped them to adapt to changes. Financial wellbeing gave them increased security. Technological aids helped, like turning on GPS

in the phone of the person with YOD and connecting it to the family member's own phone.

The dyadic relationship between the person with YOD and their family member was a great resource for both parties, and it included shared interests and common actions. The dyads shared physical activities and hobbies that were meaningful for both parties. If the family had a pet, it brought rhythm and content to daily living. Emotional connection created a basis for the dyadic relationship: stories included love, gratitude, reminiscence of shared experiences, sharing and reciprocity. Humour and shared jokes were important for many participants. Seppo, Salme's husband, gives an example of this:

Seppo: Sometimes we also have humour. Salme's sense of humour has been preserved, just changed a little; it's different. She notices some funny things that I don't.

Humour had been part of their relationship and when dementia disturbed communication and function in daily living, humour was an important way to lighten situations; laughing together and joy helped maintain togetherness in the relationship.

Altogether, each story was unique. The participants narrated about a wide variety of resources, helpers and sources of support in their current life situation.

Hinderers of action

Opponents and anti-subjects introduce hinderers into the stories (Törrönen 2000, 2014). The diagnosis was the greatest opponent. Anti-subjects strengthened the opponent and hindered the action to achieve the aim of the story. Symptoms of YOD increased the burden of illness and reduced agency. People with YOD talked about burdensome feelings such as despair or low mood. These feelings arose owing to experiences of guilt because of forgetting, loneliness and isolation in changed life situations, losing independence or finding it difficult to ask for or accept help. Giving up one's own skills and agency was also burdensome, as Mikko says related to the driving licence:

Mikko: Well, I got my driver's licence again for a while. But there will be a time when I can't get it anymore.

This awareness of one's reduced agency and uncertainty about how the YOD will progress diminished the participants' sense of internal agency. Family members narrate other things that reduced agency: symptoms of illness; reduced action; forgetting, which complicated daily living; impairment in initiative and learning abilities; emotional variability; and unpredictable variation of symptoms. People with YOD had started to blame or accuse their family member, to increase alcohol abuse or to become isolated and lonely. Reino describes Anja's difficulties in going out:

Reino: She doesn't want to go anywhere. Her hair is always dirty or there is a stain on her trousers. Or something else. It doesn't matter where we're going, it takes so damn long to get out the door. Even if I say half an hour earlier about leaving, I'll have to wait ten minutes in the car.

Anja's initiative was weakening and she preferred to stay home, which in turn led to increased isolation. Family members reflected on their own action in these changed situations. They were aware that if they lost their temper, it was stressful, complicated the situation, caused a conflict and hindered the action of both parties.

The diagnosis and the progressive nature of YOD aroused uncertainty, which stimulated the narrators to imagine dark and scary scenarios for the future. Both people with YOD and their family members mentioned the unknown future as an opponent in their stories, but did this in different ways, as it was differently burdensome for different participants. Teuvo talks about how he sees his wife's YOD:

If the illness worsens from this, what will happen? We're currently living in somewhat uncertain feelings about which direction it's going in. It doesn't improve in any way; so our living depends on how quickly it progresses.

Participants were uncertain about the future and the progression of the YOD, even though the changes it caused were still mild, as Teuvo describes above. In the stories where the YOD diagnosis and symptoms had affected daily living a lot and changes were perceived as unavoidable, the diagnosis was a powerful opponent. One family member, Mikko's wife Leena, describes this in their situation:

Leena: Mikko gets angry about small things, and doesn't have the same endurance as earlier. Sometimes I feel that I always have to be on my toes, so I don't in any way make the other person angry. It's so stressful for me.

Mikko's behaviour was unpredictable and he showed signs of aggression, which was very burdensome for Leena. Family members noted other changes in the behaviour of the person with YOD: depression, changes in personality and loss of self-confidence. These changes required the family member to change their own agency, to become aware of early signs of difficult situations, to be more patient or pay extra attention to communication. These changes were related to slow abandonment of the loved one and loss of togetherness in the relationship. The changes took up a lot of energy for both parties.

Hinderers impacted all the time for Leena and Mikko, but in other stories they impacted only occasionally, as was the case when Riitta was called by the hospital:

Riitta: She (the hospital's social worker) took no way into account the fact that if she just lists those foreign things (the sick person asked about benefits) to anyone like bla-bla-bla on the phone, the person doesn't understand. At least not a person who has Alzheimer. And I'm thinking also about people whose illness has progressed. It's completely stupid to assume that the person is able to take care of things based on that. If she could say it simply and clearly, or send the basic things by email. You don't want to ask 'repeat that please' many times, when you value yourself somehow, you don't want to say like repeat again, repeat again, repeat again. I know for a fact that I can manage at work and I'm a smart person.

In this example, a social worker, health services and also (use of) the phone were hindering actors of the story. Hinderers were linked to interaction with other people: Riitta did not get the help she was asking for from the professionals. Hinderers

increased discomfort, showed the person with YOD that their abilities were changing and impaired their functioning. This started to happen from the beginning of the illness, even when changes came up only occasionally and were so mild that the communication partner probably did not even notice.

