

‘Just ask me what it means to live with dementia’ – people with mild dementia’s strategies and techniques shared through in-depth qualitative interviews

Abstract

Aims and objectives: This article presents results from interviews with twelve persons with mild dementia about how life had changed since they received their diagnosis, exploring their experiences of dementia and how they manage life by using different strategies and techniques.

Background: Knowledge about how people with mild dementia experience life is important to explore through their unique perspective, providing clinical practice with knowledge to improve dementia care.

Design: Twelve participants were recruited at a Danish school service for people with mild dementia where they receive cognitive stimulation. Semi-structured interviews were conducted, video recorded, transcribed and analysed by using Max Van Manen’s five lifeworld existentials: spatiality, corporeality, temporality, relationality and materiality. SRQR checklist was used.

Results: Five themes were identified, illustrating the dilemmas and challenges the participants experience, as all existentials are compromised in some way: Living a social and active life regardless of difficulties; Trying to look at the bright side of life with dementia; It takes time to adapt but at the same time, time is being lost; It is possible to learn, but it is challenging; To try to remember but keep forgetting.

Conclusion: The article concludes that all existentials are negatively influenced by dementia, setting the lifeworld of the participants under pressure. However, they still try to live their lives regardless of the difficulties. The study shows it is possible for people with mild dementia to describe their lived experience of dementia and what strategies and techniques they use to manage life.

Relevance for clinical practice: The experienced dilemmas and challenges in the lifeworld of people with mild dementia is of great relevance to be aware of and address in clinical practice. To support people with dementia to identify relevant strategies and techniques, as expressed in the study, that can support them managing life with dementia.

Introduction

Dementia is an umbrella term characterising several cognitive and behavioural symptoms from degenerative conditions of the central nervous system leading to deterioration in memory, thinking, behaviour and the ability to perform everyday activities (WHO 2019). The progression of dementia is often defined via three stages; the mild stage, the moderate stage and the severe stage (Alzheimer's Society 2020, WHO 2019). This paper focuses on people living with mild dementia, where the cognitive impairment causes slight deterioration of performance in everyday life but may experience symptoms such as forgetfulness and losing track of time (Alzheimer's Society 2020, WHO 2019). Worldwide, it is estimated that around 50 million people currently live with dementia, with nearly 10 million new cases every year, affecting not only older people but also younger people (WHO 2019). Thus, there is an estimated rise to 82 million in 2030 and 152 in 2050, partly due to an increased aging population, and rise in numbers of people living with dementia in low- and middle-income countries (WHO 2019). There is a huge financial impact associated with the provision of care for dementia, and with the predicted rise in prevalence over the next few decades, this presents a great challenge, globally, for health and social care (Winblad, Amouyel et al. 2016).

Understanding how dementia affects people, how they experience living with dementia and what strategies they use to manage daily life are therefore important to provide dementia support, care and nursing in an efficient and economically way. One way of exploring what it means to live with dementia, is through the lifeworld perspective. This is a phenomenological approach that enables an in-depth

understanding of how a person experiences a particular condition or situation. With the forementioned predicted rise in the number of people living with dementia worldwide (WHO 2019) and no imminent cure (Caspi 2019), there is an increasing need to learn what can be done to support people with dementia now, and in the years to come. In order to ensure that care meets the needs of people with dementia and their family, it is important to understand the experience about life of those who live with the diagnosis.

The perspective of people with dementia in research

Although people with dementia have, historically, not been involved in research, either as participants or as co-researchers (Alzheimer Europe 2019), the last 10 years has seen a gradual shift towards greater involvement and understanding of the personal experiences of those living with this condition. For example dementia activists, such as former nurse Kate Swaffer (2015) and former biochemist, CSIRO, senior executive Christine Bryden (2018) speak out about what it means to live with dementia and challenge for greater rights, and organisations such as Alzheimer's Europe promote the need for health and social care, and dementia research to work 'with' rather than 'on' people with dementia (Swarbrick et al. 2016; Gove et al. 2017; Brooke 2019). Helping to promote greater recognition that the voice of those living with a diagnosis are vital in understanding what it means to manage life with dementia and how this understanding can influence the way treatment and care is delivered and developed, so that it is best meeting the needs of those who live with dementia (Swarbrick et al. 2016; Gove et al. 2017; Brooke 2019).

In recent years, there has been an increase in the number of research about the lived experiences of people with dementia (Sharp 2019, Wolverson 2016). A recent meta-synthesis review (Bjørkløf et al. 2019) describes the challenges people with dementia may experience, which are related to a loss of independence, control and connection with others and society. People with dementia worry as their dementia progresses, and symptoms, such as memory, loss worsen, leading to an increased reliance on others and on health and social care services (Boustani et al. 2007). Bjørkløf et al's (2019) review highlights how people with dementia may feel stigmatized, embarrassed or stupid, and that feelings of self-worth and

identity can be negatively impacted by their dementia. Furthermore, they report that personal relationships change and feelings of increased isolation can be experienced, particularly as the confidence to socialise and take part in activities can be lost (Odzakovic et al. 2019). However, people with dementia can develop coping strategies, to help manage the dementia. These can be related to emotional strategies such as humour, acceptance, or avoidance; compensatory and behavioural, such as seeking support, adapting to their changing circumstances, and holding on to a normal life (Górska et al. 2018; Bjørkløf et al. 2019). This understanding of how they cope is important in helping health and social care to support those with a diagnosis. More research is still needed to explore these coping strategies, the capabilities of people with dementia, and the success of such strategies in order to support those living with dementia (ibid).

