

“I still want to be part of the world...where I belong.” A case study of the experiences of a man with Alzheimer’s of dementia-friendly guided tours at an art museum

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Abstract

There is a growing interest in the role art museums might play in enriching the lives of persons with dementia. The literature has started incorporating the views of persons with dementia in the knowledge production, but in-depth explorations of their art experiences are still rare in the literature. This article adds to the research with a case study of a man with Alzheimer’s, who regularly takes part in dementia-friendly guided tours at his local art museum. The article examines, through a narrative analysis, the role his visits to the art museum might play in the way he navigates life with Alzheimer’s. The authors argue that the art experiences are important cultural resources in the man’s effort to “hold his own” faced with Alzheimer’s. This study is bound to a Norwegian context, but the art programme has similarities with related programmes at art museums in other countries.

Keywords: dementia, art museum, narrative analysis, dementia-friendly art programmes, cultural citizenship, case study.

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Introduction

As the population is aging globally, the number of persons with dementia is growing exponentially. By 2050, an estimate of 131 million persons be living with dementia (World Health Organization 2016). In May 2017, the World Health Assembly approved the “Global action plan on the public health response to dementia 2017–2025” (World Health Organization 2017). One of the seven key areas of action is increasing dementia awareness, inclusion and friendliness. In order to create awareness of dementia and include persons with dementia in society in ways that allow them to live active and meaningful lives, it is important to think of dementia and participation in novel ways.

A growing number of studies have recognised the role that art museums might play in enriching the lives of persons with dementia (Camic & Chatterjee 2013; Johnson et al. 2017; Schall et al. 2018). This emergent field has started incorporating the views and opinions of persons with dementia in knowledge production (Burnside et al. 2017; Camic et al. 2014; Flatt et al. 2015). However, in-depth explorations of persons with dementia’s experiences are still rare in the literature. The goal of most participatory arts programmes tailored at persons with dementia is to create meaningful personal experiences for the participants (de Medeiros & Basting 2014). It is therefore imperative to listen to their voices and opinions in depth to better understand the complexity of the personal experiences such programmes may facilitate. This article adds to this strand of research with a case study of John, a man in his mid-60s with Alzheimer’s disease, who regularly takes part in dementia-friendly guided tours at his local art museum. We adopted an explorative case methodology (Stake 1995), and interviewed John (a pseudonym) about his experiences at the museum over a 2-year period. The case study of John presented in this article is a case within a larger explorative qualitative case study about the encounters of persons with dementia with art at dementia-friendly guided tours at a Norwegian art museum. As far as we know, this is the first article in the arts and health field that attempts to understand how visits to a local art museum by a person with dementia over a longer period of time interconnects with the person’s experiences of living with Alzheimer’s. We chose to present John as a case study because we considered him to be a person we could learn a great deal from about the complexity of the personal experiences that can emerge from participating in an art programme at

a museum. Such knowledge adds to our understanding of the impact community arts programmes may have on how persons with dementia navigate their everyday lives. Our analytical approach is influenced by Arthur Frank's "Dialogical Narrative Analysis" (DNA) (2012a). One central question in DNA is how the storyteller is "holding his own" in the face of illness, which refers to a person's effort to preserve a particular version of the self as she or he wants to believe it can be against forces that threaten to diminish that self (Frank 2012a: 3). Our research questions are as follows: How is John holding his own faced with Alzheimer's illness? What role do his visits to the art museum play in this effort?

To contextualise John's storytelling, John and the narrative approach are presented before we describe the art museum programme. This is followed by the analytical approach and methodological considerations of the study. John's stories are succeeded by a discussion of his stories in light of perspectives on agency, narrative resources and citizenship, to illuminate personal and societal aspects of how John is holding his own.

Methodology and Research Design

The Participant: Why John?

John received his diagnosis in his early 60s. He lives with his wife. He has a university college degree in natural sciences and has a successful career until he was diagnosed. John was not preselected at the onset of the larger study. As noted by Abma and Stake (2014), this is typical with naturalistic cases studies: "The case is not known beforehand but stands out of a set that has been studied and, given its ambiguity, begs for a more detailed understanding" (p. 1157).

The first author met John for the first time on a guided tour at the art museum. During the social gathering after the tour, he told her how he enjoyed the art programme. It made him both proud and happy, he said. He signed up for the upcoming tours in the programme. Based on this first impression of John, the first and second authors inferred that it might be interesting for John to take part in the research where he could explore and share more of his experiences. John has been interested in music and literature for most of his adult life. He has no special experience or training with the visual arts.