Non-human actors played a smaller role, but were also hinderers. Participants from both groups narrated financial uncertainty due to changes in work and lack of appropriate services. Other diseases were also hinderers that restricted movement and caused pain (e.g. rheumatism or migraine) or led to a high risk of heart attack or stroke. Matti, Ritva's husband, tells the interviewer about his own chronic illness and their home situation:

Matti: As long as I'm standing on my own two feet, I'll help her. The danger is that if something happens to me, Ritva will immediately be placed in some care home. Ritva wouldn't manage alone, and even home care wouldn't be sufficient.

When family members included their own other illnesses in their stories, they raised the additional concern about the wellbeing of the person with YOD if something happened to them.

Senders: the diagnosis as a driver of change

In the actantial model, the sender and the receiver represent the axis of knowledge, and the sender gives the obligation for action (Møller and Brøgger 2019; Törrönen 2014). In the participants' stories, the sender was the diagnosis. The diagnosis of YOD acted as a catalyst for change. The appearance and the significance of the sender in the stories were individual. In the stories of the person with YOD, diagnosis changed other people's behaviour; relatives started to visit or call more often to see how the person with YOD was doing. Family members' roles also changed as the person with YOD gave up some responsibilities. Because knowledge of the diagnosis changed other people's behaviour, narrators considered who it was worth talking to about the diagnosis. For some, openness about the diagnosis made life easier, since others knew why things were changing and the narrators did not need to pretend. Reasons for keeping the diagnosis to oneself or to just a small group included fear of pity or of the illness getting too big a role in relationships with others. Some participants considered who to tell very carefully:

Riitta: In the spring, I told my mother that I couldn't become her legal guardian. I explained that my illness made it impossible. She got upset and insisted I tell her about my illness and details of it. Fortunately, Osmo was there and reassured me that I didn't need to disclose it – it was a private matter. My mother eventually accepted this, because my husband said it to her... She is a person who can't keep things to herself, she would shout about it to everybody. I don't want pity or to be defined by my illness. But I did decide to share it with my sister, explaining that, with this diagnosis, I'm not qualified to be our mother's legal guardian. Surprisingly, my sister took it well, and perhaps it even brought us closer together.

Riitta could not be the legal guardian for her mother, but, when the family were making arrangements related to this process, she had to reconsider who she would tell about her

diagnosis. She got support from her husband in the conversation with her mother and was able to act as she wanted. Telling others about the diagnosis was related to individual situations, relationships and attitudes towards illness. The diagnosis incurred other restrictions; the person with YOD was not able to be a professional bus or truck driver, and might lose their car driving licence. The diagnosis increased the need to make a will and advance decisions or to plan for the future. Furthermore, the diagnosis altered societal roles: people with YOD mostly stopped doing paid work and started receiving benefits or some services, such as visits to a psychologist.

For a family member, the diagnosis as a sender started new agency. The diagnosis could create a new need to observe and assess the functioning and abilities of the person with YOD, to make sure that they could cope with their own daily life, as Teuvo, Sylvi's spouse, tells us:

Teuvo: This doctor sent me a message, that I should monitor how Sylvi's car driving goes. Well, we drive together and she also sometimes drives by herself to the store.

For the family member, this responsibility was new and important in the new situation. The diagnosis also created needs for information about the illness, services, financial benefits and opportunities for peer support. Some of the family members started to be the caregiver of the person with YOD. Overall, the diagnosis and the progression of YOD initiated new actions and changes in an ongoing process.

Receivers show achievements in the changed life situation

All the receiver actants represented something achieved owing to this new life situation. The ideal story contained several receivers, from the person with YOD to the whole family. In non-ideal stories, the receivers were more hidden or totally absent, because in the burdensome situation participants could not notice any benefits or achievements owing to the changed life situation.

Receivers were notions about positive changes, which were particularly related to human actors. A person with YOD was a receiver because of retirement: freedom to do things had increased and stressful, time-consuming work had ended. Some participants reflected on how their feelings of meaningfulness, self-awareness and devotion to loved ones had increased because the illness forced them to reconsider these issues. Family and loved ones (including pets) were also receivers; more time was spent together and concrete help was given to each other. These were noted to strengthen relationships:

Sylvi: It's nice when you get freedom and don't have to go anywhere. It's really nice to be at home, to walk in the nearby forest and on the roads with the dog and things like that.

Sylvi enjoyed her retirement and her daily walks in the forest with the dog were important to her.

In their stories, some family members saw themselves as receivers because the new life situation taught them to understand the illness and the behaviour of the person with YOD. Mutuality in the family relationship increased: family members talked about how important it is to care for each other. Marja, Mikko's daughter, describes her experience:

Marja: I want to live this with them. I want to be up to date, and he (Mikko) is quite agreeable about me going with him to the doctor. And he even thanked me; even though I quite critically said things to him right there at the doctor's surgery, he still thanked me right after that, took my hand, and said thank you. I don't have my own children and I have the freedom to come and it's my own decision. I feel that this is my thing, and I want to be here. They have raised and helped me, I feel that now it's my turn. Parents have their own duty, so now I feel it's my turn. I couldn't live with myself if I wasn't part of this and I was an outsider.