There is also a gap in developing this understanding from a theoretical framework, as few papers identify the methodological underpinnings for their approach, furthermore, such an approach could provide a new way of exploring the 'adaptability of dementia' (Górska et al. 2018, pp. 194). Frønsund et al.'s (2018) systematic meta-synthesis also argues for the importance of exploring the lifeworld of people with dementia (focusing on the lived space) to preserve their identity and provide a truly person-centered care (Frønsund et al., 2018). The experience of dementia cannot be developed from proxy reports, and service providers, and policy makers can benefit from speaking directly to people with dementia in order to know what they want.

This paper presents aspects of a qualitative participatory PhD study where twelve people with mild dementia were engaged in individual semi-structured interviews to capture the perspectives of their lifeworlds (XX 2017; XX et al. 2018). It contributes with knowledge, through a theoretical framework of hermeneutic phenomenology, about the lifeworld of people living with mild dementia, illustrating what it means to live with dementia within a societal context, and how it impacts on life, beyond that of the medical implications. It demonstrates how life is experienced and managed with mild dementia in a Danish context but the results are relevant beyond the study, providing clinical practice with important knowledge

about what may work as relevant strategies and techniques for people with mild dementia. This knowledge is relevant for improving dementia services, care and nursing.

Aim

The aim of the interviews was to explore the lifeworld perspective of how people with mild dementia experience and manage everyday life with dementia. This paper presents the results of these interviews providing knowledge about how life is experienced and what strategies and techniques people with dementia use to manage life with mild dementia.

Methodology

The aim of hermeneutic phenomenology is to gain an understanding through interpretation, and adopting a process that makes sense of the phenomenon under investigation, in its own setting (Dowling 2012). Max Van Manen represents a critical humanistic phenomenological methodology that is discovery oriented in exploring what phenomena mean and how they are experienced.

For him, phenomenology focuses on everyday situations and relations. Hereby, being a phenomenology of practice, exploring how everyday involvement with the world are enriched by knowing as in-being (Van Manen 2014). Often, the lifeworld is functioning implicitly in the background, but it is possible to explore the lifeworld. We just need to be aware that we cannot observe it from an outside perspective as our existence is a co-existence where people who are studied and the researcher who studies them are inseparably connected (Bengtsson 2006). Humans live in a social world, and when studying people's lifeworld, it is important that their actual connections and networks are taken into consideration. For this reason, living with dementia must be understood in terms of human connectedness as it is correlated with the life story, life situation, societal norms, etc. (Bengtsson 2006).

Methods

This study used qualitative interviews to generate knowledge about people with dementia's social worlds (Kvale & Brinkmann 2009), enabling an insight into subjectivity, voice and lived experiences (Rapley 2007). The interview guide included topics about life before and after receiving a dementia diagnosis with questions about memory, learning, activities and experiences related to receiving the diagnosis, the course of the condition and dementia services.

Individual interviews were scheduled at a convenient time for participants and lasted no longer than one hour. The interview was conducted in the late morning or after a break. At the end of the interview all except three participants showed signs of tiredness and some explained that it became more difficult to concentrate and answer the questions. In general, it was difficult for them to remember recent past experiences, leading to more brief answers when compared to talking about other topics, e.g. childhood memories. While given an option to take a break, none of the participants chose to pause/stop the interview before time. The interviews were conducted (by the first author) on the service premises, in a room that was known to the participants.

Data analysis

All interviews were video recorded and transcribed, including notes of non-verbal signals to illustrate the mood of the participants. The transcripts were analysed using a framework inspired by Van Manen's (2014) five existentials: spatiality (lived space), corporeality (lived body), temporality (lived time), relationality (lived relation) and materiality (lived things and technology) together with his six analytical "steps", including a process of recovering structures of meanings in a text. The existentials offered an analytical approach through which to manage the transcripts, offering a counterbalance to data immersion, familiarity and closeness with data (Rich et al. 2013). The transcripts were uploaded to NVivo (QSR International 2016) and in accordance with the first analytical step of Van Manen, the transcripts were read several times to get an overview by asking "*What is going on here?*" (Van Manen 1997). Notes and comments were written in annotations within NVivo. Each transcript was coded using the lifeworld

existentials from Van Manen’s framework. Each existential was coded with a unique colour and node across all data together with annotations. Following this process, an open coding process was performed within each lifeworld existential. A list of themes was derived for each existential by using coloured child nodes (subordinated to the first codes) and in-depth annotations. Then the themes were isolated and consolidated. Statements which revealed the themes were found and written down, illustrating the essence of each theme. Hereafter, the themes were discussed with an advisory group (two teachers and two students from a Dementia school). No major differences were identified in this process. In the final stage all transcripts were looked through to ensure that there was coherence between what was interpreted via the existentials and what data said (Van Manen 1997). See table 1 for an example of the analysis process.

