

SHE IS A VERY SPECIAL PERSON: MALE CAREGIVER IN THE INTERSECTION BETWEEN INFORMAL AND FORMAL CARE

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ABSTRACT

This paper presents the story of a Norwegian man in his mid-70s, primary caretaker for his wife who suffers from Alzheimer's disease. Focus is on the cooperation with home-based public health-care services. The case is part of a larger qualitative research project on the topic.

The story has come into being through narrative interviews followed up with telephone conversations and is analyzed with Antonovsky's Sense of Coherence as a frame of reference. Three topics are highlighted: 1) The carer's journey during the time of his wife's illness; 2) His description and construction of meaning and ways of coping; 3) The interaction between him as a caregiver and professional health workers.

The research project aims to highlight the rationality of caring facing the organizational/bureaucratic framework conditions of home-based public health care.

As the caregiver is watching his loved one being changed into someone who is unrecognizable he needs to adjust to a new reality of which a working relationship with home-based public health care is an element. Concerning the latter, a very important factor is the respect for the uniqueness of the couple's story and situation, as well as the acknowledgement of the caregiver's expertise – or lack thereof.

Keywords: Male Caregivers, Informal Care, Rationality of Care, Sense of Coherence

JEL Classification: I12, I14

1. INTRODUCTION

Informal male caregivers with a responsibility for spouses/partners with long-term care needs, in which the care is home based, is a significant area deserving of more interest than it seems to receive. The primary purpose of this paper is to call attention to challenges that might arise from the interaction between the informal male caregiver and the formal home-based service.

Male care is easily associated with being a father or with men in caring professions. In spite of the fact that approximately 30% of the caregivers in private care are men, there is not a lot of Nordic research that deals with this matter. In Romøren's (2001) longitudinal study on the development of the helping needs of elders related to public and family care, it appears that in 27% of the cases the closest caregiver is a man. This roughly corresponds with numbers from the US (Houde, 2002; Russel, 2007), and the percentage seems to be growing (Sanders & Power, 2009). A recent study from Portugal on elderly informal care shows some surprising figures, suggesting 56.4% of spouses who were informal carers were men (Pego & Nunes, 2014).

Considering an anticipated future situation, an increasing number of old people will make family-based care vitally important. Male caregivers are an important group in that respect, though the lack of knowledge about the situation of this group calls for more research. Since it is evident that when the care is based on a joint effort by formal and informal caregivers, the quality of the care is influenced even more by how this working relationship functions. This also applies to how the informal caregivers experience and cope with the situation.

Traditionally, care research, in which men as (informal) caregivers is a topic, has been marked by a comparison of men and women, with gender socialization as a point of departure (Ducharme *et al.*, 2007; Thompson Jr., 2005). In that context, men tend to function as a contrast group to female caregivers (Kramer, 2005), but the female caregiver constitutes the norm. Using somewhat short and apt wording, men's experiences as caregivers are examined as deviating from the normative female experience (Bokwal *et al.*, 2005). The point is that the female caregivers constitute the norm and the men are judged by how close to that "golden standard" they come.

In the current project, the male caregiver's situation is explored on its own terms and not as a contrast to a predefined standard. As far as how the concept of caring is understood in the current project, in addition to being informal (Andersen, 2011), it can also be said to be based on a *rationality of caring* (Wærness, 1999). Rationality of caring is rooted in the unique characteristics of the caring relation, and is connected to "[...] a way of thinking that is contextual and descriptive rather than formal and abstract" (Wærness, 2004:275). In order to exercise good care, the caregiver needs to hold not only personal knowledge, but also a certain ability and possibility of identifying with the care receiver's situation as a basis for practice. The perspectives laid out above, which might be said to characterize the caring relations we deal with in this project, could also be said to contrast a results-oriented, means-end thinking.

2. OBJECTIVES

The thematic frame around this project is voluntary, family-based care. The center of rotation is the collaboration between a municipal, home-based service and a voluntary and family-based care by men, with a considerable responsibility for spouses/partners with long-term care needs living at home. User perspectives, meaning family members, are crucial. Generally speaking, the aim of the project is to learn about how this reality is understood and described by the male caregivers (Kvale & Brinkmann, 2009). How do these men cope with their life situation, what are their needs for assistance and how are these needs understood and met by public social- and health care? More specifically: How do men with a caring responsibility for their spouse/partner experience and describe their situation as caregivers? Secondly, what are the challenges that arise in the encounter between public home-based service and private informal (male) care? Last, but not least: What do the male caregivers express concerning their needs for assistance in order to be able to maintain and manage their care work?

3. DATA & METHODS

Participants for the study are recruited in collaboration with municipal home-based service. The criteria for inclusion are male caregivers doing home-based care for their spouse/partner with considerable needs for care, and being in some type of cooperation with a home-based service. We talk about purposeful sampling and expect to interview approximately 20 persons (Malterud, 2011). The participants are interviewed in an open fashion, i.e. with life

history/life story interviews consistent with the approach known as BNIM (The Biographic-Narrative Interpretive Method). Based on a single opening question, the participants are encouraged to tell their story as much as possible without interruptions or questions from the researcher (Wengraf, 2001).

In general, and more specifically in connection with the choice of methodological approach in the project, an important point here is the awareness of how “gendered” pre-understandings can be an obstacle for comprehending what the interviewee wants to get across (Sandberg & Eriksson, 2009). The interviews aim to obtain the caregiver’s experience, understanding and description of his lifeworld, as well as what his need for assistance and support related to his care work may be. Openness is necessary to develop an understanding based on the phenomenological experience of the interviewees and not on pre-constructed categories.

The analytical approach leans on Interpretative Phenomenological Analysis (IPA), which is described as “a two-stage interpretation process or a double hermeneutics, in that the findings convey the researchers’ interpretation of the participants’ interpretation of their experience” (Smith *et al.*, 2009). “The participants are trying to make sense of their world; the researcher is trying to make sense of the participants trying to make sense of their world” (Smith & Osborn, 2008).

IPA can be used to examine a single case, as is done with Arne, whose story this paper is based on. Arne was interviewed twice face-to-face and several times via telephone. The latter were shorter conversations, in which the intention was both to ask specific questions and to follow up on how things were developing in a more general sense. The interviews were transcribed verbatim by the interviewer. In the first interview, Arne talked freely about the time from when his wife turned ill until the present day. He told of his experiences and the challenges he faced and how he handled these, in addition to his experience with home-based service related to his wife’s condition and his position as an informal caregiver.

