


Embodied meaning-making in the experiences and behaviours of persons with dementia

Dementia
2021, Vol. 0(0) 1–15
© The Author(s) 2021
Article reuse guidelines:
sagepub.com/journals-permissions
DOI: [10.1177/14713012211042979](https://doi.org/10.1177/14713012211042979)
journals.sagepub.com/home/dem


Tor-Arne Isene

Centre for Psychology of Religion, Innlandet Hospital Trust, Ottestad, Norway

Centre of Diakonia and Professional Practise, VID Specialised University, Oslo, Norway

Hilde Thygesen

Faculty of Health Sciences, Department of Occupational Therapy, Prosthetics and Orthotics, Oslo Metropolitan University, Oslo, Norway

Faculty of Health Studies, VID Specialised University, Oslo, Norway

Lars J Danbolt

Centre for Psychology of Religion, Innlandet Hospital Trust, Ottestad, Norway

Hans Stifoss-Hanssen

Centre of Diakonia and Professional Practise, VID Specialised University, Oslo, Norway

Abstract

Background: The aim of the study was to explore and articulate how meaning-making appears and how meaningfulness is experienced in persons with severe dementia. Although there is little knowledge about meaning-making and experience of meaningfulness for this group, this article assumes that persons with dementia are as much in need of meaningfulness in life as any others, and hence, that they are involved in the process of meaning-making.

Methods: The study was conducted using a qualitative method with exploratory design. Ten patients with severe dementia at a specialized dementia ward at an old age psychiatric department in hospital were observed through participant observation performed over four months. The field-notes from the observation contained narratives carrying with them a dimension of meaning played out in an

Corresponding author:

Tor-Arne Isene, Centre for Psychology of Religion, Innlandet Hospital Trust, Postboks 104, Brumunddal 2381, Norway.
Email: tor-arne.isene@sykehuset-innlandet.no

everyday setting and thus named *Meaning-making dramas*. The narratives were analyzed looking for expressions where experiences of meaning-making and meaningfulness could be identified.

Results: The narratives demonstrate that persons with severe dementia are involved in processes of meaning-making. The narratives include expressions of meaning-making, and of interactions that include apparent crises of meaning, but also transitions into what may be interpreted as meaningfulness based on experiences of significance, orientation and belonging. The role of the body and the senses has proved significant in these processes. The findings also suggest that experiences of meaning contribute to experience of personhood.

Conclusions: The relevance to clinical practice indicates that working from a person-centred approach in dementia care also includes paying attention to the dimension of meaning. This dimension is important both for the person living with dementia and for the people caring for them. Acknowledging meaning as a central human concern, it is crucial to seek understanding and knowledge about the significance of meaning in vulnerable groups such as persons with dementia.

Keywords

severe dementia, meaning-making, meaningfulness, spirituality, personhood, embodiment

Introduction

Meaning is widely acknowledged as a central human concern (Yalom, 1980), and Viktor Frankl postulates a *will to meaning* as the basic interest of the individual person to find meaning in life (Frankl, 1988). Meaning-making is the process of searching for a sense of meaningfulness in life. This article assumes that persons with dementia are as much in need of meaningfulness as any other people, and hence, that they are involved in the process of meaning-making.

Modern healthcare and treatment provide the world's population with longer life, and consequently, the prevalence of persons with dementia is increasing (World Health Organization, 2012). Dementia is an umbrella term for conditions caused by a variety of organic diseases of the brain and is characterized by chronic and irreversible cognitive impairment (American Psychiatric Association, 2013; Engedal & Haugen, 2018). Memory loss and confusion are the common symptoms in dementia, affecting most aspects of daily activities and social functioning (Engedal & Haugen, 2018; MacKinlay & Trevitt, 2012). The severity of symptoms of dementia is quantified in stages from mild, moderate to severe dementia (Engedal & Haugen, 2018; Hughes et al., 1982; World Health Organization, 1993). This article is focusing on persons with severe dementia. At this stage, the majority of individuals require extensive care. The accessibility to the person's senses and verbal expressions of meaning is challenged at this stage, especially when it comes to identifying meaning-making and meaningfulness. The research on this subject is scarce (Kevern, 2015).

Background

Meaningfulness in this article is understood in line with Schnell's definition as 'a (mostly unconscious) evaluation of one's life as coherent, significant, oriented and belonging' (Schnell, 2009, 2021, p. 8). Meaning is formed by a variety of orientations represented by sources of meaning (Schnell, 2009, 2021). A crisis of meaning is experienced when sense of coherence and continuity is violated and can be triggered by psychological, social or environmental processes (Schnell, 2009). From this perspective, a crisis of meaning is not the opposite of meaningfulness, as meaning may be experienced in

life while having a crisis of meaning. However, ‘...crises of meaning are usually followed by a search for meaning’ (Schnell, 2009, p. 487), and consequently, the process of meaning-making.