Table 1: Example of the analysis process

The lifeworld existential node: Relationality	The child node: The role of the family	Annotations: Researcher’s notes	The child node: Social relations and activities	Annotations: Researcher’s notes	The revealed theme
Interviewer: <i>“So you have good help in your wife?”</i> Bent: <i>“Definitely”</i> ... Bent: <i>Also in my children”</i>	Interviewer: <i>“So you have good help in your wife?”</i> Bent: <i>“Definitely”</i> ... Bent: <i>Also in my children”</i>	Bent talks positively about his family and the help he receives from his wife and children. He is aware of his need of help.			<i>“We still live an active and social life regardless of difficulties”</i>
Bent: <i>“... one must be careful - you do not sit down and then say to yourself: “Now it’s good enough that over there...”</i>			Bent: <i>“... one must be careful - you do not sit down and then say to yourself: “Now it’s good enough that over there...”</i>	Bent explains the importance of being active and not give up	<i>“We still live an active and social life regardless of difficulties”</i>

Inspired by XX (2017)

The study followed the Standards for Reporting Qualitative Research (SRQR) (see Supplementary File 1).

Setting

Twelve participants with mild dementia were recruited from a Dementia School in the Northern Denmark from 2014-2016. The school focuses on lifelong learning and compensatory teaching as it is anticipated that people with mild dementia can (re-)learn for some time regardless of their disease (XX 2017; XX 2018).

They tailor a cognitive stimulation programme to meet the individual. Cognitive stimulation (Spector et al., 2003), aims to support and stimulate cognitive and social functioning to improve wellbeing and quality of life of people with dementia (Clare & Woods 2008, Orrell et al. 2014). At the school, people with dementia are named students (XX 2017; XX 2018).

Participants

The participants were aged between 65-82 years old, and included three women and nine men, reflecting the normal distribution of students at the school (See table 2). Recruitment was done in collaboration with the teachers at the school through a convenience sampling, of who was available and possible to contact. This approach benefits from providing access to participants and data quickly (Bjørner 2015), something that can be difficult to achieve with vulnerable groups. The inclusion criteria meant participants had to be diagnosed with mild dementia at least six months before recruitment, they had to give informed written consent, and they should understand their diagnosis and its implications. Finally, it was important that they felt comfortable talking about their experiences and were willing to contribute to research.

The definition of mild dementia was examined by the result of a Mini Mental State Examination test (MMSE) and by the judgement of the participant advocates (two teachers at the school not involved in the study) in the inclusion process of participants. A MMSE score between 10-26 is defined as mild to moderate dementia (Alzheimer's Society 2012). The MMSE test is one of the most widely used screening tool for

dementia. The reason for including people with mild dementia was to ensure they met the inclusion criteria of being able to understand and willing to talk about dementia.

Table 2: Participants characteristics

Person	Gender	Age	Occupation	Type of dementia	Marriage status	MMSE score	Teacher advocate Judgement
Johan	Male	68	Electrician	Alzheimer's disease	Divorced	29	Score in line with judgement. Had minor memory problems.
Ernst	Male	65	Bricklayer	Vascular dementia	Married	30	Score in line with judgement. Had minor word finding problems.
Victor	Male	74	Nursing assistant	Alzheimer's disease	Married	25	Score in line with judgement. Had short-term memory problems.
Emma	Female	76	Nurse	Alzheimer's disease	Widow	24	Performed surprisingly well. The test suited earlier work qualifications as a teaching nurse.
Elsa	Female	73	Librarian	Alzheimer's disease	Widow	%	Normally, able to cooperate. Got emotional. Test not completed.
Bent	Male	79	Auditor	Unspecific dementia	Married	14	The score lower than expected. Become talk-active and humoristic.
Henrik	Male	66	Pedagogue	Unspecific dementia	Married	22	Score in line with judgement. Able to overview the tasks.
Jette	Female	78	Teacher	Alzheimer's disease	Widow	29	Performed surprisingly well. The test suited earlier work qualifications as a teacher.
Wilhelm	Male	74	Director	Unspecific dementia	Married	%	Normally, able to cooperate. Got stressed and angry with himself. Test not completed.
Peter	Male	72	Engineer	Vascular dementia	Married	%	Had formulation problems. Got emotional. Test not completed.
Ove	Male	74	Lifeguard security	Alzheimer's disease	Married	26	Score in line with judgement. Had short-term memory problems with loss of initiative.

Kurt	Male	72	Trade union	Unspecific dementia	Married	30	Score in line with judgement. Had minor short-term memory problems.
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Inspired by XX (2017)

Ethics

All participants were informed about the research project verbally and in writing to obtain voluntary informed consent based on a full understanding of the research (Heggestad et al. 2012) as stated in “The declaration of Helsinki” (World Medical Association 1964). Special leaflets and consents were developed to meet the needs of the participants. These were developed through a consultation process with a class of students at the school, where feedback was requested on the readability and understanding of the material. The focus of the consultation was to seek the views on key aspects of the material. Feedback was provided to reduce paragraphs, shorten sentences, delete/change words, create more space for pictures and write mild dementia throughout, these changes were incorporated in the final documents. The information leaflet outlined the research, aim, methods and what was being required of the participants. Also leaflets for the relatives were developed to allow them to support the potential participants to decide whenever they wanted to take part or not.