Reflections and questions that arose during the transcription of the first interview provided the basis for the second interview. The first telephone interview was done as a follow-up after a couple of months, while the second was conducted about six months after the last face-to-face interview. This case was then compared to others in the group, and the discovery of additional themes led to a turning back to the original case for further analysis – which was an iterative process.

Working with individual stories is rewarding in many ways, as it is striking as to how an individual story can shed light on phenomena that go beyond the particular. The sociologist Pierre Bourdieu uses the phrase “[to] grasp particularity within generality and generality within particularity” (Bourdieu & Vaquant, 1992: 75), and further, “A particular case that is well constructed ceases to be particular” (op. cit: 77). Individual narratives are sources of knowledge about how cultural and structural factors make their deposit in a person’s self-perception. This knowledge can contribute to the development of theories and extend our understanding of offense/acknowledgement experiences as both an individual- and social phenomenon. Furthermore, it sheds light on how this is influenced by social and political factors, and how it could contribute to a political discourse about the relationship between agent and structure (Chamberlayne, 2001). The latter is something that would definitely be a desired result.

Through the unique autobiographical stories about their lives, persons create meaning and identity. This point is made topical by Antonovsky (1987) in a way that is also relevant in relation to the current project. Referring to Cassel (1979), he warns against the danger of focusing on the pathology, and not on the human being who has a particular medical problem. Secondly, he stresses the importance of knowing the person’s history in order to

know how to meet and help the person. Let me add that this is also true concerning the caregiver.

Using narrative structures to make sense of experiences also applies to the researcher. The participant gives away his story, his understanding of himself and his social world, and the story goes on to re-interpretation, analysis and re-presentation, a process of re-telling and re-writing with a second-order narrative as a result (Mishler, 2004; Elliott, 2005). This stands in contrast to a first-order narrative, in which the person talks about himself and his experiences. The version constructed on the basis of the interview material is the researcher's interpretation of their interpretation.

On the remaining pages, we will first look at "Arne's history," meaning a "factual" description of what took place in his and his wife Astrid's life in the period relevant for this paper. Next follows "Arne's story," i.e. the way he experiences and describes this period of their life together. Nonetheless, the story is not untouched by the researcher, who organized it under headlines in order to make it more accessible and easier to read. Lastly, "the researcher's story" presents results and understanding/interpretations within a salutogenic frame.

4. ARNE'S HISTORY

Arne, a participant in the current project, is a retired teacher of 76 living in a home in the countryside with his one year younger wife, who suffers from Alzheimer's. They have two children living elsewhere with families of their own. Up until three years ago, Arne lived a life characterized by nature experiences, outdoor life, painting and music, which were areas of interest he shared with Astrid, his wife of 50 years. Moreover, they both have a past within the educational system. Arne is creative, interested in art and is also a performing musician, playing a string instrument in a local orchestra and doing oil paintings.

Arne uses the term mental tsunami to describe what has taken place in his life during the past two-three years. It contains dramatic situations that have brought about a total change and readjustment of life and reality. Another name for it is Alzheimer's. Two days prior to their golden wedding anniversary two years ago, Astrid received a definitive diagnosis. Quite some time before that she had been having some physical symptoms (febleness, dizziness, etc.). Then on a rather easy skiing trip a half year before she received the diagnosis, she felt unwell and they had to return home. She had diffuse symptoms, became confused and did not recognize Arne. He tried in various ways to help her remember who he was, but his efforts were in vain. He finally had to contact their daughter on the phone and get her to help, and this tactic worked. The following day they went via the public health center to the nearest hospital, where a stroke with a temporary comprehensive loss of memory was ascertained. Arne thought that she would recover, but now says that "it was the first sign of Alzheimer's." She had several acute incidents of memory loss during the spring, and Arne started to mark the incidents on a calendar. The crosses became more and more compressed until it all culminated in the early summer with the Alzheimer's diagnosis. The symptoms had been present over a long period of time and to an increasing extent, so the conclusion was hardly any surprise. Four months after the diagnosis was made, he sat down with his daughter and looked at x-rays of Astrid's brain, which he described as a frightening sight. The doctor stated that the illness had already developed considerably, and recommended that Astrid be placed in a nursing home.

The Alzheimer's diagnosis offered Arne an explanation for Astrid's inexplicable episodes. After the diagnosis was made, the illness developed rapidly, and Arne experienced her repeatedly losing control and having severe panic attacks. Arne was given several medical

explanations (a couple of extra diagnoses in addition to Alzheimer's) as reasons for these attacks, something that possibly made it a little easier to understand and relate to. The panic attacks seemed to be connected to her believing that he had disappeared, with Arne saying that the latter has been an ongoing subject. He also experienced several times that Astrid believed that he was replaced by an identical looking person, as other persons could be trusted, but not the person who looked like the one who was not there (called Capgras syndrome).

There had been several instances in which the situation had been saved by a phone call to their daughter, who has managed to adjust Astrid's perception of reality, hence becoming an important support person.

Arne was recommended by health professionals to get Astrid into a nursing home, which occurred after a medical check approximately four months after the initial diagnosis was made. He accepted the advice, feeling that there was no other option, as for him to take responsibility for Astrid at that time was not a choice.

For various reasons, they chose a reputable nursing home in a larger town. He and their daughter spent a good deal of time at the nursing home, attempting to closely monitor Astrid's situation. He thought his presence was necessary in order to stabilize the situation and make her safe in the new environment, which often meant sleeping overnight on a folding bed in her room. Based on his knowledge of Astrid after 50 years, he also tried to hint to the staff what he thought she needed, but unfortunately he found that this was not paid much attention to.

Astrid had been in the nursing home for a couple of months when he was asked to meet with the home's management. He was told to stop being so involved, and that from then on they were to act as ordinary relatives, coming for visits and going for walks with Astrid. The nursing home regarded itself as being qualified to take care of what was necessary regarding Astrid's needs. Arne also got a clear impression that he was looked upon as a burden and a pain in the neck. Arne found the situation so difficult that he made up his mind to terminate the agreement with the nursing home and instead apply for a local placement. He informed the management about his decision and returned to his home, and immediately after arriving back home he made contact with the local nursing home. While having a conversation with the management there, he got a phone call from the staff at the nursing home where Astrid was still living. She was having a severe anxiety attack, as the situation was out of control and they had to call and get his help to handle it. Arne talked to a totally terrified Astrid on the phone, the result of which was that he immediately took her out of the nursing home and brought her home.