The changing situation was stressful to Marja, and it forced her to consider meanings, her motivations and her relationship to her parents. Storytelling about her own situation enabled her to say these things out loud and to incorporate her father's illness into her own story. The notions of receivers did not come up in each family member's stories, but if receivers were mentioned, the story included some positive outcome in the changed life situation, which promoted coping with the illness.

Non-ideal storylines of agency

The final part of the findings consists of two non-ideal storylines. These two storylines sum up the elements and the flow of narratives that differed from the ideal story. The structure and the action in these storylines are more scattered and fragmented because, in these stories, burdensome elements are increasing and resources are decreasing. The YOD is a heavy burden in these stories, and it steers action. The subject, whose sense of their own agentic abilities is declining, has low capacity to reconstruct agency in the midst of ongoing changes. These elements and the flow of the narratives lead to two different storylines of diminishing agency. These storylines are shown in [Figures 3 and 4](#), where the size of the actant boxes indicates the intensity of the actant. The agency is described with an arrow whose size and direction indicates the typical action of the storyline.

The readjust storyline is shown in [Figure 3](#). The subject's sense of agency was fragmented owing to declining abilities and changes in the relationship between the participants. The YOD and the changes it brought about were ongoing and both parties had to try to adapt to those continually, which made the situation stressful. This story's key point was the action of the subject. Both the person with YOD and the family member were acting in the same direction because they had the same object. The object for both was the shadowy future, owing to the unknown progress of the illness. The action of the subject faced a strong opponent, the disease, and a wide variation of anti-subjects. The family member's role as a helper was important; therefore, the subject was empowered owing to the family member's supporting action and the mutuality of relationship was maintained.

Another non-ideal storyline was the 'no way out' story ([Figure 4](#)). The name of the storyline describes the main action of the story: the person with YOD is trying to adjust to their own reduced ability to act alone in the situation where burdensome changes come one after another. The action of the person with YOD and that of the family member proceed in different directions. The object of the person with YOD is in shadow; the person is waiting for the illness to progress. Therefore, their own action is weak and they feel at a loose end. The family member is in the role of helper, but the

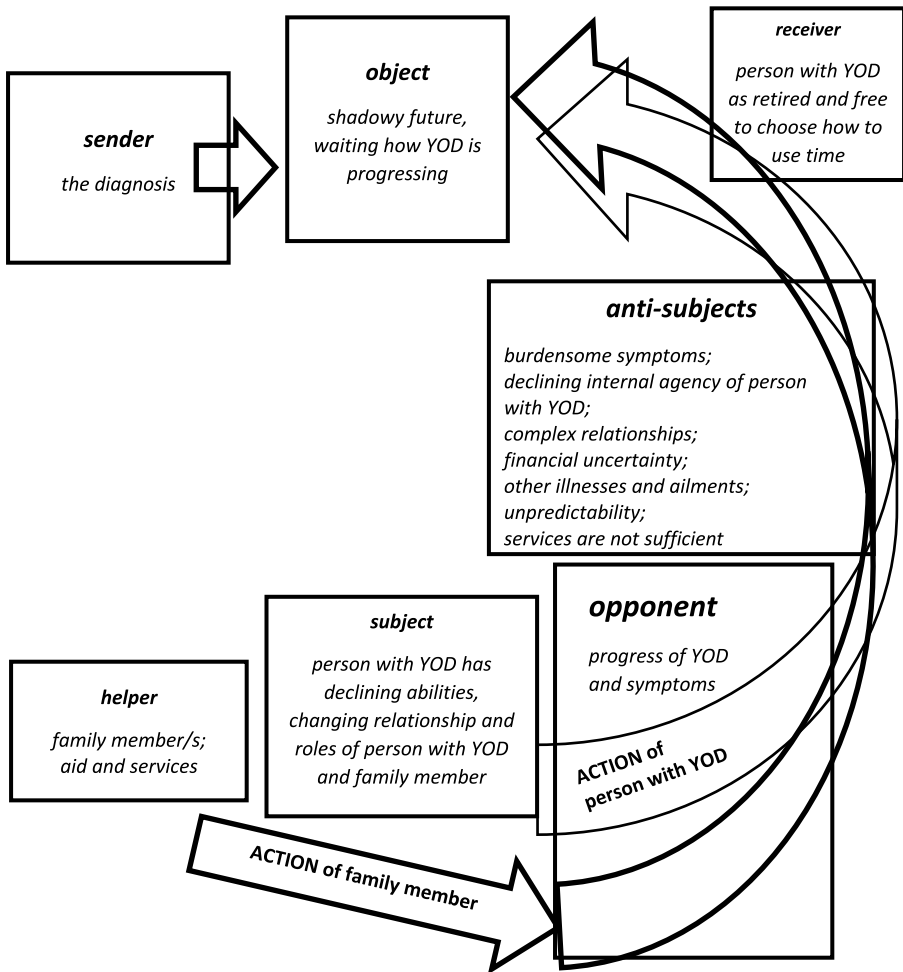


Figure 3. The readjust storyline: action (arrows) and actors (in actant boxes).

family member’s own vision about the object is different, for example to improve the situation. Owing to this object conflict, the family member’s action does not support the subject’s action but goes straight to the object. For the person with YOD, this complex relationship acts as an anti-subject. The main opponent, the YOD and its symptoms, dominates and creates dark scenarios for the future. The subject, the person with YOD, remains mostly alone in this vicious circle, which causes stress and takes up energy. There is no receiver in this storyline.