The project was approved by the Danish Data Agency and was registered by the Ethic Committee of the Northern Denmark (J.nr. xxxx). To prepare for the interviews, the researcher (first author) undertook a three-month period of participant observation of two school classes as a way to familiarise with the students, and for the students to get to know the researcher in an informal way. This helped to develop a relaxed and trusting relationship, and enabled the researcher, who is an experienced interviewer and a nurse, to learn about the competences and challenges that the participants experienced and how best to support them during the interviews. During the recruitment, the participant advocates supported the planning of how to approach, recruit and interview the participants to ensure they were not harmed by taking part in the study. The participants’ names presented in this paper are pseudonyms.

Findings

The analysis identified five themes, based upon the coding of the Van Manen's five lifeworld existentials (See data analysis), that reveal how life was experienced before and after the diagnosis of dementia. The identified themes are interpreted in relation to what data revealed around these existentials. The first two themes reflect how people still try to live a social and active life and stay positive regardless of their dementia by using different strategies and techniques. The third theme explored how time is experienced after the dementia diagnosis. Finally, the last two themes concern difficulties in learning and remembering and how they try to compensate for this.

Living a social and active life regardless of difficulties

This theme primarily relates to Van Manen's relational existential, as it reveals the importance of the participants' social relationships. All participants, except Johan, explained how they appreciated being together with family and old friends as it was associated with positive feelings and enjoyment. For instance, Emma said:

"I try to find all the benefits that come with it, and then e-enjoy them with others at a similar level or with my children."

Here Emma focuses on the positive things in life and enjoy time with people with dementia and her children. In contrast, Johan had withdrawn from family and old friends as it became complicated to socialise after the diagnosis. He had sporadic contact to the family which he was able to manage. Instead, he appreciated new friends with dementia he met by attending different services. Most participants prioritised their existing relations even though their dementia complicated their relationships. They no longer felt as equal to other people and especially Jette worried it might come to a point where it was no longer possible for her to socialise.

Most participants enjoyed the activities and hobbies they had always appreciated and continued with these for as long as possible. They found it important not to give up because of age or dementia as it would make them passive. Yet some activities were difficult for them to continue because of the dementia, e.g. cycling, cooking and swimming, which influenced their quality of life negatively. For example, Elsa found it difficult to remember where she put her clothes in the swimming station, and Henrik to find his way when cycling alone. The loss of activities could lead to isolation and decrease the spatial existential (outside home). They tried to cope by for example attending different dementia services and Jette got a befriender. All reported that developing new relationships with people with dementia was positive as they represented a more equal relationship than was often shared with family. They could talk openly about their situation, how they managed it, and how they did not feel judged due to dementia when being with dementia peers. In the following quote, Emma talks about identifying ways to support each other, which she experiences as positive:

"I think we talk a lot about things, and I think we're trying somehow to find something that can benefit (support us) ... are some of the things we discuss. And I think that's good." (Emma)

However, close family were reported to be the primary social supportive relations (exclusive Johan as earlier mentioned). Bent explained how he found quality in life through the family, the grandchildren bringing joy and laughter into his life and helping him to stay active.

"T-thus, you must be careful – that you do not sit down then and say to yourself: 'Now it's good enough, this over there (to sit in that chair over there).'"

He thought that if he did not stay active but instead sat down and did not fight the dementia, he would somehow give up life. While the family unit was experienced as supportive and helped to maintain social connections, family challenges were also brought up. Some described how old roles were lost because the family took over, which could lead to a feeling of being redundant and having a negative impact on the relationship. Conversely, Henrik explained how his wife had taken over their economics, for which he was

grateful, although it was difficult to accept as he had previously been responsible for most of the decision-making and felt that this changed their relationship to one not on an equal status. However, others talked more positively about receiving help when experiencing difficulties, as it made them feel safe.

Trying to look at the bright side of life with dementia

This theme also related to the relationality existential, as they shared ways of staying positive and the impact this had on current relationships. The participants also talked about dementia, its symptoms and progression. They were open and honest about their situation, finding it helped ease the stress of trying to hide the dementia and made it easier to get help. Otherwise, life with dementia could become challenging and lonely. Emma thought that being open about dementia might strengthen her current relationships by raising awareness of dementia amongst others. Being open meant that she could talk freely and it was ok for others to tell her when she said something wrong.

"...You can say: 'I have, I have Alzheimer's disease', right? But then, we can certainly talk and things like that. If you think I say, make some nonsense, then tell it to me. Then you are on the way, and then there is not anything, 'Hu, they, just do not find out ...'"

The participants reported that the reality of living with dementia was difficult to manage and they tried to avoid thinking too much about the situation as it could make them feel sad. Especially for Elsa and Henrik, not thinking about their situation was a way to cope. Henrik told how dementia had changed his expectations towards life and that his focus was now on the present, as the future had become uncertain. Other participants as Victor, Emma and Jette reported different coping mechanisms such as going for walks to be able to think, drawing or painting. Many also talked about having a positive attitude towards life even though it was difficult. Victor put an effort in explaining to others that he tried to live a good and happy life:

"It is my wish, yes. To get as good a life t-t-together with, with my disease ... I can have much joy in my life, and so that others also can understand that I also may well be ... comfortable and happy and joyous."