John was also recruited because he offered a perspective of great value to understanding the complexity of the larger case study. The main objective of an intrinsic case study is to explore the case in its ordinary situation from multiple perspectives (Abma & Stake 2014: 1150). The present article is the third article from this larger study (Lea & Synnes 2020; Lea et al. 2020). John provided the research with an in-depth understanding of the personal and situational meanings of the dementia-friendly programme.

A Narrative Approach to Understanding John

We have chosen a narrative approach in our analysis of the interviews with John. During the first interview with John, the first author noticed that he often presented himself and his experiences through stories, or what Riessman (2008) calls every-day oral storytelling: “in everyday oral storytelling, a speaker connects events into a sequence that is consequential for later action and for the meanings that the speaker wants listeners to take away from the story” (p. 3).

Whilst Riessman above underscores the verbal aspects of narrative, Cheryl Mattingly (1998, 2007) understands stories also as enacted. She emphasises the close connection between the stories we tell and the active shaping of our lived experiences by seeing stories as something that can be acted as well as told.

Stories, whether acted or told, explore and create possible worlds. When healing means living with chronic illness or disability, it cannot be reduced to matters such as taking away the pain, restoring life, or curing disease. Instead, it involves an active exploration of how life can be lived, how there can still be a way to act, to desire, to participate in the world, even with this body and under these circumstances. (Mattingly 2007: 17)

Mattingly found that the occupational therapists she studied not only constructed stories with their patients to make sense of experiences but also shaped situations and ongoing actions to create enacted stories. In this way, the patient and therapist were “...finding some way to actively construe and connect clinical actions into a larger, cumulative process – making a larger story out of a series of on-going actions” (1998: 83). Referencing Paul Ricoeur, she claims that their actions are driven by “a quest for a narrative” (1998: 46). “Being an actor at all means trying to make

certain things happen, to bring about desirable endings, to search for possibilities that lead in hopeful directions" (1998: 47).

In our analysis, we are especially interested in understanding the dynamic between John's telling and his actions. We investigate how various cultural resources seem to provide guidance for his subsequent actions, and if and how these actions might influence and become part of his storytelling.

After the first couple of interviews with John, the first author's experience was that John's storytelling could be interpreted as an attempt to link his previous life experience with his present situation, which also guided or influenced the coming events, actions and plans he had for the future. Gubrium and Holstein (2009) underscore that storytelling is a collaborative process, created in a particular context, at a specific time, for a specific audience. In the subsequent interviews with John, the first author supported his storytelling by asking open-ended questions that invited him to elaborate on his experiences in a narrative form. In this way, the first author was an active participant in John's effort to tell his stories.

The Context: The Art Museum

It is John's experiences about his encounters with the art at the museum and his life with Alzheimer's that is in focus in our analysis. In order to illuminate John's experiences at the art museums, it is important to understand the context for his storytelling.

The art museum programme consisted of guided tours in small groups led by two art educators who initiated discussions in front of three to five selected artworks. The art tour typically began with the art educators inviting the participants to familiarise themselves with the artwork by visually scanning the surface of the painting in silence for a short while. Then, they asked open questions with no preconceived answers, such as "what do you see?" "what do you think is going on?" or "what kind of relationship might the characters in the painting have?" (Lea & Synnes 2020). The art educators encouraged the participants to use their imagination and share the thoughts and associations that came to mind. They were told that there are no right and wrong answers when it comes to art. The questions from the art educators elicited numerous responses from

the participants. A guided tour lasted 1 hour and was followed by a social gathering with coffee and biscuits.

The artworks were selected by the art educators. They were mainly influential works from the museum collection, including paintings by Norwegian painters such as Edvard Munch (1863–1944), Nikolai Astrup (1880–1928), Christian Krogh (1852–1925), J. C. Dahl (1788–1857), Peder Balke (1804–1887) and Harriet Backer (1845–1932). Many of the motives in the paintings are of scenes from everyday life with recognisable characters engaged in an activity.

Data Construction

The data construction comprises participatory observations and interviews between January 2017 and May 2019.

Interviews

The first author conducted six open-ended interviews with John. The interviews were tape-recorded and ranged in length from 17 to 68 minutes. The files were transcribed verbatim by the first author. Four of the interviews took place at the art museum. Two interviews took place at a day-care facility where John visited a couple of times during the week. Five of these six interviews were conducted immediately after John and the first author had participated in guided art tours at the art museum.¹ The interviewer had a loosely structured interview guide on topics such as discussion of artworks, associations and emotions, the museum space, the art educators and the group experience. The conversations, thus, initially dealt with John's opinions about the art he had seen and his thoughts and feelings about what the experience meant to him. Over time, the first author became increasingly intrigued by how his visits to the art museum were intertwined with a bigger project John seemed to have – to live a good life with dementia. She increasingly followed up on stories he told about how he navigated through the experience of living with dementia in general, and conducted one interview in between two of John's visits to

¹ On one occasion, another person with dementia who had taken part in the guided tour participated in the interview.

the art museum that was more focused on the experience of everyday life with dementia. As the research developed and she and John got to know each other better, the interview style became more open and closer to a natural conversation.