Soon after returning home, she settled in and seemed satisfied and at ease. Because of that, the local placement she was offered was put on hold. He made up his mind to try to take care of her, a decision that was supported by the local health system. Arne has been Astrid's primary caretaker for more than a year and a half, which is still the current situation. Arne has agreed with the local health service that the situation is as good as it can possibly be at present. The municipal home based service has come in, primarily milieu therapists, whose task by and large is to make it possible for Arne to take time off, do things on his own or just get a break and relax.

Arne is eager to be helpful in our conversations, wondering what I am looking for and what I need to know. He regards talking with me as "going a step further," and is at my disposal if it can be of any help.

5. ARNE'S STORY

In many ways, Arne's story forms a "thick description" that contains a sum of the experiences shared by several of the participants in the project. Thus, he can be thought of as representing the group of male caregivers in the current project. Subsequent to this, (main) factors taken from a wider selection demonstrate how one story offers important lessons about the coping and meaning-making process for a male caregiver.

5.1 Turning Points

Within a frame of narrative concepts and understanding, turning points in a story play a vital part. Generally speaking, turning points are incidents or transitions that seem to have had a considerable influence on a person's life and/or view of life. Turning points mark where the story "turns" in a new direction. The new direction is usually caused by a choice or dilemma faced by the characters. The concept is used in somewhat different ways. In the current context, it is more of a phenomenological/hermeneutical understanding that focuses on the subject's interpretation. Denzin (1989) uses the term *epiphany*, characterizing epiphanies as interactional moments, "which leave marks on people's lives" (p.70). These are often moments of crisis.

In Arne's story, there have been a series of powerful events. Based on his description, some experiences are of a character that could qualify for a status as turning points or at least defining moments. The epilogue was the first time Astrid, the person closest to him, did not recognize him, and he strived to try and find ways to convince her. This first time was interpreted as a stroke that would heal itself, but in retrospect it was a crucial point in the story.

Two days prior to their golden wedding anniversary, the Alzheimer's diagnosis was established, which was a symbolically heavy incident, prompting Arne to say: "Golden wedding anniversaries are usually celebrated if people stay together long enough. Some divorce and lose the chance to do so. I have also lost this possibility to raise glasses with relatives and friends. Life is vulnerable and unpredictable. We have stayed together, but nevertheless cannot celebrate." This is an event with strong feelings that have left their emotional mark. Getting an explanation was a relief, but at the same time it was a fateful sentence over their life. What they had shared was not washed away, but their future perspectives were dramatically changed, and they could never return to the life they used to know.

What seems to stand out as *the* turning point is what took place at the nursing home. Arne gradually took in that the illness had developed to the point that something had to be done. What he described as the intense and sick character of the situation led to this solution because she was psychotic, after all. There also appeared a noticeable decrease in social contact with a feeling of isolation and aloneness after the illness showed its ugly face. He thought she eventually would quiet down at the nursing home, and that life could be normalized. This was "the way people handled situations like this," but in the nursing home everything turned out badly. He will never forget Astrid desperately calling his name over the phone, describing the experience as horrifying, as a traumatic situation and as the reason for the direction that everything took. From believing that the nursing home was the only reasonable answer, he has now gone in the opposite direction. This has led to a change in his outlook on life, altering his relationship with other persons and surroundings, thereby causing changes in his self-understanding. Concerning the latter, he has discovered and developed capabilities he did not now he had, capabilities that the situation has made possible.

5.2 Arne vs. Alzheimer's

It was in their outdoor life that Astrid's illness first appeared with limpness, cramps and dizziness. They were unaware of the illness lurking in the shadows, and outdoor activities, a skiing trip, were also the context for the first time that Astrid did not recognize Arne. However, this was understood as an isolated incident. Sometime after the first "stroke," he managed to rationalize away her forgetfulness and confusion, and for as long as possible he refused to take in what the symptoms represented. "I did not allow myself to believe that she was ill. I explained it as a minor stroke that would be normalized and become ok." He denied the warning signs for as long as possible, though he gradually came to understand that something was fundamentally wrong. This made him join classes for relatives of persons with dementia. Even so, none of the lessons or seminars he attended on the subject offered descriptions of attacks like some of the worst that Astrid had gone through, neither from lecturers or from other participants.

From a certain point, things accelerated. Arne summed up in the changes in Astrid in this way: "Avalanche after avalanche, like a dike bursting open. I thought it was scary and weird. I have never experienced anything as scary and weird in my life. A healthy, vigorous girl like Astrid being hit by an illness that develops in such a way. It was... I can hardly find words to describe the development of the illness and what it did to her." Arne has been a bystander who witnessed a dramatic change in his wife, with him describing it as something that takes total control over you, and which over time causes you to lose your ability to reason and your personality. When the situation arose that she did not recognize him, he found no way to convince her of who he was. "I could not help, no matter what I tried to say. I thought I was going nuts. I had to join her in looking for me while she was talking with our daughter on the phone." At times, the situation was surrealistic, like some type of absurd theatre. In retrospect, he finds it difficult to understand how he managed to pull it off. The situation went downhill so quickly that Arne was simply unable to adapt to the situation, in addition to losing the aforementioned ability to reason. Life was turned upside down in a matter of few months, which he described as almost being like a long-lasting state of shock. He was unable to adjust to the new reality. "And... it came so suddenly, and right in my face, it is such a shocking experience that I, I have put a solid lid over it because I almost don't ... I hardly dare to mention what, what it, how I experienced it and what it was like. But I do not risk going into it. If I do, I am afraid I will need professional help, though I still might need that in the future."

Arne's perspectives and his outlook on life have changed through all of this, but he finds it difficult to put words to how it has influenced his ways to think and act. The reality is that there is not always a correct answer, which must be doubly underscored. He says, "There has come a new kind of fear and anxiety into my life, witnessing what this illness is capable of doing." From being a creative and active person, Astrid has turned into something completely unrecognizable. She has jumped off over the edge and been taken out of circulation.