Discussion

Young onset dementia threatens agency as it changes social roles, affects communication skills and impairs functions (Larochette et al. 2020; Wawrziczny et al. 2016).

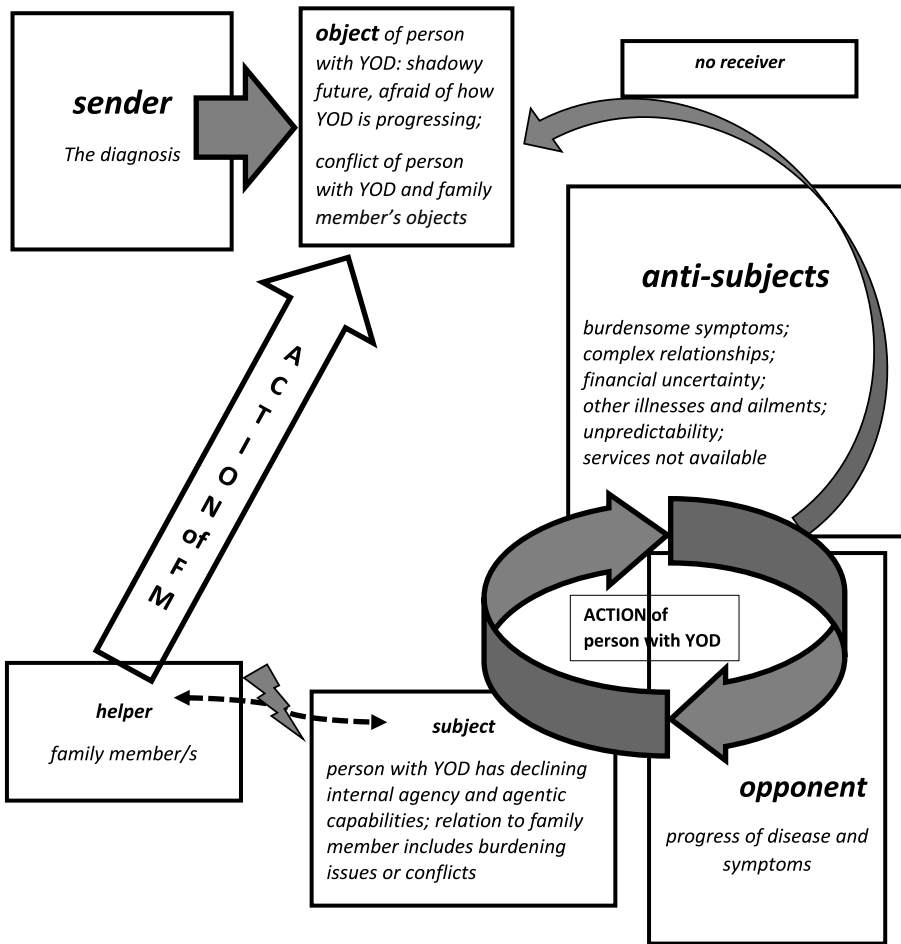


Figure 4. The ‘no way out’ storyline: action (arrows) and actors (in actant boxes).

The new situation needs evaluation and a person with YOD has to adjust their agency to their new way of daily living. This study shows the similarities and differences in factors that influence the reconstruction of agency. In their stories, people with YOD constructed their agency around their perceived agentic abilities and how they saw their aims and possibilities for their own future.

Adapting to YOD and agency were described in ideal and non-ideal storylines. Each storyline had similar elements and narrative flow. In the ideal story, adapting consisted of maintaining previous agency and continuously modifying action in line with changes brought about by YOD.

In the ideal storyline, the person with YOD’s own abilities, possibilities and sense of meaningfulness were strong and relationships with family members endured, so the narrator’s own sense of agency was strong. The narrator had an active desire to

achieve their own aims (like serenity in life and wellbeing) and to slow down the progression of dementia; individual actions in hobbies, interpersonal relationships and work were adjusted to support these aims. If both the person with YOD and their family member strove for the same aim, this fostered a sense of agency and dyadic agency appeared in the story. This brought out the relationality (see Gergen 2009), which becomes more important after diagnosis with YOD. Loss of identity or sense of self is common (Shoesmith et al. 2022) and maintenance is an important factor in managing life with dementia (Pinkert et al. 2021), as this study also showed. Action to maintain agency starts from diagnosis, even if symptoms are very mild and occur only occasionally. Because the YOD is unpredictable, it fragments the person with YOD's sense of their own agency and their abilities to act.

In the non-ideal storylines (readjust and no way out), the person with YOD did not dare to set aims for the future or even to think about the future because surviving the present took all their attention. Desire to reach some aim or to achieve something important for oneself was low or missing in these storylines. People with dementia concentrate on the present and living in the moment because it enables connection to the situation, a sense of meaningfulness and keeping up (Hautsalo et al. 2021; Keady et al. 2022). The sense of an unknown and threatening future may lead people with YOD to reduce their own activities. The illness and the changes caused by it can mark and weaken agency (Hautsalo et al. 2021, 2023) and may reduce agency (Honkasalo 2009), turning the person with YOD towards a receptive phase of action, which fastens remaining social bonds and keeps the person within their restricted everyday life.