What sort of meaning-making can persons living with severe dementia experience? All areas in Schnell’s definition of meaningfulness represent potential struggles, which may relate to the person with dementia’s experiences of impairments of memory, attention, learning, abstract thinking and reduced capacity for verbal communication (American Psychiatric Association, 2013; Engedal & Haugen, 2018). This was also the main challenge in this study; to identify meaning-making processes in persons with severe dementia, despite the limitations in their cognitive abilities.

The subject in the process of meaning-making in this present study is the person with dementia. This leads us to the notion of personhood which in this study is understood as representing an attitude or stance taken towards treating people as persons, in line with Kitwood’s theories of personhood in dementia (Kitwood, 1997). This implies taking the person with dementia’s identity and rights for granted (Lindemann, 2014). Confirming a person with dementia as an individual person is important to maintain the person’s dignity (Heggestad et al., 2013), or using the words of Kitwood: *The person comes first* (Kitwood, 1997). Personhood is according to Kitwood not solely based on cognitive capacities, but it is ‘a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust’ (Kitwood, 1997, p. 8). This means that personhood in a person with dementia cannot be reduced to just capacities for cognition and reflection but is conditioned by relations to other persons and the social context.

Hughes takes a broader view of personhood, emphasizing the importance of the body when he argues that as persons we are *situated embodied agents* (Hughes (2001, 2014, p. 64). As persons we are embedded in a history and culture, and the person is intimately connected to the body: ‘The body is, as it were, more than just the body. It is the means by which my world, including my world of others, exists’ (2014, p. 20). This understanding of personhood as embodied derives from Merleau-Ponty’s famous words ‘The body is our general medium for having a world’ (1962, p. 169). This understanding of personhood as embodied is important for the person with severe dementia. The body is in itself understood as intentional, which means that a reflective understanding is not needed in order to relate to the world (Kontos, 2005; Merleau-Ponty, 1962). What it is to be a person in search of meaningfulness is therefore closely connected to the senses and the body.

Lindemann (2014) uses the expression ‘to be held in personhood’ (p. 19) as acts of preservative love. Seeing personhood as a social practice Lindeman suggests that persons with severe dementia are held in personhood in a similar way as children, by the recognition and response from significant persons, including carers. Holding persons with dementia in personhood includes treating them as persons and nurturing the social relationships that contribute to their humanity (2014). As many persons with severe dementia have reduced capacity for active participation in personhood, they may be held in personhood by people caring for them (2014).

Interacting with people with dementia and treating them as persons enhances the understanding that dementia is as much as a relational disability as it is a physical or neurological one (Kitwood, 1997; Swinton, 2011). Drawing parallels to Swinton’s writing about spirituality and cognitive disability, it can be argued that meaning-making is not necessarily an intellectual or cognitive concept, but about a relational reality (Swinton, 1997). These arguments strengthen the idea that persons with dementia need, and are involved in, meaning-making. Our research question is the following: How can meaning-making and meaningfulness be identified in persons with severe dementia? The aim of this article is to present empirical research material that identifies meaning-making or what is interpreted as experiences of meaningfulness in persons with severe dementia.

Methods

Data were collected through participant observation. Participant observation is one of the most common methods in qualitative research with the advantage to come close to the participants in their own environment. It provides the opportunity to explore expressions and actions in environments that are not structured by the researcher (Fangen, 2010). Participant observation allows the researcher to come closer to the participants compared to other methods in qualitative research and gives access to information that does not appear in interviews (Fangen, 2010). Observation allows for exploring how the participants experience meaningfulness and meaning-making rather than their conceptual understanding. Spending time with the participants makes it possible to observe their bodily actions, reactions or emotions communicating what is not necessarily expressed verbally, which makes it a particular useful approach for this study. Participant observation also provides opportunities for the researcher to act as a subject in interactions with the environment and being part of the conversation (Fangen, 2010).

Data construction

The participant observation was situated at a hospital ward with a capacity for five patients. The researcher was dressed in white workwear like the rest of the care workers on the ward and participated in daily activities like meals, outdoor walks, sing-alongs, exercise, etc. Much of the time the observer was following the patients, either individually or in groups, observing with an open mind to potential meaning-making moments.

A total of ten patients were observed, two men and eight women. A pilot observation over seven days was carried out a few months ahead of the main period that lasted four months. Altogether, the pilot and main period added up to forty-five days of observation. Typically, the observation days were clustered in two weeks with observation and two weeks without. Observations were conducted at different times of the day, from early morning before the patients got out of bed, to late evenings after bedtime. In this way, the observation covered most of the time the patients were awake. As the patients admitted to the ward in the period of observation were all sleeping through most of the nights, observation at night was not conducted.

Most of the patients on the ward were diagnosed with moderate-to-severe dementia in accordance with the hospital ward's admission criteria (C. P. Hughes et al., 1982). As some of the patients were more accessible for observation than others due to health status and condition, the amount of data from each individual patient varied. The duration of the observation sessions varied from just short situations to the full length of a day, but a typical session lasted four to five hours. Observations were first jotted down in a notebook along the session and written out in full text in field-notes right after the observation session finished. For longer sessions, some writing was done in breaks during the day.