From his position as a witness, Arne describes Alzheimer's as "frightening and cruel, an alien, a monster or a creature that absorbs you in the end." It has changed and destroyed the person he loves the most, being like an external enemy ready to attack. How can you defend yourself against something that you cannot see? It seems as if he has a fear of being afflicted by the illness, and that it can overpower and overwhelm him and make him unable to act. To be able to relate to the illness, and to protect himself, he has to create a distance. He has had to take a step back and objectivize it, attempting to understand it as a medical phenomenon and thereby control it.

5.3 Local Care

At the time that Arne decided to take Astrid out of the nursing home, he contacted the local health-care service. Here, he felt that he had been met and listened to, and he was granted a placement for Astrid. He says that, "She was in such a bad shape that I didn't entertain the possibility of being responsible for her in our home." By a fortunate coincidence, the emergency call from the nursing home where Astrid was came while Arne was having a conversation with the section leader. Besides being a demonstration of the situation for the local health-care system, it was a confirmation of his evaluation of the situation. To terminate the agreement with the nursing home and take Astrid out was the correct decision. In many ways, this symbolizes the incident as a turning point. It was emotionally charged and called for action. She called his name in desperation, and he answered.

He talks now about how the situation is just fantastic compared to what it had previously been. There is no acting out on Astrid's part, and he wonders if the illness has come to a calmer phase, if she has somehow burned all the gunpowder.

The relationship with the local health- and home-based service is an open one, with a leader who seems to understand, as Arne feels seen, respected and heard. He feels that there is an openness to learning about the particularities of the situation. Thanks to Arne's efforts, the leader describes Astrid's current (caring) situation as optimal. They contribute with skilled persons to assist Arne so he can get some time off from time to time. The appreciation they show, as well as their concern about him becoming overloaded, has given him a good feeling and a sense of meaning.

Arne has experienced that the desirability of routines in home-based service is a challenge when it comes to getting through with his picture of Astrid as a special person who needs special treatment. He has had to take several turns. "They are benevolent and wish the best, but I have to explain to them what works and what doesn't based on my knowledge about Astrid. If it is not adjusted, if it does not work for her, it doesn't work for me," says Arne. Understanding her as a person is a precondition for getting her the best possible help. She was one of a kind before she became ill and is no less so in her present condition. He thinks it important that those dealing with her know who she was before she became ill in order to give her the proper help. It is not about bedsores and physical care, it is about mental wounds.

Taking Astrid home was an emergency solution that has become permanent. In no way was it planned like that, but Arne's understanding of the situation has changed. The nursing home experience is a reference point in that respect, while the present arrangement with Astrid living at home is in concert with the local health-care system. Her placement in a local nursing home is on hold, and has been given to someone else for the time being. Arne comments that, "She calmed down very fast when she came home. She has a far better life now, and as a consequence, I too have a far better life."

The understanding on the local level is very different from what he experienced at the nursing home, which is something Arne believes is related in part to the local community as being smaller and more transparent. There are many persons (health personnel) who know them and know what Astrid was like before she became ill. He has been open and told them about Astrid's background (traumas, childhood), including her GP. On his initiative, a group meeting was held so he could inform them about the time before the illness appeared, the period before the nursing home, the experiences at the nursing home and the time after. They were free to ask, they talked and the whole setting was very constructive and clarifying. It is about being seen and heard. Additionally, he has met with the staff at the institution that might be a future home for Astrid.

Arne has spent a lot of time being Astrid's spokesman and advocate. The relationship with the local health system has been "a good experience, actually," and he feels that they

have been treated like individuals (Høilund & Juul, 2005). It is a context in which the professionals appear as being flexible and understanding, which is in contrast to how Arne experienced the nursing home.

5.4 Relationship

Arne was born outside Norway by missionary parents, and he met his wife through a mutual friend. They both lived in Oslo at that time and were frequenting the same youth group in a religious setting. He tells about how when they met, the chemistry immediately was just right. He thinks they suited each other so well that he wonders if it was meant to be. Is there such a thing as accidental circumstances?

Now the situation has totally changed, as the illness has made him unsure of who he is to her. Does she recognize him? At the same time, he has become more important in her life. "After 50 years of married life, I have a whole new set of duties and experience, a totally different reality."

Arne describes his wife as a fantastic person in so many ways. "She has accomplished so much, and that has made me so grateful." She was a very special person when she was well, with Arne using the phrase "the illness took her." She was spontaneous, open, philanthropic and preoccupied with a nearness to people in a natural way. However, now she is nearly the opposite of what she used to be; she has become unpredictable and finds herself in a world that cannot be understood. "This is a reality I have had no possibility to foresee or imagine" he says. In reality, she is an anxious person. While she was in good health, this was something she managed to keep a lid on, instead concentrating on caring for others. He thinks it is terrible and unfair that she should be stricken by this, but he wishes to hold on to the picture of who she was and what they shared through 50 years. So doing creates a motivation to do the best possible for her. She is a person with Alzheimer's, not the Alzheimer's itself. She was one of a kind before Alzheimer's took her, and that is also true now that she is ill. She is still in there somewhere, even if the illness has done so much to change her.

The old Astrid can still appear in glimpses, and Arne strives for that to happen. It is like the troll has kidnapped her into its cave, and he is trying to get her out of there. It is possible if he finds the right means to do so. He feels that he can sometimes beat Alzheimer's by reaching her with, e.g. music. Managing to catch sight of her gives him an experience of succeeding. He also thinks that the illness' progress can be delayed by enhancing her quality of life, something he claims to have scientific arguments for. She used to be someone who stood out from the crowd, and she has not ceased to be very special. He exemplifies this with the story about the nursing home, in which she took the blame and apologized for what happened that led to her leaving the place.

5.5 Construction of Reality

Arne describes their life before the illness manifested itself as being predictable and regular. He could cultivate his interests, creative activities like painting and music. Life was characterized by double underscored answers like in math. Regularity provided balance and a quality of life, thus making it possible to look forward. There was no need to think of other possibilities. Now all of this has been "flooded and absorbed in the illness." "I try to maintain as much as possible of the old life, but nevertheless it gets very different."