This study shows that the relationship between the person with YOD and their family member is a remarkable factor in agency reconstruction. In a dyadic relationship, understanding of the situation is congruent and agency towards a shared aim is constructed together. The possibilities and limitations of both parties are expressed openly and noted in daily living. Positive dyadic coping requires positive communication, common problem-solving and negotiation (Bannon et al. 2021) but also receiving help, tools to cope with symptoms, and effort to preserve as much autonomy of the person with YOD as possible (Wawrziczny et al. 2016). Incoherent relations in this study included conflicts between the family member and the person with YOD, especially if the parties had different attitudes towards the illness or different aims in the situation. In these instances, the person with YOD did not get reassurance and support for their agentic abilities or individual factors from their family member and the relationship became less mutual. These situations reduced agency, which was under construction and in flux, as the agency was directed differently. The person with YOD was left alone in the situation; their agency was reconstructed based on their declining abilities and skills. At the same time, the family member acted to realise aims that they saw as most important. Previous studies confirm that coping in a dyadic relationship is interrupted by mutual avoidance, negative communication (Bannon et al. 2021), irritation and anger about mistakes (Johannessen et al. 2018) and/or social isolation, loneliness and frustration about the uncertain future (Wawrziczny et al. 2016).

Different factors strengthen or weaken the sense of agency of the person with YOD. An accepting and flexible attitude towards the illness, suitable communities and hobbies, pets and sufficient aids are examples of supportive, positive factors. Previous work

has noted positive strategies for empowering identity and coping with illness: positive attitude, physical and social engagement, adapting the environment (Beard et al. 2009) and modifying stressful situations (Johannessen et al. 2019). Negative and hindering factors reduce the person with YOD's experience of their own abilities and agency. In this study, the most burdensome issue was dementia, which had impacts like self-doubt and blame owing to forgetting, despair, unpredictable variation of symptoms, and fears of the unknown future and of the progression of both the dementia and other illnesses. The balance between helping and hindering factors differed in each story. These factors strengthen or weaken the agency of the participant and impact the flow of the narrative. Non-ideal storylines were overshadowed by dementia and diminished agency (see Honkasalo 2009). In the 'no way out' storyline, the narrative flowed towards the idea that the story was over. This storyline has similarities with narrative foreclosure (Freeman 2000), in the narrator's vision about the future and the end of life. Narrative foreclosure refers to a narrative of inexorable decline, which excludes the person's image and experience of their vital self and self-sufficiency. To support the sense of agency of the person with YOD and their family member, helpers can notice resources and generate appropriate aims for the life situation. This can promote reconstruction of agency and adapting to the changed situation.

Based on the findings of this study, we make three recommendations for clinical practice. First, professionals should ask people with dementia and their family members to narrate how they experience their abilities and resources. This would enable professionals to understand individual situations and to promote the agency of both parties, individually and in dyadic relationship. Hinderers and needs should also be discussed because these are key factors in well-tailored support and help. Narration from both perspectives is important for the storyteller, too, because it helps narrators to reconstruct understanding of their own situations and promotes coping.

Second, professionals need understanding and sensitivity to observe the dynamic changes that YOD causes. Changes in agency are individual, mostly related to social relationships, and start occurring from diagnosis, even if symptoms are very mild and appear only occasionally. Adapting to ongoing changes owing to dementia is a continuous process that families experience together and as individuals. These changes should be considered in all services, taking person-centred and family-oriented approaches to their needs, being aware of service-users' biographies and attending to the continuity of services.

Third, the dyadic relationship between the person with YOD and their family member should be supported as the changes caused by dementia affect the mutuality of that relationship. Conversations about how both parties experience YOD and their aims in the situation help to reveal both parties' feelings, meanings, attitudes and values. These conversations may help the person with YOD and their family member to find shared aims and understand each other's motivations for action; they may also promote shared agency and maintaining the dyadic relationship.

A strength of this study is the narrated stories, which are a unique document of existential living with YOD. The life situations, relationships with family members and symptoms of dementia varied, making it possible to take a broader view of the reconstruction of agency. A limitation of the study is that most of the participants with YOD were women and used to expressing themselves verbally; another

is that most participants were in the initial stage of dementia. Also, in this study, most participants with YOD had Alzheimer's, only one had Lewy body dementia and one had frontotemporal dementia. In general, the most frequent causes of YOD are Alzheimer's, frontotemporal dementias and vascular dementias (Loi et al. 2023); the latter two conditions were underrepresented among our participants. For these reasons some symptoms of dementia and their consequences may be absent from our data. Nevertheless, we believe that the findings of our study may be transferred to other contexts where people are living with the initial stages of dementia, and that professionals may use these results when supporting and helping families with YOD.