Researcher's role

The researcher had previously worked as a chaplain in the hospital where the observation took place. None of the patients at the observation site had met the researcher in the role of chaplain, as it was a period of nine months from the chaplaincy work ended until the observation started. Still, the researcher's professional background could cause an unintended bias. From the participant's side, there is always a risk that the researcher's background affects their behaviour and focus in a way that gives skewed results. An advantage of doing participant observation is that the

observer may blend into the context, so the participants forget the researcher's role and background, behaving more naturally in the situations (Fangen, 2010). Disadvantages of the method are that it is quite time consuming and the risk of not balancing between being an observer and a participant.

Observation site

The ward where the observation took place was one of the four units of an old age psychiatric department of a hospital in eastern Norway. Patients were typically admitted because of problems with disruptive behaviour or due to a need for adjustments of their medication. Treatment with reduced use of medications, grounded in knowledge and research, was emphasized. Normally a patient was admitted for about two months. The professional carers included social educators, nurses, occupational therapists and medical doctors.

Ethical considerations

The patients in this study had varying degrees of ability to consent. Research on groups considered to be vulnerable, raises some special ethical concerns. It can be argued that persons with missing or reduced ability to consent should not be included in research (WMA, 2013). On the other hand, it can be argued that if people, considered to be vulnerable, are never allowed to be included in research, it might as well increase their vulnerability instead of reducing it as improved treatment and care depend on research for a better knowledge about their situation (NEM, 2005).

The project was registered (#47488) and approved by the Norwegian Social Science Data Services (NSD) in April 2016. Written informed consent was obtained by proxy from patients' next of kin (Slaughter et al., 2007). NSD confirmed that the study met the requirements for ethical soundness in relation to standards and codes of ethics. The study was also performed according to the Declaration of Helsinki. All data were anonymized.

As a participating observer, the researcher entered a context where he did not belong. At the same time, the patients at the ward might easily have forgotten his role as a researcher and considered him to be one of the staff. Coming close to people in their everyday life and privacy, it was important to treat the information the researcher received with caution and confidentiality (Fangen, 2010). Persons with dementia are particularly vulnerable as they do not have the prerequisites to understand what the research entails. A participant observer therefore needs to be continually aware of this and show respect for the boundaries of privacy. In this study, the researcher cooperated with the carers who functioned as gatekeepers and assessed which situations he could be invited into to observe.

Analysis

The process of analysis started through the observation and writing of field-notes. The field-notes attempted to describe what the observer experienced as openly as possible. However, it was not possible to do so without making choices about which observations should be included or left out from the material. The field-notes were written by the researcher using his own words. When the field-notes were written, the questions of *what* the content was and *how* to describe it were already asked and partially answered. Hence, the field-notes were abstracted observations and analyzed texts in themselves.

Four times during the period of observations, field-notes were sent to the co-authors who read them individually. Following the reading of each part of the field-notes, the authors met to discuss

overall impressions of the material, including how the observations were implemented, possibilities and limitations of the observation site and the observer's role. These discussions allowed for some adjustments along the way. In the beginning of this study, the focus was set on exploring spirituality. However, as the participant observation proceeded, we found that spirituality was too abstract and distanced to relate to for patients with severe dementia. Changing the perspective to look for experiences of meaningfulness and meaning-making opened up, allowing to focus on the moments, what happened there and then, and how concrete situations were experienced.

The analysis of the field-notes, after the participant observations were finished, did not follow any standardized method. Starting with an inductive approach, the authors read through the whole material again to get an overall impression. Rather than looking for specified analytical units, we found that the field-notes contained several narratives. These narratives stood out and touched us in a way that made us curious to find out what they could tell about meaning. As these narratives were played out in everyday settings, where interactions, physical expressions and actions were important, we chose to call them *meaning-making dramas*. These meaning-making dramas opened up and gave access to the themes we were looking for. The selection of meaning-making dramas presented in this article was chosen because they all together covered a variety of meaning-making situations and experiences of meaningfulness in persons with dementia.

Results: Meaning-making dramas

We will here present six narratives, understood as meaning-making dramas, from the data material. Building on Schnell's (2009) definition of meaningfulness, the meaning-making dramas found in the data were analyzed looking for expressions where an experience of coherence, significance, orientation or belonging could be identified. The narratives articulate and display expressions and experiences of meaning-making that is difficult to convey through verbal communication due to reduced cognitive capacity.

Anne's birthday I am sitting with Anne in her room. She is complaining a little over her aching legs and back, after the morning care. Then one of the carers enters the room approaching Anne. 'Today is the fifteenth of October! Do you know whose birthday it is today?' the carer asks. Anne, who until now has been sitting slumped and sleepily in her chair, lightens up. 'The fifteenth of October...' she says smiling. 'It is your birthday today, Anne!' the carer continues. 'Yes, it is' Anne replies. A second carer enters the room and the three of us are standing in front of Anne dancing and singing a birthday song. Anne covers her mouth and nose with both hands. She is smiling, and tears appear in her eyes. 'Thank you so much' she says emphasizing each word. One of the carers leaves the room and comes back with a tiny flag she puts on the table.