The acute incidents caused by Astrid's condition could be quite intense with much confusion and bafflement. A red thread in this was the panic attacks she was having because she thought he was gone. "So I have the role of being a life preserver." Being afraid that he was gone is connected to her past history, and is marked with loss (she has lost many important persons in her life, including two children). He thinks that her past may have triggered the illness, being almost like a Nemesis. She has suppressed and pushed aside

these experiences, though now they catch up with her and cause illness. “I feel that this is predestination really, a consequence of her life history in total. From what I have learned about this, dementia can be activated by, e.g. depression. It is not just about genes, heredity and age. As such, I feel that psychological processes can also lead to dementia.”

For him as a caregiver in this situation, Arne says it is about finding attitudes that can keep him going mentally, mobilizing the instinct of self-preservation. He plays a major part in her drama, and tries as much as possible to be a life preserver. When everything surfaces, he needs to be there for her.

5.6 Caregiver’s Identity, Self-care and Self-perception

As previously mentioned, Arne is a creative person with interests within both music and art. At times, his language is almost poetic, and he has a rich repertoire of striking metaphors. These sides of his personality have largely had to be set aside insofar as the way the situation has developed. His engagement is intact, however, and some of it can be revitalized if he finds ways to take care of her. He is preoccupied with finding creative solutions to get Astrid as good a quality of life as possible, while at the same time giving him some elbow room. “I try to hold on to my creativity, to who I am,” he says. When he finds a loophole (when she has gone to bed at night or is resting in the middle of the day, or when the home-based service comes around), he tries to consider these interests. Nonetheless, these areas of interest, e.g. visual art, are to a large degree on hold.

When it comes to mental challenges, the situation is comparable. Problems and needs emerging from his experiences related to the illness, as well as from the caregiving process, have to be set aside in order for him to be her helper. One could say he sacrifices this for her. He thought of getting some therapy when she was admitted into the nursing home, but then she returned home. He has decided not to give in to difficult feelings or psychological needs around the situation. He feels he has accepted the state of affairs, mobilized a defense, and that he is no longer as vulnerable and excoriated as before. Factual knowledge from lessons he has attended for relatives of people with dementia have helped, and he does not let the scary stuff come too close. He cannot go too deep into how this whole thing has afflicted him because this would be too painful and difficult. “I just feel shaky when we touch the subject,” he says. It is like he is afraid of losing his grip if he goes into this. He has built a defense and tries to be realistic, and he knows there is a progression and no return when it comes to Alzheimer’s.

He has turned down offers of practical help from the home-based service. “It is very important for me to know that I am on my own two feet and healthy. I can live like I used to in relation to all practical things. I want to go on feeling like that.” Accepting the offer will make him feel handicapped and that he is bending for the illness. It would weaken his capacity or his feeling of sufficiency – living up to the stereotypes of helpless men. After all, he is healthy and in good condition.

This does not mean that it has been a joyride. He says that the task is mentally exhausting, there is sometimes a lack of sleep, and that he has to get up several times during the night, “Sometimes I am so worn out that I...” The sentence is not completed. However, he likes to think of himself as a stayer, someone who does not easily give up or give in. If it gets too complicated, he lets it rest for a while, “I sort of look a little at it from a distance and then I approach it again, and it seems like I often then succeed in accomplishing it. On the question, “Are you afraid of going down yourself?” he replies: “I do not dare to think that thought. No, I say to myself, I am a stayer, yes as long as... I nearly said if God willing. Much of the reason why I say it like that is that I have followed her through her entire life history, her story from when she was born, right? They put her in an orphanage. And later it happened so... Oh God it is, you just have to manage.”

Arne shows me a clipping from a magazine in which the interviewee expresses having lost her life because her spouse got Alzheimer's. He uses this as a starting point to maintain an opposite point of view on his own behalf. Arne rejects the martyr position. He views it as a position of powerlessness, "With an attitude like that, you deprive yourself of the possibility of doing something with your life. It is about attitudes and about choosing an outlook on life." Shortly thereafter, he states: "Realize the situation and choose a focus." He thinks that he has a propensity towards depression, but chooses instead to focus on the small things that give joy and light. He says that, "I experience a special love for a person that becomes more and more helpless and needs me more and more. I experience a new kind of closeness." He sees himself as someone who knows Astrid and is able to communicate what is good for her. To say that the brakes are on mostly regards her life. "For her, it means a full stop eventually, but maybe not for me?" It is about creating a distance to the illness, to not let it scare you or get too close to you. "You must not let what has happened overshadow what life offers and lead you to avoid looking around in the landscape," he says. It is about not losing sight of the possibilities that exist. "If I just see the illness, I miss a lot. I will lose my creative power, that which I can use to better her life." If you avoid blinding yourself to reality, but instead open up, you will experience new ways of thinking, feeling and being. You also develop creativity in relation to challenges that arise as a result of the new life situation.

5.7 Coping

Initially, Arne's thoughts were traditional: Astrid needed to get into a nursing home and settle there. This was how situations like these were handled. He had to reorganize his life and go on living, start his own life again, get it normalized. However, now his intention has changed. He has started anew with Astrid living in the house. Arne has installed an internal video surveillance system, where he has cameras in four of the rooms in the house. With this, he has found a way to monitor and take care of her at the same time as he can consider his own interests and needs. When he can be in control in this way, or when he gets external assistance from the home-based service, when she is safe and taken care of, he can relax.

In many ways, Arne has a practical approach to getting his life together. Building a foundation made of stone for a garage is one example, while practicing his music in the evening is another, "It is about being in motion, mentally and physically, not allowing room for heavy thoughts." Arne says that he attempts to avoid situations that cause this. It is easy to end up with your thoughts going in a circle like a mental rotary. "I can become very sad and feel sorry; first and foremost by the thoughts of her, what life has done to her. My God, what kind of life does she have ahead of her?" The defense is to put a lid on it, "If you talk about it, it manifests itself. Therefore, I cannot go into it. If I do, I'll be in need of help."