This study shows that the actantial model is appropriate for studying YOD stories and finding out the factors that change agency. The actant analysis demonstrated that agency changed in different ways and that there was a tension in how desire, power and knowledge appeared in the stories (Törrönen 2000, 2014). Agency on diagnosis was multi-dimensional, individual and diverse. Actors, the meaningful things found in the stories, included all entities – human and non-human – participating in action. The same actor could appear in different roles in different stories. The YOD changed the person's abilities and cognitive functioning, causing certain actors to appear. The cognitive abilities of a person with YOD cannot be taken for granted as before, and therefore some of the person's own or dyadic factors, like an accepting attitude or impairment of initiative, became discrete actors. This can be seen as black boxing (Latour 2005), that is, a situation where inoperability or changes in operativity cause internal factors to emerge. These internal factors scarcely existed in the original situation, but when this situation was disrupted owing to YOD, they appeared and became essential to how the illness was accepted and adjusted to as part of life. The actors produce action, which directs the agency of the person with YOD and the family member. In the future, it would be interesting to find out what changes occur when YOD progresses and how these affect the stability of the actors, the actants and agency.

Conclusion

This study adds to the understanding of how people recently diagnosed with YOD experience reconstructing their own agency in a new life situation. The diagnosis of dementia and the process of adjusting to the illness as a part of life are together a diverse and dynamic process, for individuals and for their families. How the person with YOD can reconstruct their own agency depends on the integrity and flexibility of that individual's agentic abilities, the family member(s)' support and the cohesion of the dyadic relationship. How agency is reconstructed depends on how the subject of the story experiences their own future and what they are aiming for. Hindering and helping resources need to be balanced in an ongoing process that is a combination of each person's attitudes, emotions, social connections, living context, symptoms and other unique factors in their situation. Narration enables each person to reconstruct their understanding of their own situation and eases their emotional burden, which may make it easier to adapt to changes. Narration also gives listeners the opportunity to hear that person's interpretations of their own situation, experience of changes, needs and resources. If professionals and family members can understand these things, they can respond to needs and provide resources. This supports the person with YOD and

their family from diagnosis on, giving them a sense of agency. Based on the findings of this study, narrating one's situation, for coping, is not just a means but its very basis.

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References

- Aarva P and Pakarinen M (2006) Studying the striving and opposing forces in newspaper journalism: The actantial model of health promotion. *Health Promotion International* **21**, 160–168. <https://doi.org/10.1093/heapro/dal010>.
- Alzheimer's Disease International (ADI) (2015) *World Alzheimer Report 2015: The Global Impact of Dementia – An Analysis of Prevalence, Incidence, Cost and Trends*. London: Alzheimer's Disease International. www.alzint.org/WorldAlzheimerReport2015.pdf (accessed 31 October 2024).
- Bailey A, Dening T and Harvey K (2021) Battles and breakthroughs: Representations of dementia in the British press. *Ageing & Society* **41**, 362–376. <https://doi.org/10.1017/S0144686X19001120>.
- Bandura A (2001) Social cognitive theory: An agentic perspective. *Annual Review of Psychology* **52**, 1–26. <https://doi.org/10.1146/annurev.psych.52.1.1>.
- Bannon S, Reichman M, Popok P, Grunberg V, Traeger L, Gates M, Krahn E, Brandt K, Quimby M, Wong B, Dickerson B and Vranceanu A-M (2021) Psychosocial stressors and adaptive coping strategies in couples after a diagnosis of young-onset dementia. *Gerontologist* **62**, 262–275. <https://doi.org/10.1093/geront/gnab053>.
- Beard R, Knauss J and Moyer D (2009) Managing disability and enjoying life: How we reframe dementia through personal narratives. *Journal of Aging Studies* **23**, 227–235. <https://doi.org/10.1016/j.jaging.2008.01.002>.
- Bury M (1982) Chronic illness as biographical disruption. *Sociology of Health and Illness* **4**, 167–182. <https://doi.org/10.1111/1467-9566.ep11339939>.
- Bury M (2001) Illness narratives: Fact or fiction? *Sociology of Health and Illness* **23**, 263–285. <https://doi.org/10.1111/1467-9566.00252>.
- Clemerson G, Walsh S and Isaac C (2014) Towards living well with young onset dementia: An exploration of coping from the perspective of those diagnosed. *Dementia* **13**, 451–466. <https://doi.org/10.1177/1471301212474149>.
- Czarniawska B (2004) *Narratives in Social Science Research*. London: SAGE. <https://doi.org/10.4135/9781849209502>.
- Dewing J. (2007). Participatory research. *Dementia*, **6**(1), 11–25. <https://doi.org/10.1177/1471301207075625>.
- Educalingo (n.d.) Reference point – Definition and synonyms of reference point in the English dictionary. <https://educalingo.com/en/dic-en/reference-point> (accessed 19 October 2022).
- Falconier M and Kuhn R (2019) Dyadic coping in couples: A conceptual integration and a review of the empirical literature. *Frontiers in Psychology* **10**, 571. <https://doi.org/10.3389/fpsyg.2019.00571>.
- Freeman M (2000) When the story's over: Narrative foreclosure and the possibility of self-renewal. In Andrews M, Day Sclater S, Squire C and Treacher A (eds), *The Uses of Narrative: Explorations in Sociology, Psychology, and Cultural Studies*. London: Routledge, 81–91.
- Gergen K (2009) *Relational Being: Beyond Self and Community*. New York: Oxford University Press.
- Giddens A (1984) *The Constitution of Society: Outline of the Theory of Structuration*. Berkeley: University of California Press.
- Greenwood N and Smith R (2016) The experiences of people with young-onset dementia: A meta-ethnographic review of the qualitative literature. *Maturitas* **92**, 102–109. <https://doi.org/10.1016/j.maturitas.2016.07.019>.