The carers have left. Anne and I are sitting alone in her room. She is holding a cup of hot chocolate and is sitting thoughtful in silence. Tears start flowing from her eyes. I move closer to her and put my hand on her back. 'You look sad' I say to her. 'Are you thinking of something?' 'Yes. Home.' She looks at me. 'I am thinking of those back home. They are gone. I am old.' 'Yes, you are eighty-three years old today. That is a high age,' I say to her. 'Yes,' she replies. 'It is.' Then Anne becomes quiet again. She is complaining a little bit over her aching back again and expresses that her pains are strong today.

The body was telling its own story in this narrative. It was morning, the sleepiness was still present in the body, and Anne's legs and back were aching. Being reminded of her birthday, Anne lightened up and even started smiling. As a response to the singing and dancing, she was touched and delighted.

In addition to verbally expressing it, she expressed thankfulness through her body's gestures. This could be seen as an experience of meaningfulness related to Schnell's (2009) notion of *belonging*. Then, sitting by herself after the carers had left the room, contrasted emotions appeared that also conveyed a *loss of belonging*. Celebrating a birthday implied acknowledgement of being old. Death was a reality. Those close to her were gone. She was old – and experienced herself as alone?

Anne expressed experiences both related to her past and to her present situation. Some days Anne believed that her parents were still alive, living in a white house visible from the hospital ward. However, that day when her birthday was celebrated, she appeared to be in her present, experiencing the pain of losing those close to her. This was expressed both verbally and through her tears. Then she became quiet. There were maybe no words for the feelings she was experiencing. Complaining about her backpains, which were physical and concrete, was maybe easier for her to express than the internal existential pains (crisis of meaning).

Celebrating Anne's birthday was built on the principles of person-centred care (Kitwood, 1997) and was done with the intention to show Anne who she was. Celebration is by Kitwood listed as one type of interaction in what he describes as positive person work (1997). The carers saw Anne's reactions of joy and gratitude when they sang for her but were not present to see what happened afterwards. From the carers' perspective, celebrating Anne's birthday was a successful and enjoyable event. But for Anne, this happening was given a meaning which might not have been possible to foresee, and nor was it discovered by the staff as they were no longer in the room when Anne's reactions came. The story shows that actions in the face of people with dementia are also important in meaning-making.

Gerda's poem Gerda was usually very cautious, often apologizing to people around her saying 'I can't do anything anymore' or 'I don't know what to talk about anymore'. I met Gerda in the corridor when she was on her way from the living room to her bedroom. 'I am so sad today,' she said. She had just been helping the carers to prepare waffles for the 'Chaplains' hour' later. We agreed that Gerda would lay down on her bed, and that someone would tell her when the chaplain arrived about half an hour later.

Chaplains hour was once a week. The table in the living room was decorated with a nice tablecloth and some neat crockery. Patients, carers and the chaplain were drinking coffee, eating waffles, chatting and singing songs together. The chaplain's hour was a popular change in the everyday life on the ward. It was not a devotional gathering. We were singing folk songs, hymns, religious and non-religious songs. Some of the songs could be related to the current season of the year.

Gerda rose from her chair when the chaplain arrives and shook hands with her. One of the carers had brought a poem that Gerda had written some 15 years ago. The poem had been printed in a book. The chaplain read Gerda's poem. The poem was about the significance and power of words. Gerda sat with her back straight while listening to the Chaplain reading her poem, and she smiled. 'I cannot believe that I have written this poem' she said shaking her head. For a moment the anxious old woman expressed calmness, happiness, and pride for herself. A carer told her that it was her son that brought the poem. 'Did he really?' she answered and smiled even more.

'Anymore' is a keyword of this narrative and can be seen to reflect a *crisis of meaning*, especially a lack of *significance* (Schnell, 2009). Gerda acknowledged that she did not manage to do the things she used to and did not know how to express this. Her repeated statements 'I can't do anything

anymore' reflected an experience of functional impairment and loss in coping and cognitive capacity. Along with these losses of functions, it is possible to resonate that Gerda experienced loss of identity: she did not feel like the person she used to be.

At the beginning of the Chaplains hour, the chaplain met Gerda and greeted her. This was an action that recognized her and confirmed her person and identity. She was acknowledged by the chaplain and rose up off her chair when she greeted her. Her body responded appropriately and was given a function in the situation. By rising up off her chair, Gerda expressed reverence towards the chaplain, concretized that a meeting had happened, and that a relation was established. The body remembered and knew what to do in that situation. The chaplain's approach and Gerda's response were both actions giving significance to Gerda.

When the chaplain read the poem Gerda had written, Gerda was connected to cognitive abilities she once had, but which were now lost to dementia. She had written something with significance which gave meaning to herself and others. Her body responded by straightening up to a straight posture, expressing dignity and pride. By reading Gerda's poem, she was connected to the past when her cognitive functions were not affected by dementia. Meaningfulness was identified in this narrative through an experience of having or being of *significance*. Connecting the past with the present could be identified as *coherence*.