He finds it difficult to answer the question about how this has influenced him or will influence him in the longer term. He escapes the question; he cannot give it room, "I do not dare to think of it." To avoid ending up in depression, he must try to seize the day, picking flowers along the road, "Make life as meaningful as possible today, now, right: I try to do that, the small things close at hand, right. To get a distance to what is dragging you down and to get closer to what is pulling you up." He almost does not dare to think beyond the current situation, considering all the knowledge he has concerning the illness. To focus on what can be done for her today is a defense against all these frightening experiences. Mobilizing positive energy, to "win over" (or at least challenge) the illness, is about focusing on where she is in her process and adapting to that in as a meaningful manner as possible, all the way through the process. Try to think creatively, find solutions, and then arrange and make them possible. To the extent that he feels that he has succeeded, he talks about a "a little feeling of happiness." It works as a counterweight against the illness, which is

so frightening. He knows that the illness will have its way, but it is a motivation that the progress can be delayed by her having a harmonious and meaningful life.

The agreement (with the home-based service) is to keep it going as it is now for as long as it goes. He feels that he has no choice, as he is in the situation and that is where he has to be. The question is then what you chose to do in the situation. She has had enough in her life and the question of why this happened to him is of secondary importance.

5.8 Current Need for Help

There are limitation as to what can be done from the side of the local nursing home or the home-based service at present. It took some time before they understood that the assistance he needed was not of a practical kind like nursing things or cleaning the house. The practical aspects are minimal compared to the mental strain. He is clear that the need for assistance is on a psychological level, i.e. about meaning and contentment for Astrid. The rest he can take care of, saying that “It is no sweat. He also finds it natural and okay to take care of her personal hygiene. She gets uncomfortable if someone else does it, and this is something he can handle.

At present, the assistance he gets with regard to “stand-ins” at home, i.e. qualified staff is working well. There has been a decision to get more help for him, but there is a lack of qualified personnel. There is good will, but they are short of staff. They take Astrid for a walk, talk with her, spend time with her and so forth, which is about all they can do. That also gives Arne a chance to talk and discuss things a little with skilled people, who are specialists on dementia. What he needs is to feel relief and really take some time off, but that is not possible unless he knows that she is OK. It is not an option to place her temporarily in a sheltered care department in a nursing home just to give him some time off to relax, as she will become anxious and panicked. This would be awful for both her and for him, which is understood and accepted from the home-based services.

5.9 Network

His daughter is a close collaborating partner, although she lives quite some distance away. His son is more absent in this picture since he is busy with his life and family. Father and daughter are a team, and they have no relatives close by. Arne has two younger brothers and one sister who back him up as best they can. However, they live many hours away, though one brother in particular has been helpful in securing surveillance cameras to help monitor Astrid.

Arne tells that their network has shrunk since Astrid became ill, and he wonders if the diagnosis has scared people and turned them off, saying “I can meet people outside or in the store, and they cannot avoid asking how things are going. It happens that they ask stupid questions or demonstrate some strange reactions.” A few friends have been loyal, but he experiences little concrete support in the local context. He uses the term, “I have put his behind me.” Here, Arne draws on more generalized knowledge, what others have experienced in similar situations. “I have experienced what many others do. But my focus is not on that, I want to concentrate on what works,” he says.

He takes Astrid along to the store from time to time, which on a good day can be quite a positive experience. She used to be very social and knew a lot of people. Some of that can appear when they are out, but lately this has not happened so often. He needs to use the opportunity when he has assistance at home to do the necessary errands.

6. THE RESEARCHER'S STORY

In my memory (or my fantasy), there is a video of Edith Piaf. It is in black and white. She is standing on a stage singing. The spotlight is on her, while around her it is dark. She is alone in the picture. At one point, the lights and camera start moving around, and you can see that there is an orchestra and an audience.

At all stages of the process, research is about choosing what to highlight, what to make visible and what to leave outside the circle of light. In the above, we have followed Arne and Astrid's history and story the way it was heard by the interviewer. Despite the intention and ambition of letting the participant tell his story the way he wanted, the interview situation is a co-product, in that it is told to a specific person at a specific time in a specific context. Another researcher might have come out with a more or less different version, even more so when it comes to analysis and re-presentation, in which the researcher is attempting to make sense of the participants trying to make sense of their world.

In the current research project, the perspective is salutogenic (Antonovsky, 1987), which implies the question: Who are these men that stay in a (often demanding) position as caregivers and seem to manage, and what lessons can we learn from their stories about being able?

One important addition: When the focus is on the intersection between informal and formal care, one question arises: To what extent is the context the informal caregivers operate in a salutogenic one, an environment for health? (MacDonald, 2005). Viewpoints from Axel Honneth (1996) are made use of concerning the manner in which a professional or public health service meets the informal carer. Here, the concept of recognition is central. The knowledge the men in the project communicate shows that ways to "survive" or manage are diverse. This emphasizes the importance for the researcher to respect and recognize the uniqueness of individual stories. This is where we start.

6.1 Acknowledgment and Disregard

At the nursing home Arne experienced that his intimate knowledge and expertise was not paid attention to. Astrid's need for safety, contact and attention was not taken into consideration by the staff. Several times when he returned after having been away, he noticed what he perceived as major deficiencies in the care Astrid was receiving. He says he became worn out because it did not work for her, that there was too much to repair. If he was not there, she went wandering around alone in the corridors at night looking for him "It took a while before I realized that it did not work. A nursing home should work as a relief for relatives, but it ended up with exhaustion instead," he says.

A crucial moment in the story is when Arne and his daughter were told to start acting like ordinary relatives, and that the nursing home should "take over." This was experienced as a major lack of respect that added to a general feeling of not being seen or recognized. According to Arne, "We were not seen as a resource, but as a burden and troublesome freeloaders. I hold this as an allegation against the nursing home. We were personal assistants for a patient that needed attention, something they were not able to compensate for. We were not wanted and were squeezed out." It was not any kind of dialogue or understanding; it was more like an ultimatum, a penalty – a red card. He felt the attitude from the side of the nursing home as being very mortifying, with a total lack of acknowledgment. "We were not in it for our own pleasure." Arne's description captures what Høilund & Juul (2005) call not being regarded as a morally autonomous person. A certain understanding was forced on him, his self-understanding was neglected and overlooked and his intimate knowledge was not regarded as relevant. His final answer was to terminate the relationship with the nursing

home. This sort of reaction can also be explained as an outcome of feeling disregarded (op. cit.).

Alternatively it can also be described as a conflict between two different, and may be in some contexts, incompatible forms of rationality, a rationality of caring and a rationality based on a means-end thinking. In an institution, or in services based on rosters, marginal staffing, procedural regulations and so forth, conditions are often not optimal for a rationality of caring. At times, this approach is rather instrumental and limited by time. Quite a few of the project participants reported about home-based services with tight time schedules that only allowed room for specified tasks, whereas a formal decision had to be made for any operations to be added.