- Greimas AJ** (1980) *Strukturaalista semantiikkaa/A. J. Greimas*. suomentanut Eero Tarasti: *Sémantique structurale*. Helsinki: Gaudemus.
- Gwyn R** (2001) *Communicating Health and Illness*. London: SAGE Publications Ltd. <https://doi.org/10.4135/9781446219553>.
- Hänninen V and Koski-Jännes A** (1999) Narratives of recovery from addictive behaviours. *Addiction* **94**, 1837–1848. <https://doi.org/10.1046/j.1360-0443.1999.941218379.x>.
- Harris P and Keady J** (2009) Selfhood in younger onset dementia: Transitions and testimonies. *Aging and Mental Health* **13**, 437–444. <https://doi.org/10.1080/13607860802534609>.
- Hautsalo K, Pirhonen J and Pietilä I** (2021) Muistisairauteen sopeutumisen tarinatyypit työikäisenä sairastuneilla ja heidän läheisillään. *Gerontologia* **35**, 138–155. <https://doi.org/10.23989/gerontologia.100584>.
- Hautsalo K, Pirhonen J and Pietilä I** (2023) Continuity, coping and finding meanings in everyday life: Storytelling by family members of people with young onset dementia. *Journal of Family Research* **35**, 574–594. <https://doi.org/10.20377/jjfr-962>.
- Hedman R, Norberg A and Hellström I** (2019) Agency and communion in people with Alzheimer's disease, as described by themselves and their spousal carers. *Dementia* **18**, 1354–1372. <https://doi.org/10.1177/1471301217706268>.
- Hendriks S, Peetoom K, Bakker C, van der Flier W, Papma J, Koopmans R, Verhey F, de Vugt M, Köhler S, Withall A, Parlevliet J, Uysal-Bozkir Ö, Gibson R, Neita S, Nielsen T, Salem L, Nyberg J, Lopes M, Dominguez J, De Guzman MF, Egeberg A, Radford K, Broe T, Subramaniam M, Abidin E, Bruni A, Di Lorenzo R, Smith K, Flicker L, Mol MO, Basta M, Yu D, Masika G, Petersen M and Ruano L** (2021) Global prevalence of young-onset dementia. *JAMA (Journal of the American Medical Association) Neurology* **78**, 1–11. <https://doi.org/10.1001/jamaneurol.2021.2161>.
- Honkasalo M-L** (2009) Grips and ties: Agency, uncertainty, and the problem of suffering in North Karelia. *Medical Anthropology Quarterly* **23**, 51–69. <https://doi.org/10.1111/j.1548-1387.2009.01037.x>.
- Hydén L-C** (1997) Illness and narrative. *Sociology of Health & Illness* **19**(1), 48–69. <https://doi.org/10.1111/j.1467-9566.1997.tb00015.x>.
- Johannessen A, Engedal K, Haugen P, Dourado M and Thorsen K** (2018) ‘To be, or not to be’: Experiencing deterioration among people with young-onset dementia living alone. *International Journal of Qualitative Studies on Health and Well-Being* **13**, 1490620. <https://doi.org/10.1080/17482631.2018.1490620>.
- Johannessen A, Engedal K, Haugen P, Dourado M and Thorsen K** (2019) Coping with transitions in life: A four-year longitudinal narrative study of single younger people with dementia. *Journal of Multidisciplinary Healthcare* **12**, 479–492. <https://doi.org/10.2147/JMDH.S208424>.
- Kallio H, Pietilä AM, Johnson M and Kangasniemi M** (2016) Systematic methodological review: Developing a framework for a qualitative semi-structured interview guide. *Journal of Advanced Nursing* **72**, 2954–2965. <https://doi.org/10.1111/jan.13031>.
- Käypä Hoito [Good Care]** (2023) *Current Care Guidelines*. Helsinki: Finnish Medical Society Duodecim. www.kaypahoito.fi/en/ (accessed 5 June 2024).
- Keady JD, Campbell S, Clark A, Dowlen R, Elvish R, Jones L, Kindell J, Swarbrick C and Williams S** (2022). Re-thinking and re-positioning ‘being in the moment’ within a continuum of moments: introducing a new conceptual framework for dementia studies. *Ageing and Society*, **42**(3), 681–702. <https://doi.org/10.1017/S0144686X20001014>.
- Kilty C, Boland P, Goodwin J and de Róiste Á** (2019) Caring for people with young onset dementia: An interpretative phenomenological analysis of family caregivers’ experiences. *Journal of Psychosocial Nursing and Mental Health Services* **57**, 37–44. <https://doi.org/10.3928/02793695-20190821-02>.
- Larochette C, Wawrziczny E, Papo D, Pasquier F and Antoine P** (2020) An acceptance, role transition, and couple dynamics-based program for caregivers: A qualitative study of the experience of spouses of persons with young-onset dementia. *Dementia* **19**, 2714–2731. <https://doi.org/10.1177/1471301219854643>.
- Latour B** (2005) *Reassembling the Social: An Introduction to Actor-Network-Theory*. New York: Oxford University Press.
- Lejot E** (2017) Requests for help in a multilingual professional environment testimonies and actantial models. *Open Linguistics* **3**, 516–539. <https://doi.org/10.1515/opli-2017-0026>.
- Loi S, Cations M and Velakoulis D** (2023) Young-onset dementia diagnosis, management and care: A narrative review. *Medical Journal of Australia* **218**, 182–189. <https://doi.org/10.5694/mja2.51849>.