Baking Christmas cookies The other day, Gerda had been very anxious in the morning. Three times during breakfast she had left the dining room and gone back to her room.

After breakfast, baking traditional Christmas cookies was on the agenda. The dining room was cleared and prepared for baking cookies. Cookie dough was already prepared in a bowl at the table. Gerda was invited to join in on the baking activity. She first excused herself saying 'I don't know how to bake cookies anymore.' But eventually, she came along.

Carefully entering the dining room, she noticed the cookie dough at the table. She went to the table, picked up a knife and started to cut the cookie dough into smaller pieces. I put an apron over her head, and she tied it, without looking, with a knot on her back within seconds. The anxious insecure woman was now in charge and in command of baking Christmas cookies. Together with one of the other patients, they rolled, sliced, put the cookies on a baking tray, brushed them with eggs and sprinkled them with chopped almonds. Within 15 minutes several trays of cookies were ready for the oven.

Gerda often expressed that she was not coping, repeatedly saying 'I don't know how to...'. However, seeing the cookie dough at the table stimulated something in her and activated her body. Her hands knew what to do, and Gerda was transformed from an uncertain patient to a competent house economics teacher taking command. This could be seen as a transformation from a crisis of meaning, expressed as an experience of anxiety and low self-esteem, into an experience of meaningfulness, which was manifested as self-confidence and control.

Gerda's initial experience of not coping is possible to interpret as absence or loss of *orientation*. The baking-activity connected Gerda to her own professional background as a teacher in home economics. Her knowledge and skills had *significance* in a context where she was able to contribute. Baking Christmas cookies related to strong traditions in preparations and celebration of Christmas. Being part of this and being able to contribute with her own resources could be experiences of *significance* and *coherence*.

Emma's Lucia celebration Emma had trouble speaking but could express herself in short sentences of two or three words at a time. Frequently she was not able to remember the words she wanted to use. Several years ago, Emma had been singing in a choir for many years.

One afternoon in December Emma went together with one other dementia patient and two carers to a cafeteria. This was on the St. Lucia day and an invited choir performed a Lucia celebration in the cafeteria. As we sat drinking coffee at a table, the doors opened, and the choir entered the room in a procession wearing white robes and holding candles in their hands. They were singing the Lucia hymn as they entered the room.

As the choir entered the cafeteria, Emma stood up from her chair and almost in a spellbound manner watched and listened to the choir in the procession. Emma started to hum along with the choir.

After finishing the procession, the choir held a little concert in the cafeteria, singing a few Christmas carols. Emma was standing a few meters in front of the choir. She was humming along with the choir and slowly moved the body to the music. After a few songs Emma started to hum the alto voice to one of the carols.

In this story, there was no verbal dialogue. Nevertheless, communication was going on between Emma and the choir. Emma was communicating through her body and sensed as she was listening and moving her body to the music. As the choir entered the room, Emma stood up off her chair. It could be spontaneous, or it could be a deliberate act – it is impossible to know. The situation resembles being in a church when the congregation stands up as the procession walks up the aisle. Clearly Emma was experiencing an attraction towards what she saw and heard. Emma was responding to the choir and the music through her body by standing up, listening, humming, moving to the music and even joining in on the alto voice.

When the choir was singing, it seemed to be something Emma recognized as valuable, connecting on to her to her past as a choir singer. At the same time, the singing and the music was an experience there and then. It connected her and made her a participant in that present situation and happening; it represented in this way *coherence* and *belonging*.

A walk in the rain Emma was sitting in a chair in the living room. She was crying, and a carer was sitting next to her, trying to comfort her. I sat down with them. 'Life is over now' Emma said. For a moment she was sitting in silence with us. Then suddenly she got up, left the living room and started wandering down the corridor. 'It will pass when I am allowed to be alone by myself!' she said.

After walking up and down the corridor for a few minutes, Emma came over to me, looked into my eyes and asked, 'aren't there anything to do when things are like this?'

I asked her back 'is there something you like to do, when things are like this?'

'I like going for long walks,' she answered.

'Good! Then the two of us can go outside for a walk' I answered.

We put on outdoor clothing and went outside. The rain was pouring down. We stood outside the front door and I asked her if she wanted to wait until the rain had stopped. 'It doesn't matter!' she replied and started walking out in the rain.

It was late in the autumn and we walked carefully on the icy and slippery roads. Most of the time we were walking in silence without talking. 'Awful weather!' Emma exclaimed a couple of times. At the same time, it appeared that her mood was lightening up as we were walking in the rain.

After fifteen minutes' walk in the rain, we returned to the ward. We were cold and soaking wet to the skin.

'Was it ok to walk in the rain?' I asked her when we came inside.

'It was wonderful,' she answered with a smile and appeared to be very pleased.

There was a hopelessness in Emma's statement 'life is over now'. It could be she was thinking of death, or it could be the feeling of hopelessness of her own situation; indicating a feeling that life in general as she knows it, was over. Emma's reactions, sitting in the living room crying, could be seen as an experience of a crisis of meaning. However, something in her caused her to stand up and start wandering up and down the corridor. A feeling of unrest and restlessness is a likely explanation. But it may also be that a part of her refused to give up, and that in the midst of despair she wanted out of the difficult situation. Emma asked if there was anything she could do, but she was the one who came up with the suggestion to go for a walk.