It is interesting to see what occurred when Arne brought Astrid back to their local context. His intention was not originally to take care of her at home, but to find a local placement, as he did not think himself competent as a main caregiver. Like many others, Arne thought that this was too complicated and demanding, a task for public health service and professionals. This is also what he thought to be proper and good care. This is very much a general and predominant understanding, reinforced and maintained by a modern health-care system. However, when Arne heard Astrid call on him, he was mobilized on an existential emotional level and responded to the calling, which was an ethical demand that overruled the cognitive and “professional” (Løgstrup, 1971). He did not think of the future, he just wanted to help her. When he decided to take care of Astrid, he experienced a professional service that respected him and was willing to listen. He felt an openness toward his attempt to explain who Astrid was/is, as well as an interest in learning about the unique sides of the situation. Over time, he felt that they had reached a mutual understanding that worked, and that he was recognized. Leaning on Axel Honneth’s work, Høilund & Juul (2005) lay out the importance of recognition. Their phrasing is “to be recognized as the person you regard yourself to be” (p. 30, author’s translation). If that is the situation, the suggestions and contributions from the professional side will more likely be listened to.

It is clear that the positive and open attitude from the home-based service has been an energizer in Arne’s case, making him feel competent and able. In a situation that seems difficult and challenging, Arne is able to focus on what gives meaning. “Subjective appreciation of life” might be an appropriate term to use in his case (José et.al., 2013:189). He also feels that he has been growing with the task. At the nursing home, he tried to be of assistance to the professionals, subordinating their professional knowledge. That failed. In the current situation, he is Astrid’s primary caregiver. He is the expert with professionals assisting him. In other words: In this case, the rationality of care is the basis for cooperation.

6.2 Sense of coherence

The results of the analysis are read through salutogenic lenses, i.e. Aaron Antonovsky’s concept of a *Sense of Coherence* (SOC) (1987). The concept was developed to explain why some persons became ill under stress, while others seemed to cope well. Antonovsky defined a Sense of Coherence as:

...a global orientation that expresses the extent to which one has a pervasive, enduring though dynamic feeling of confidence that: (1) the stimuli deriving from one’s internal and external environments in the course of living are structured, predictable and explicable; (2) the resources are available to one to meet the demands posed by these stimuli; and (3) these demands are challenges, worthy of investment and engagement (p.19). Rephrased in a shorter way: the SOC is comprised of the three components: *Comprehensibility, Manageability,*

*Meaningfulness.*¹ These three components are reference points in the remaining part of “The researcher’s story.” In accordance with the SOC, one seeks to understand “how people manage stress and stay well.”

6.2.1 Sense of Comprehensibility

Arne is a realist. As a teacher, he used to work with math and the like. As he phrased it himself, he used to think that every question has a right answer, doubly underscored. When Astrid started to act in unusual ways, he did not know what to think or how to understand it. His term “mental tsunami” indicates a chaotic situation, and in order to survive a tsunami you first need to get your feet on solid ground. You can then attempt to get an overview, start to re-orientate yourself and re-establish yourself in a reality that might have changed considerably.

When he began to suspect that Astrid’s “episodes” were not incidental, he started marking the episodes on a calendar. This can be seen as a familiar way to gain some control. The Alzheimer’s diagnosis brought sense into the picture. It explained former incidents. Getting Astrid’s situation laid out as a medical phenomenon gave a direction for collecting knowledge, as now he knew a little more about what he was dealing with. In his search for information, he also learned about psychological factors in the development of Dementia/Alzheimer’s. His knowledge of Astrid’s past has made him believe in “predestination,” i.e. her past is catching up with her. He has realized and accepted that the future is not as predictable as he used to think it was. It cannot be controlled. Sooner or later, Alzheimer’s will have its way.

For him, the point is not only to understand Astrid, her condition and her reactions, but just as much to make sense of his position. He understands himself as playing a major part in her drama. He believes

that she lives in sort of a parallel universe that becomes easily filled with her former losses. He does not know much about what this universe is like, but he knows her story. When everything surfaces, he is her life preserver. It is him she is looking for, and she is afraid he is gone. He tries as much as possible to be this lifepreserver, but he is also her advocate and translator. It is his duty to explain who she is and act on her behalf in order for her to get the help that is right for her, the help that she needs.

He also needs to take in the fact that their network has shrunk considerably. One way he deals with that is to refer to this as a phenomenon that has various causes, and that “people in their situation” often experience. Actually, by using the phrase, “I have left this behind,” he means that he has accepted it as the state of affairs. He has to concentrate on his task.

In summary, Arne has acquired knowledge about Astrid’s condition. He feels he has reached an understanding of the background, and maybe also some of what has caused it. He has an idea as to what the illness contains, meaning some of Astrid’s experiences and feelings. He is the closest one to read her and her needs, and this knowledge determines and gives direction for his position and duties. He feels that the working relationship with the home-based service makes sense, and he has come to terms with the changes in the network. Even if he does not approve, he can understand how and why it has changed. He has accepted that this situation calls for a different kind of logic, a lack of predictability means that the future is today. To plan means to plan for the day, which is “surrender” to the situation. In one way it is to take control by letting go, not letting the lack of predictability control you.

¹ Comprehensibility: A belief that things happen in an orderly and predictable fashion, in addition to a sense that you can understand events in your life and reasonably predict what will happen in the future.

Manageability: A belief that you have the skills or ability, the support, the help or the resources necessary to take care of things, and that things are manageable and within your control.

Meaningfulness: A belief that things in life are interesting and a source of satisfaction, that things are really worth it and that there is good reason or purpose to care about what happens.

6.2.2 Sense of Manageability

In the process Arne has been through, he has discovered and developed capabilities he did not now he had, which were made possible by the process he has gone through and the situation that exists. His sense of manageability depends on several factors. He feels that he is in a good shape, physically and mentally, and that he is able to handle the situation under the current circumstances. He demonstrates this by his rejection of assistance from public services regarding practical- or care-related tasks. The recognition and acknowledgement communicated by the home-based service is essential, with the same being true of their support and assurance of being there for him if needed. He feels competent, able to cope and in control of the situation. This is in accordance with what Høilund & Juul (2005) call “human flourishing,” a result of being seen and acknowledged.