The analysis reveals how coming to terms with dementia also depended on the participants' personalities. Some explained that they had always been optimistic by nature, and that this helped them now. The participants suggested that having a positive attitude involved focussing on remaining abilities even though their lives were changing.

Humour was also talked about as a coping strategy, both telling everyday jokes and dementia related jokes. As humour could be a response to all the correctness and make it easier to bare mistakes and laugh about them e.g. when missing words, not being able to answer a question or when talking nonsense. Johan explained how it was important not to take things too seriously and to laugh off mistakes, otherwise it became difficult to socialise:

"The whole thing should not be so straight and so ... there must also be room for mistakes. And one must also, of course, oneself be able to take it (laugh of it). Otherwise, it is worth nothing."

It takes time to adapt but at the same time, time is being lost

Temporality (lived time) was identified as an important existential as the participants explained how it took time to get used to and come to terms with dementia. Shortly, after the diagnosis, they felt alone. It was a painful and lonely time, and it was difficult to accept that there was no cure. Receiving a dementia diagnosis was described as getting a conviction by Victor. It was described as a difficult and demanding process that needed time to learn to live with. Wilhelm explained that, with time, it was something he had come to terms with:

"That I ... was told what it was (the diagnosis). Well, it was horrible, right? But, uh ... about a year probably went by, right? And now I feel you see as good as ..."

The participants also explained how their experience of time had changed as it was difficult to hold on to time. For instance, it could be difficult to remember one's birthday and age. Many also had difficulties in explaining when they were diagnosed. However, Johan and Kurt described in detail the time just around and after their diagnosis, naming the months and years and different professionals they had met.

The experience of time and how it had changed was also reported through the difficulties of responding immediately when communicating with other people. Participants reported how this could be demanding and that they needed time to be sure what the situation required. Johan explained:

"You've got to take a phone when it rings and you have to respond to what is being asked for, when standing with the phone in the hand. And sometimes I need half an hour to think."

He found that it was better to use emails than a telephone because then he had time to think and respond. When answering a phone call, he had to respond immediately, which was not always possible for him as he needed time to think. The participants also got tired if they communicated for a longer period as they were able to concentrate for a certain amount of time. Furthermore, the time of the day influenced their ability to communicate as they experienced greater challenges later in the day.

All participants talked about different coping techniques to structure the objective time and most of them used a calendar, either electronic or paper - illustrating Van Manen's materiality existential. Many found it helped them to remember appointments, birthdays and other activities. Ove explained his need for a calendar as he had problems in remembering the weekdays:

"I, I fail somewhat to remember many times. Whether it's Monday or Tuesday or Wednesday or Thursday and Friday and things like that, right? ... Yes. And I must say; it, it (the calendar) helps me a lot"

Some participants explained it was mostly their spouse or other family members who managed their calendar, writing down their activities, and creating an overview for them. Participants experienced this as helpful and as providing security, so they did not need to use too much energy trying to remember. Johan, Ernst and Emma tried to remember the daily activities before checking their calendar to train the memory, stay active and take responsibility for their own life. Even though the calendar was a useful tool, it could also be difficult to use and understand. They reported that their dementia affected their ability to use a calendar, meaning the calendar could become incomprehensible at times.

It is possible to learn, but it is challenging

The corporeality (lived body) existential was also identified in the analysis as the participants expressed experiencing changing learning abilities due to their dementia. Most participants said they had no problems learning before they got dementia, although could not explain exactly *how* they used to learn. Now, they explained, they were aware that their memory and ability to learn had decreased. It had become more difficult to understand, learn and remember and more energy was needed if they wanted to get a grip of things. Ernst emphasised:

"Well, y-y-you have to think more than you should in the past ... I may become a little slower to grasp or understand or learn. And, and, and remember those new things."

While there were challenges, learning was not experienced as impossible, especially if they got help to understand, learn and remember new things. This was something they experienced as possible at the dementia school. Some talked about reading books and newspapers, completing puzzles and crosswords as ways to train the brain and remain active. For example, Johan had learned to do Sudoku and use an iPad. Jette explained how she had re-learned to knit. In the learning process repetition was the key, as Johan explained:

"It's repetition, repetition and repetition, and so at some point, it's like, then it goes maybe a tiny bit better."

Johan experienced that if he repeated the learning again and again it was possible for him to remember. Other learning techniques, or ways of keeping the brain active, were identified by the participants as: writing notes, asking others, trying to remember before checking books and using associated words.

It was experienced as positive to learn new things. However, this was not true for everyone, especially Henrik, Elsa and Victor, who stopped challenging themselves and only did what they felt they could manage. Victor explained:

"Well, it's the only thing with, with, with remembering things - it is, but then I-I-I-I don't do anything that I do not juust ... I will say 100-100 percent sure that I can ..."

This showed how the participants reacted differently towards challenges as Victor no longer wanted to do things, he was not sure he managed.