Emma had always been fond of nature and outdoor activities. She and her husband had been physically active running, doing orienteering and marathons. As we walked, we felt the wind, the rain and the cold weather on our bodies. It seemed as if this closeness to the rain and wind and physical exercise had an impact on Emma. She connected with nature and to something in herself which had been an important part of her life.

We walked together without talking. Instead, it was the body that was doing its job. Through her body, Emma sensed and experienced the weather as we were walking. By using her body, Emma seemed to find her strength to fight hopelessness. The story could be read as moves from despair (crisis of meaning) to hope (meaning-making) and to well-being (meaningfulness) and *coherence*.

Working in the garden David's dementia had worsened severely over the last few months, and he had experienced a substantial functioning-fall. He was repeatedly saying 'Sorry' or 'I'm sorry,' which by the surroundings often was perceived as a kind of tics, since he was saying it continually.

One afternoon David was sitting in his room, drinking a cup of coffee. The gardener had just mowed the lawn outside, and I suggested for David that we could go outside to collect the grass from the lawn. At first, he declined, but then he decided to come along as one of the carers and I went outside into the garden. He said 'sorry' several times on our way outside. The lawn was divided into sections between the walking paths. David fetched a rake and started raking the grass together with habitual movements. I was working close by. David was thorough and systematic. Every time we moved to a new section, he started raking by himself without further instructions. After raking the grass into small piles, he asked for something to put the grass in. One of the other patients was operating the wheelbarrow, and the two of them were cooperating smoothly. 'It is fun to rake!' David said and appeared to be very pleased. There were no 'sorry's' at all when we were outside in the garden working together.

From a medical perspective, David's repeatedly expressed 'sorry's' were considered as tics and as characteristic symptoms of his frontotemporal dementia. However, seeing it from another perspective, why did he repeat the word *sorry* all the time? Was it a coincidence, or did it relate to a previous experience, or was it an expression of an inner sense of meaninglessness? David was in

a full-time job a few months before being hospitalized and moved to a nursing home after being discharged from the hospital. It was difficult for his spouse to accept that he would not be able to live at home anymore. This raises the question of how David was experiencing this situation. Was ‘sorry’ an expression for a crisis of meaning?

In the garden, David got an experience of mastering, in contrast to his decline in overall functions. He used his body and experienced that it worked. In the garden, he knew what to do and how to do it. He took management and control, cooperating and working together with the other patient operating the wheelbarrow.

Discussion

In the meaning-making dramas presented above, a deeper understanding related to specific incidences was described. In the following, we rediscover and interpret these dramas as stories of embodied meaning, experiences of coherence, significance, orientation and belonging and as contributions to experience of personhood.

Dramas of embodied meaning

The meaning-making dramas in this study are stories about how living with severe dementia violated the experience of meaning. Like dramas in the world of theatre and literature, the meaning-making dramas were characterized by emphasizing the action conveying that something was at stake, and that ‘something’ in these dramas was the experience of meaning. The main characters were persons with dementia in processes of meaning-making. It was not said if this meaning-making was intentional or just happened in the situations there and then. As persons with dementia have difficulties to intentionally search for meaning, the body seemed to take this role demonstrating that it was in itself intentional in meaning-making.

The body played an important role in all of the dramas as it *sensed* different contexts, it *conveyed* emotions, and it *responded and functioned* in certain ways in the situations. The senses registered and took in the context and seemed to stimulate reactions like in the situation when Gerda was baking Christmas cookies. Seeing the cookie-dough and smelling the aromas from the baking could be an activation of the procedural memory that stimulated the body into action. Seeing the choir in St. Lucia procession, as well as hearing and listening to the music, seemed to connect with something in Emma. The senses also connected Emma with the nature when she walked outdoor feeling the cold temperature, rain and wind to her body.

Beyond the more obvious bodily expressions like tears and smiles for sorrow and happiness, the body also expressed pride when it straightened during the reading of the poem, uncertainty when it dropped or withdrawn, self-confidence when it took action and control in baking or working in the garden and also a sense of connection and participation when it moved and hummed along with the choirs singing.

The body ‘talked’ in situations like standing up when the chaplain shook hands, or when the choir entered the room in procession. It showed decisiveness in baking when the cookie dough and baking equipment were presented, and it started raking grass when receiving a rake. In those situations, the body responded appropriately even if it was probably not intentional at a cognitive level.

Meaning as experiences of coherence, significance, orientation and belonging

Schnell’s empirical research (Schnell, 2009, 2021; Schnell & Becker, 2007) was conducted in a general population. Our study was carried out as an extensive fieldwork in a hospital ward for

persons with severe dementia. The findings revealed that meaning for this population first and foremost was an embodied experience. How can Schnell's theoretical model on elements of meaningfulness be applied contributing to interpret and understand meaning in this population?