For him as a caregiver in this situation, Arne says it is about finding attitudes that can keep him going mentally, thus mobilizing the instinct of self-preservation. To be able to maintain his sense of manageability, he must avoid going too deep into the emotional aspects of the situation. That will weaken his capacity, make him less able to focus and reduce his ability to act in a rational way. He cannot look back on all the complicated experiences or into the future with its prospects. Today is what matters. Concentrating on today gives a feeling of control and achievement.

The video equipment is a good support for the feeling of control. He attempts to make workable routines in his care work, and uses his fantasy and creativity to find ways to reach Astrid and improve her quality of life. By opening up for all possibilities, Arne experiences new ways of thinking. He develops creativity when confronting the challenges arising from his new life situation.

One strategy that Arne seems to share with several others as a defense against the illness is to objectify it. Rephrased, this means to study it like you would study your opponent in order to beat him. Attending classes for relatives, doing literature studies and talking to others in a similar situation all help you do something in relation to the illness. You recognize things you have heard or read, which makes it more “controllable,” which is close to what is called externalizing (White, 2007). As is known in therapy, externalizing is about finding new positions where you can deal with the problem as an acting person, as an actor in your own life instead of being a victim of the oppressive problem.

So in sum, being in good shape mentally and physiologically, having external support and a “guarantee” of extra support if needed, the ability to control the dark sides of the situation (thoughts, memories, feelings) and externalize the illness make Arne feel that he can handle the present situation. Added to this, having technical equipment makes it possible to relax and still be in control.

6.2.3 Sense of Meaning

Arne’s way of describing the importance of meaning making seems to echo what Victor Frankl (2006) advocates. Frankl claims that everything can be taken from a man but the freedom to choose one’s attitude in any given set of circumstances, to choose one’s own way. Somewhat oversimplified, it is about finding a way to describe and understand the situation that gives meaning. This is also what Antonovsky describes as the most important of the three components in the SOC. The meaning dimension is the motivational element and forms a pre-condition for comprehensibility and manageability. It is about what “makes sense” in the emotional, and not only the cognitive meaning, of the term.

The way Arne explains what gives meaning and motivation in the situation covers what many others have told me in different ways. To put it simply: Astrid is worth it. Arne says: “It might sound strange, but it gives life meaning. It gives meaning to be able to give her a good life.” It also does him good to know that he will have no reason to regret, as this is the

person he has shared his life with. Holding on to the picture of the Astrid he used to know, as one of a kind, makes it meaningful to do the best possible for her. He says that, “A small victory gives energy to go on.” In essence, this is how Antonovsky characterizes the meaning dimension, as giving energy to the two other SOC dimensions. The “original” Astrid is still somewhere in there. She has meant so much for him for 50 years, and she deserves the best. To be able to outsmart Alzheimer’s by reaching Astrid in creative ways or doing things for her that improve her quality of life is rewarding and give “small moments of happiness.” In a positive sense, he has no choice. He does what he must do. Should we simply call it love?

Being told by professionals that Astrid’s situation at present is optimal strengthens his sense of meaning and adds to it.

7. SUMMARY AND CONCLUSIONS

Antonovsky has an interesting term, “the deviant case.” He asks, “Who are the smokers that don’t get lung cancer?” (1987:11). In other words, who are those making it in spite of the risk factors? Modified for our use: Who are the men that seem to be able to handle a demanding caregiver situation? Antonovsky emphasizes the importance of developing a theory of coping (op.cit.:13). So what can we learn from Arne about coping in a life situation such as his?

We learn about a process of avoidance and adaption, in which adaption seems to be the dominant reaction. From trying to cope with confusing and unintelligible incidents, it culminates in a medical explanation with a traditional solution (nursing home) as the answer. Then follows a dramatic change, which results in an entirely new understanding and arrangement. This process requires a re-construction of- and adaption to a new reality. He has to re-map the terrain and not least, redefine his own position. This would most probably have turned out differently without a local context communicating a respectful and recognizing attitude. The working relationship with local health-care and home-based service works in a salutogenic manner, and makes Arne’s project practicable. It functions as a complementary relationship that serves a purpose of care. In that connection, the social network is often affected when a serious or long-lasting illness appears, as Arne’s story bears witness to. This increases the significance of the professional helping systems.

Arne represents a very important group. More often than not, informal care is predicted to be of increased importance in a future situation – in combination with public care. Arne’s story illustrates the difference between an ideology marked by effectiveness and a means-end rationality, and a rationality of care based on intimate knowledge.² The latter rises beyond medical and technical needs, and is different from “effective care.” He teaches us about emotional and cognitive understanding and coping and the importance of openness and willingness to listen from the side of professional helpers. To be able to function in a salutogenic way and enter into a trusting working relationship with the informal caregiver, the professional helping systems need to be open to the uniqueness of the particular story. The needs for assistance are varied. They can be instructions and training (instrumental skills, knowledge about sickness or medical conditions, etc.), psychosocial needs such as being seen and acknowledged, respite care to be able to participate in social activities, direct professional social- and health-related assistance, etc.

Having an “illness focus” without paying attention to the caregiver’s non-instrumental needs has a pathogenic effect, and will ultimately exert a negative influence on the care receiver’s situation. Arne is one of several who underscore the need for getting off and doing

² In our context, this is understood as, “a particular, but totally fundamental kind of knowledge building on a person’s ability to enter the other one’s world, and from there establish an understanding of the situation (Høilund & Juul, 2005:71 My translation).”

their own thing. Generally speaking, this seems to be a challenge for the professional caring systems, even if it is quite clear that caring for the caregiver pays off for the care receiver. To be salutogenic, the focus needs to be relational, family- or couple based, not individualistic- and illness focused.

Incidentally, gender has not been a topic in this paper simply because it has not been a topic in my talks with Arne. He has not regarded it as being of relevance in his case. As a matter of fact, this is a general experience in talking to male caregivers. They do not question it. If this is done, it is by the environment. They simply do what they feel is right. For a lot of them, the task is not gendered.

We might ask then: Will this work in the long run? How long can Arne keep it going? Of course, there is no definitive answer to that question. However, what we do know is that this does not only rest on Arne.

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