- Mayrhofer A, Shora S, Tibbs M-A, Russell S, Littlechild B and Goodman C (2021) Living with young onset dementia: Reflections on recent developments, current discourse, and implications for policy and practice. *Ageing & Society* 41, 2437–2445. <https://doi.org/10.1017/S0144686X20000422>.
- Millenaar J, Bakker C, Koopmans R, Verhey F, Kurz A and de Vugt M (2016) The care needs and experiences with the use of services of people with young-onset dementia and their caregivers: A systematic review. *International Journal of Geriatric Psychiatry* 31, 1261–1276. <https://doi.org/10.1002/gps.4502>.
- Møller J and Brøgger M (2019) How do residents perceive and narrate stories about communication challenges in patient encounters? A narrative study. *BMJ (British Medical Journal) Open* 9, e029022. <https://doi.org/10.1136/bmjopen-2019-029022>.
- O'Bryant S, Waring S, Cullum C, Hall J, Lacritz L, Massman P, Lupo P, Reisch J and Doody R (2008) Staging dementia using clinical dementia rating scale sum of boxes scores. *Archives of Neurology* 65, 1091–1095. <https://doi.org/10.1001/archneur.65.8.1091>.
- Øksnebjerg L, Diaz-Ponce A, Gove D, Moniz-Cook E, Mountain G, Chattat R and Woods B (2018) Towards capturing meaningful outcomes for people with dementia in psychosocial intervention research: A pan-European consultation. *Health Expectations* 21, 1056–1065. <https://doi.org/10.1111/hex.12799>.
- Pesonen H-M (2015) Managing Life with a Memory Disorder: The Mutual Processes of Those with Memory Disorders and Their Family Caregivers Following a Diagnosis. PhD dissertation, Faculty of Medicine, University of Oulu, Finland.
- Pinkert C, Köhler K, von Kutzleben M, Hochgräber I, Cavazzini C, Völz S, Palm R and Holle B (2021) Social inclusion of people with dementia – An integrative review of theoretical frameworks, methods and findings in empirical studies. *Ageing & Society* 41, 773–793. <https://doi.org/10.1017/S0144686X19001338>.
- Roach P and Drummond N (2014) 'It's nice to have something to do': Early-onset dementia and maintaining purposeful activity. *Journal of Psychiatric and Mental Health Nursing* 21, 889–895. <https://doi.org/10.1111/jpm.12154>.
- Shoemith E, Griffiths A, Sass C and Charura D (2022) Effectiveness of counselling and psychotherapeutic interventions for people with dementia and their families: A systematic review. *Ageing & Society* 42, 962–989. <https://doi.org/10.1017/S0144686X2000135X>.
- Simpson C (2010) Decision-making capacity and informed consent to participate in research by cognitively impaired individuals. *Applied Nursing Research* 23, 221–226. <https://doi.org/10.1016/j.apnr.2008.09.002>.
- Spreadbury J and Kipps C (2019) Measuring younger onset dementia: What the qualitative literature reveals about the 'lived experience' for patients and caregivers. *Dementia* 18, 579–598. <https://doi.org/10.1177/1471301216684401>.
- Sulkunen P and Törrönen J (1997) The production of values: The concept of modality in textual discourse analysis. *Semiotica* 113, 43–69. <https://doi.org/10.1515/semi.1997.113.1-2.43>.
- Törrönen J (2000) The passionate text: The pending narrative as a macrostructure of persuasion. *Social Semiotics* 10, 81–98. <https://doi.org/10.1080/103503300114568>.
- Törrönen J (2014) Situational, cultural and societal identities: Analysing subject positions as classifications, participant roles, viewpoints and interactive positions. *Journal for the Theory of Social Behaviour* 44, 80–98. <https://doi.org/10.1111/jtsb.12029>.
- Virkola E (2014) Toimijuutta, refleksiivisyyttä ja neuvotteluja: Muistisairaus yksinasuvan naisen arjessa. PhD dissertation, Faculty of Social Sciences, University of Jyväskylä, Finland.
- Wawrziczny E, Antoine P, Ducharme F, Kergoat M-J and Pasquier F (2016) Couples' experiences with early-onset dementia: An interpretative phenomenological analysis of dyadic dynamics. *Dementia* 15, 1082–1099. <https://doi.org/10.1177/1471301214554720>.
- Wentzer H and Bygholm A (2013) Narratives of empowerment and compliance: Studies of communication in online patient support groups. *International Journal of Medical Informatics* 82, e386–e394. <https://doi.org/10.1016/j.ijmedinf.2013.01.008>.
- Williams G (1984) The genesis of chronic illness: Narrative re-construction. *Sociology of Health and Illness* 6, 175–200. <https://doi.org/10.1111/1467-9566.ep10778250>.

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