Coherence is possibly the element of meaning where persons with dementia encounter the biggest loss as it is based on an experience that perceptions, acts and goals make sense and are consistent with each other (Schnell, 2021). How can coherence be understood when the timeline seems to be cut and the connection to the identity and the person that once existed appear as inaccessible? The contexts of the meaning-making dramas seemed to give an experience of coherence as the patients were reconnected with their former life as a poem writer, house economic teacher, choir singer or a handyman working in the garden.

Significance refers to our perception of how our actions are received by others and what consequences they have or may not have (Schnell, 2021). Several of the patients observed in this study conveyed experiences of being insignificant or even a burden to others. When the carers initiated and facilitated activities like baking Christmas cookies, working in the garden or reading Gerda's poem, it appeared to give contrasted experiences. These activities exemplified how treating people with dementia as persons and nurturing the social relationship seemed to contribute to their experience of dignity and significance.

Orientation is about having a direction or purpose (Schnell, 2021). For a person with dementia the time is fugacious, it is all about what happens here and now. The meaning-making dramas were instant moments which could be lost and forgotten one minute later. Talking about orientation in the sense of a direction or a purpose is problematically related to persons with dementia. However, the meaning-making dramas gave examples of certain changes or transitions that happened which could be interpreted as acts of orientation. When Emma was out walking in the rain, it appeared to direct her from a crisis of meaning into an experience of meaningfulness.

Belonging refers to an experience of being a part of a larger whole or having a place in the world and can be seen as a response to existential isolation (Schnell, 2021; Yalom, 1980). Longing for home or talking about going home was frequently a focus among some of the patients. Being away from home, one could say that the patients were observed in an alienated situation. An interesting parallel to this alienation in hospital is that dementia itself may also be experienced as a kind of alienation as a person with dementia struggles with communication and social participation and thus becomes isolated in one's own world (Svanström et al., 2013). Anna's realization of being old and alone or Emma's statement that life was over could be perceived as cases of existential isolation. Singing Christmas carols with the choir and baking Christmas cookies seemed to give experiences of belonging in a context and being part of familiar traditions.

Meaning as contribution to experience of personhood

Drawing parallels on Hughes' (2014) notion on personhood as being situated embodied agents, the interpretation of meaning-making dramas suggested that the processes of meaning-making and experiences of meaningfulness were still happening in persons with severe dementia. Meaning seemed to be embedded in the person's life-history and engagement with others. It was embodied in the sense that meaning-making and meaningfulness could be recognized and played out through the body and the senses. As personhood depends on maintenance through meaningful activities in relations to other persons and the social context (Hughes, 2014; Kitwood, 1997), one could suggest that meaning as interpreted in the meaning-making dramas contributed to strengthen the experience of personhood. Paying attention to the dimension of meaning hidden in the tacit reality of everyday

life situations could be understood, in line with Lindemann's notion (2014), as holding a person with dementia in personhood.

Limitations

Findings from this study cannot be generalized. As a qualitative study, the purpose was to gain a deeper understanding meaning-making and meaningfulness within a population where it has been relatively little research on this topic. It would be desirable to include more men in the study, but that was not possible to control as the sample was bound to the actual group of patients that were admitted at the ward in the period of observation.

Conclusion

In this study, we found that persons with severe dementia are also involved in processes of meaning-making. This study has contributed new knowledge on meaning from a population where research has been scarce. Although the context and sample are limited, the findings demonstrated an existential dimension that is important both for the person living with dementia and for the people caring for them. The relevance to clinical practice indicates that working from a person-centred approach in dementia care also includes paying attention to the dimension of meaning. Acknowledging meaning as a central human concern, we find it crucial to seek understanding and knowledge about the significance of meaning in vulnerable groups such as persons with dementia. Further research into other and larger populations is likely to increasingly complement this knowledge.

Acknowledgements

We are grateful for the support from VID Specialized University and Innlandet Hospital Trust.

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This study was financed by Innlandet Hospital Trust, Norway, (Grant No. 150332).

Ethical approval

The project was registered (#47488) and approved by the Norwegian Social Science Data Services (NSD) 20 April 2016.

ORCID iD

Tor-Arne Isene  <https://orcid.org/0000-0002-2199-3027>

References

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders: DSM-5* (5th ed.). American Psychiatric Publishing.