To try to remember but keep forgetting

The corporeality existential (lived body) was identified in relation to the dementia as the memory no longer functioned as it did before dementia became a part of life. Noticing memory problems was one of the first significant issues most of the participants experienced before the diagnosis. Elsa discovered that she could no longer remember and keep track of things as she used to, which was a painful discovery.

“... Yes, how did I find out? I think that it, I think that it was my lack of and ability to remember and for-, keep track of. I think that it was there...”

Her body was no longer able to manage everyday life and she became aware of her impairments as she could no longer remember and keep track of things as she used to. Memory problems affected daily life, most participants explained that events from the recent past took a great deal of energy to recall and it was not always possible to evoke these memories. Some noted that recent major life changes were at times easier to remember, for example Elsa mentioned moving to a nursing home and Jette explained how a relative slept in her home to make her feel secure. Nonetheless, it was easier for them to describe episodes from their childhood and younger adult life, e.g. about their school, sports, jobs and hobbies.

The interviews showed how, for some, their memory problems included difficulties remembering exact words, expressions, and the names of people and places. This was also confirmed in their narratives, making it challenging to describe things. Occasionally, it was noted that they also used words or sayings which did not fit the context. Especially, Peter, whose vascular dementia resulted in major formulation problems. Some reported that it made them feel insecure as they had to think about the right pronunciation or find other words. It also made it difficult for others to understand what they said. Several participants expressed how it became difficult to remember the names of their children and grandchildren.

Different strategies were used to practice the names before meeting people or avoiding using names. Jette practiced the names of her children to remember these correctly as she could get them wrong:

"... If I go to my children, or they come to me ... I will of course, I will of course just have gone through it ... I could be so much wrong ..."

In conversations the participants risked only picking up a few words in a sentence or forgetting what they were being asked. Johan experienced this in the interview where he forgot what question he was answering but chose to laugh about it. Johan asked the interviewer:

"What, what do you eh, do you ask about now? What did you just say? Yes, but I was thinking more about - what was it you ..." (laughs). *"It was right there, yes. I lost the thread."*

Other ways that memory issues were experienced was through especially Emma and Peter repeated themselves by telling the same stories. Many of the participants were aware of these challenges and some asked for directions and support during the interview.

Memory problems also influenced the participants' ability to get an overview of activities and keep oriented to the details. The line of actions that make up an activity were difficult to remember, which could result in daily activities becoming difficult, e.g. finding their way through well-known areas and remembering what to buy when shopping. Their strategy was to go back to where they remembered having started and try to re-orient, which was a useful way to cope as the body might then remember. However, it was difficult to accept that normal daily activities suddenly became difficult because the lived body no longer fared "routinely".

Most of the participants shared how they wrote down important things they wanted to remember, which was a helpful strategy, but at times they forgot to read the notes that either they or their relatives had written. Ove explained it could be complicated to use this strategy, as he forgot where the notes were:

"Yes. I do. I do, but I, I, I keep forgetting it. But, uh ... uh, yes – otherwise then we have a note lying at home ... in the kitchen, right?"

A few participants used notes more systematically. Jette and Johan talked about how they always had paper with them to write important things. Johan then wrote his notes in his calendar on the computer when getting home. However, many had given up using a computer because it was difficult to keep up with the new versions even though they had previously been competent users. This also included newer technologies such as mobile phones and iPads, illustrating the materiality existential was also under pressure. Johan, Bent and a few others compensated by using old mobile phones and old desktop computers which the lived body still remembered how to use (XX 2017).

Discussion

The study shows that all five life existentials are negatively influenced by dementia, setting the lifeworld of people with dementia under pressure and changing their life circumstances dramatically. However, it also shows that people with dementia use different strategies and techniques to manage daily life, try to stay positive and active and get the best out of life. This corresponds with other studies that show how people with dementia try to stay positive, hopeful and keep up meaningful activities and relationships. They try to take control and responsibility for their lives for as long as possible, whilst acknowledging the losses associated with dementia (Clare & Woods 2008; Pison Young 2012). It is therefore important not to portray life with dementia as solely negative and depressing if we want to stay true to the voice raised in this study. On the other hand, Mazaheri et al. (2013) found that even though people with dementia want to feel positive, their experiences of loss and memory, can be overwhelming. This acknowledges that people with dementia experience multiple losses, e.g. loss of communication abilities, relationships, leisure activities, control of life decisions and fear of embarrassment even when living with mild dementia (Górska et al. 2018; Tanner 2012). The relational and spatiality existential is under pressure and the emotional response to the diagnosis of dementia fluctuates, with both positive and negative feelings, as this study found.

Complementing this, Górska et al. (2018) argue that people with dementia deal with many changes with a need to keep a semblance of normality. In the study, the participants, for example highlight the change of their role in the family and the feeling of no longer being equal in their relations, together with the memory and language problems, illustrating how their lifeworld are changing. Nevertheless, the study also shows how they try to manage the diagnosis, which may provide relevant input for dementia services, care and nursing in relation to support people living with dementia.