- Engedal, K., & Haugen, P. K. (2018). Demens. In K. Engedal & P. K. Haugen (Eds.), *Demens: sykdommer, diagnostikk og behandling [Dementia: diseases, diagnostics and treatment]* (pp. 14-28). Forl. aldring og helseakademisk.
- Fangen, K. (2010). *Deltagende observation [Eng: Participant Observation]* (2. utg. ed.). Fagbokforlaget.
- Frankl, V. (1988). *The will to meaning*. New American Library.
- Heggestad, A. K. T., Nortvedt, P., & Slettebø, Å. (2013). 'Like a prison without bars'. *Nursing Ethics*, 20(8), 881-892. <https://doi.org/10.1177/0969733013484484>.
- Hughes, C. P., Berg, L., Danziger, W., Coben, L. A., & Martin, R. L. (1982). A new clinical scale for the staging of dementia. *British Journal of Psychiatry*, 140(6), 566-572.
- Hughes, J. C. (2001). Views of the person with dementia. *Journal of Medical Ethics*, 27(2), 86-91. <https://doi.org/10.1136/jme.27.2.86>.
- Hughes, J. C. (2014). *How we think about dementia: Personhood, rights, ethics, the arts and what they mean for care*. Jessica Kingsley Publishers.
- Kevern, P. (2015). The spirituality of people with late-stage dementia: A review of the research literature, a critical analysis and some implications for person-centred spirituality and dementia care. *Mental Health, Religion & Culture*, 18(9), 765-776. <https://doi.org/10.1080/13674676.2015.1094781>.
- Kitwood, T. (1997). *Dementia reconsidered: The person comes first*. Open University Press.
- Kontos, P. C. (2005). Embodied selfhood in Alzheimer's disease. *Dementia*, 4(4), 553-570.
- Lindemann, H. (2014). Second nature and the tragedy of Alzheimer's. In L. C. Hydén, H. Lindemann & J. Brockmeier (Eds.), *Beyond loss: Dementia, identity, personhood* (pp. 11-23). Oxford University Press.
- MacKinlay, E., & Trevitt, C. (2012). *Finding meaning in the experience of dementia: The place of spiritual reminiscence work*. Jessica Kingsley Publishers.
- Merleau-Ponty, M. (1962). *Phenomenology of perception* (C. Smith, Trans.). Routledge.
- NEM. (2005). *Redusert samtykkekompetanse i helsefaglig forskning : Retningslinjer for inclusion av voksne personer med manglet eller reduceret samtykkekompetanse [eng: Reduced ability to consent in health research: guidelines for inclusion of adult persons with missing or reduced ability to consent]*. De nasjonale forskningsetiske komiteer.
- Schnell, T. (2009). The Sources of Meaning and Meaning in Life Questionnaire (SoMe): Relations to demographics and well-being. *The Journal of Positive Psychology*, 4(6), 483-499. <https://doi.org/10.1080/17439760903271074>.
- Schnell, T. (2021). *The psychology of meaning in life* (T. Schnell, Trans, 1st ed.). Routledge.
- Schnell, T., & Becker, P. (2007). *LeBe - fragenbogen zu Lebensbedeutungen und Lebenssinn*. Hogrefe Verlag.
- Slaughter, S., Cole, D., Jennings, E., & Reimer, M. A. (2007). Consent and assent to participate in research from people with dementia. *Nursing Ethics*, 14(1), 27-40. <https://doi.org/10.1177/0969733007071355>.
- Svanström, R., Sundler, A. J., Berglund, M., & Westin, L. (2013). Suffering caused by care-elderly patients' experiences in community care. *International Journal of Qualitative Studies on Health and Well-Being*, 8(1), 20603.
- Swinton, J. (1997). Restoring the image: Spirituality, faith, and cognitive disability. *Journal of Religion and Health*, 36(1), 21-28.
- Swinton, J. (2011). Being in the moment: Developing a contemplative approach to spiritual care with people who have Dementia. In A. Jewell (Ed.), *Spirituality and personhood and dementia* (pp. 175-185). Jessica Kingsley Publishers.
- WMA. (2013). *Declaration of helsinki*. <https://www.etikkom.no/forskningsetiske-retningslinjer/Medisin-og-helse/Helsinki-deklarasjonen/>.
- World Health Organization. (1993). *The ICD-10 classification of mental and behavioural disorders : diagnostic criteria for research*. Geneva: World Health Organization.
- World Health Organization. (2012). *Dementia: A public health priority (9789241564458)*.
- Yalom, I. D. (1980). *Existential psychotherapy*. Basic Books.

Tor-Arne Isene is a hospital chaplain and PhD student at the center for psychology and religion at Innlandet Hospital Trust in Hamar and at the Centre for diaconia and professional practice at VID Specialized University in Oslo. He is a theologian and an ordained minister who has worked for more than ten years as a chaplain at a psychiatric hospital at Innlandet Hospital Trust. His ongoing PhD-project is about how meaning appears in persons with severe dementia and the implications of meaning-making in dementia care practices.

Hilde Thygesen, PhD, is a professor at VID Specialized University and at Oslo Metropolitan University. She holds a Bachelor of Applied Science in Occupational Therapy (LaTrobe University, Australia) and a PhD in sociology (University of Oslo, Norway). Thygesen's research has been focused on the use of technology in health and care services, with a particular interest in dementia care practices and ethics.

Hans Stifoss-Hanssen, PhD, is a professor at VID Specialized University, Center for Diaconia and Professional Practice, Oslo, Norway. He has published in psychology of religion, pastoral care and ritual studies.

Lars Johan Danbolt, PhD, is the director of Center for Psychology of Religion, Innlandet Hospital Trust, Norway and professor at MF Norwegian School of Theology. He has published in psychology of religion, practical theology and ritual studies.