As mentioned above people with dementia may experience loss of control, which may be linked to the loss of independence and being able to manage own life affairs (Górska et al 2018). This shows how their lived body is not corresponding in the way it did before. In general, people with dementia want to be involved in decisions about their lives, but they may need support to be able to do this (Górska et al 2018). However, as this study shows there may exist mixed feelings about the need of help, as the participants experienced challenges in having their roles taken over or changed. This is important to be aware of if having a person-centred approach, seeking to support the autonomy, the dignity and the individuality of people with dementia (Murray 2013). To claim that people are not competent because of a diagnosis is discriminating and they deserve a fair evaluation of their competences (Heggestad et al. 2012, Meulenbroek, Vernooij-Dassen et al. 2010). This leads to the importance of recognising and supporting the strategies and techniques people with dementia develop in a way they experience useful and relevant. Górska et al. (2018) found in their review that people with dementia used emotional strategies, to focus on the positive, or to use denial; compensatory strategies, using others or objects to support them, and using techniques to keep the brain active; also behavioral strategies, such as routines, avoiding challenges and making changes to relationships were also used. These different strategies were also revealed in this study with very concrete examples of how the participants managed daily life, for example in the techniques they use to support memory through use of calendars, notes and repetition.

In the study, the participants argue for an open dialogue as it may raise awareness of dementia in their relations, which might make their life easier and safer, supporting the relational existential. This is also what the dementia activism movement is campaigning for when seeking justice and opportunities to grow regardless of the dementia (Bartlett 2012). It is important to remove the myths about dementia and instead see dementia as a disability, with focus on remaining strengths and abilities (Pipon Young 2012, Swaffer 2015). Thus, services may focus on a strength-based approach to dementia care and nursing with a recognition that not everyone experiences dementia in the same way.

To enjoy yourself with family and friends and use humour in various ways can make life with dementia easier, create a relaxed atmosphere and make socialisation informal and non-frightening. Humour may also be used when experiencing language problems as laughing seems to make mistakes less embarrassing and can hide challenging situations (Swinnen & de Medeiros 2017). Humour may have positive benefits for people with dementia, acting as a way to support self-identity, self-esteem, to develop social bonds, to boost wellbeing and reduce stress (Takeda et al 2010; Swinnen & de Medeiros 2017). Humour may also be used in care situations, especially during challenging or intimate situations where humour, used appropriately, can ease the situation (Mallett 1993). This present study adds to this understanding of humour used as a coping strategy by people with dementia, and regardless of all the challenges, the study shows that the participants tried to find ways to socialise with friends, family and dementia peers and to be outgoing even though the character of their social relations was under pressure and their social space was diminishing together with a functional and reliable body.

The temporality existential is changed as the study reveals that the logic of objective time becomes difficult to understand and hold on to. The different weekdays might be difficult to remember, and the experience of time may differ during the day. This is important knowledge as different strategies might be needed to support people with mild dementia to stay oriented in time with focus on what is meaningful for the individual. A global priority is therefore the need to develop appropriate support, including relevant

technologies that are helpful for people with dementia (Suijkerbuijk et al. 2019). In the study, it was shown that the materiality existential was under pressure as it became difficult to use e.g. mobile phones and computers. These things can change in importance, may be interpreted in new ways and become strange and difficult to use when living with dementia (Greenhalgh et al. 2013; Suijkerbuijk et al. 2019). This highlights a need for lived things and technologies to be dementia friendly.

However, another important insight is the study's demonstration that it is possible to (re-)learn even when living with mild dementia by developing different learning strategies. Giving a sense that the lived body is no longer complete and that strategies are needed to support especially the short-term memory. The use of cognitive stimulation opportunities, such as the Dementia School, are identified as important ways of providing services for people with dementia to support their lived body. Studies have shown positive results of cognitive stimulation and training where people with dementia are able to (re-)learn, skills and information that can support their daily living, with appropriate support (Clare & Woods 2008, Forbes et al. 2013; Woods et al. 2012). However, different reviews conclude that that further evidence is required for more conclusive understandings (Clare et al. 2008; Spector et al. 2012). In this study, the participants found learning possibilities positive, enabling them to (re-)learn things which otherwise would have been lost. This adds to the idea that service provision which can support memory, learning and engagement in activities is important to keep supporting people to engage in society and live an active life that may support their quality of life. This is supported by Górska et al. (2018) who explain how the less people do and engage in activities, the less they are able or feel confident to do things in their daily life.

Though, it is possible to (re-)learn in some extent, it is essential to keep in mind that the impaired memory will affect the self-image of people with mild dementia negatively as they experience that their memory is no longer as reliable as before, becoming increasingly difficult to remember things, words, names etc. and to overview activities and actions. As memory influences the way people carry themselves, their gestures, words and language (Van Manen 1997), not being able to remember may lead to a less positive self-image.

The lived body is no longer as reliable as it was before the diagnosis. The corporality is deteriorated. This is an area that dementia care and nursing could focus, in relation to ensuring a person-centred approach where professionals see the individual behind the dementia and put the person at the centre of the care process (Buron 2010). It is essential that the care provided to people with dementia enable them to experience a dignified life with respect for their identity regardless of the progression of the dementia (Heggstad & Slettebø 2015, Kitwood 1997). To maintain the dignity of people with dementia is the essence of qualified nursing care (Heggstad & Slettebø 2015).

In summary, the article shows that people with mild dementia experience that all life existentials – relations, body, time, space and things – are under pressure and that their lifeworld is diminishing, contributing with knowledge from their unique perspective. Their perspective is essential to developing dementia care and nursing that meet their wishes and needs. This is supported by Górska et al. (2018) literature review which states that more research is needed from people with dementia's experience, especially from a theoretical perspective to provide a new view. This study contributes with this new perspective by approaching the interviews through van Maren's theoretical framework.

Limitations

This study indicates that twelve participants might be enough to reach informative power as the aim was narrow, including participants highly specific for the study (Malterud et al. 2016). However, a few potential participants refused to participate due to their experience of a progressed dementia and disease in the family. Thus, it is noted that the recruited participants might be more outgoing than other groups of people with dementia as they all visit a service where they challenge themselves cognitively. This might influence the results showing more positive experiences.

Conclusion

The article demonstrates that people with mild dementia can describe how life with dementia is experienced and managed. They face multiple dilemmas and challenges, which they try to manage by using different strategies and techniques. Some are more successful than others due to the progression of dementia. This shows that people living with mild dementia still poses many competences and qualifications that need to be recognised and supported to help them stay social and active and live a meaningful life regardless of the dementia. As researchers and professionals, we need to be aware that the lifeworld of people even with a mild dementia are changing and diminishing which is experienced challenging and hurtful. Even though, they try to compensate, all five life existentials are negatively influenced by dementia, setting their lifeworld under pressure. The lifeworld is cracking, changing their life circumstances dramatically.

Further research on how to address this and how to support the strategies and techniques used by people with dementia, also in more progressed situations, may be relevant to explore from the perspective of those living with dementia. Moreover, it can be relevant to further develop already useful strategies and techniques for people with dementia to enable them to live a meaningful and independent life for as long as possible.

Relevance for clinical practice

Knowledge about how people with mild dementia experience life is important to explore through their unique perspective, providing clinical practice with important knowledge to improve dementia care and nursing. This study contributes with knowledge about how people with dementia experience their lifeworld and life existentials are under pressure, at the same time trying to compensate by using different strategies and techniques. It is of great importance to clinical practice to be aware of and address this in order to succeed with a future supportive dementia care and nursing.

What does this paper contribute to the wider global clinical community?

- Knowledge about how life with mild dementia is experienced and managed with use of different strategies and techniques
- Knowledge about how the lifeworld and life existentials of people with dementia are under pressure
- Knowledge about the importance of including the lifeworld perspective of those living with dementia in dementia care and nursing

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Table 1: Example of the analysis process

The lifeworld existential node: Relationality	The child node: The role of the family	Annotations: Researcher's notes	The child node: Social relations and activities	Annotations: Researcher's notes	The revealed theme
<p>Interviewer: "So you have good help in your wife?" Bent: "Definitely" ... Bent: Also in my children"</p>	<p>Interviewer: "So you have good help in your wife?" Bent: "Definitely" ... Bent: Also in my children"</p>	<p>Bent talks positively about his family and the help he receives from his wife and children. He is aware of his need of help.</p>			<p><i>"We still live an active and social life regardless of difficulties"</i></p>
<p>Bent: "... one must be careful - you do not sit down and then say to yourself: "Now it's good enough that over there..."</p>			<p>Bent: "... one must be careful - you do not sit down and then say to yourself: "Now it's good enough that over there..."</p>	<p>Bent explains the importance of being active and not give up</p>	<p><i>"We still live an active and social life regardless of difficulties"</i></p>

Inspired by XX (2017)

Table 2: Participants characteristics

Person	Gender	Age	Occupation	Type of dementia	Marriage status	MMSE score	Teacher advocate Judgement
Johan	Male	68	Electrician	Alzheimer's disease	Divorced	29	Score in line with judgement. Had minor memory problems.
Ernst	Male	65	Bricklayer	Vascular dementia	Married	30	Score in line with judgement. Had minor word finding problems.
Victor	Male	74	Nursing assistant	Alzheimer's disease	Married	25	Score in line with judgement. Had short-term memory problems.
Emma	Female	76	Nurse	Alzheimer's disease	Widow	24	Performed surprisingly well. The test suited earlier work qualifications as a teaching nurse.
Elsa	Female	73	Librarian	Alzheimer's disease	Widow	%	Normally, able to cooperate. Got emotional. Test not completed.
Bent	Male	79	Auditor	Unspecific dementia	Married	14	The score lower than expected. Become talk-active and humoristic.
Henrik	Male	66	Pedagogue	Unspecific dementia	Married	22	Score in line with judgement. Able to overview the tasks.
Jette	Female	78	Teacher	Alzheimer's disease	Widow	29	Performed surprisingly well. The test suited earlier work qualifications as a teacher.
Wilhelm	Male	74	Director	Unspecific dementia	Married	%	Normally, able to cooperate. Got stressed and angry with himself. Test not completed.
Peter	Male	72	Engineer	Vascular dementia	Married	%	Had formulation problems. Got emotional. Test not completed.
Ove	Male	74	Lifeguard security	Alzheimer's disease	Married	26	Score in line with judgement. Had short-term memory problems with loss of initiative.
Kurt	Male	72	Trade union	Unspecific dementia	Married	30	Score in line with judgement. Had minor short-term memory problems.

Inspired by XX (2017)