All interviews started with a short recap of the museum tour whilst looking at photocopies of the artworks. The aim of the photo elicitation was to provide John with a non-intrusive way of recalling the experience at the museum (Harper 2002). It was also a way for the first author to tune into John's mood and energy and remind him of the context for the conversation. This also helped her adopt an appropriate conversational style. The photo elicitation was a useful communication tool in all the interviews. Even though the progression of the illness made it increasingly difficult for John to elaborate verbally on his experiences, the images helped him connect with the art that he had just seen and enabled him to share his immediate thoughts and feelings about the guided tour. The images also provided an anchor that helped focus the conversation on the art experience in a subdued way.

John came to the art museum by himself or as part of a group from the day-care facility. On two occasions, the first author drove John to or from the museum. Some of the informal conversations in the data material about art and life took place in the car. They were written down in the first author's field diary at the first appropriate time after the conversations had taken place.

The last interview started at the art museum but evolved into a walking interview. On this particular day, John appeared to be uncomfortable with the sitting-down format. Throughout the research process, the first author was attentive to verbal and non-verbal signs of discomfort or confusion about the research setting. She wanted to avoid situations that could remind him of his increasing cognitive disabilities (Hubbard et al. 2003). She asked John if he preferred walking and talking instead. Walking interviews are a method adopted by researchers working with participants with dementia (Kullberg & Odzakovic 2018). The change of scenery seemed to make John more at ease. It also helped the flow of the conversation. Keady et al. (2017) underscore the importance of adapting the research methods to the needs of persons with dementia when inviting them to participate in research.

Participant Observations

The first author participated in 24 guided tours during the larger case study between October 2015 and May 2019. John was present at 5 of these tours, and he also participated in several other guided tours at the museum at times when the first author was not present.

Participant observation (Fangen 2010) at the art museum was used to help build a more nuanced understanding of John's encounters with the art at the museum. Participant observation involved the first author watching John in interaction with the art educators, the art works and the other participants whilst concurrently taking part in the activities. She recorded her observations (movements, actions, atmosphere and dialogue sequences) and methodological reflections in her field diary. The observations were the useful background information for the interviews as the first author had observed John's actions and heard some of his thoughts and opinions prior to the interview. The fact that the first author had been present at the art exhibitions also gave her and John a shared experience they could tap into during the conversations.

Analytical Approach

Our analytical approach is influenced by Arthur Frank's "Dialogical Narrative Analysis" (DNA) (2012a). DNA is one of many approaches to narrative analysis. A core interest in DNA is to examine the content of a story in relation to what happens as an effect of telling the story (Frank 2010). This means that DNA is concerned not only with the stories people tell but also with what stories *do* for and *to* people. Another key concern in DNA is to understand how people's stories relate to other stories.

A storyteller tells a story that is his or her own, but no story is ever entirely anyone's own. Stories are composed from fragments of previous stories, artfully rearranged but never original. (Frank 2012a: 34)

We use bits and pieces from other people's stories, as well as from larger cultural and societal stories, to make choices about what to include and what to leave out in our own stories. This helps us tell stories that other people recognise and understand. In this particular case study about John, DNA sheds light on how his encounters with art at the museum might be

understood in a broader perspective as well as how the art experiences might act as a resource for John's storytelling.

One central question in DNA is how the storyteller is holding his own in the face of illness (Frank 2012b). It refers to a person's effort to preserve a particular version of the self as she or he wants to believe it can be against forces that threaten to diminish that self (Frank 2012b: 3). In our reading of John's stories, we found this question to be important. When John received his diagnosis, he decided that he was not going to just sit down and wait for things to get worse. Going to the art museum seemed to be one of several things in his life that kept him from "being an Alzheimer's 24/7," as he said at one point. His words reveal the way in which an Alzheimer's diagnosis challenges an individual's sense of himself and how the diagnosis can feel like it threatens to absorb a person's whole being. In order to better understand this tension in John's storytelling better and to gain insight into the role his visits to the art museum played in this dilemma, we decided to focus our analysis on the following research questions: How is John holding his own faced with Alzheimer's illness? What role do his visits to the art museum play in this effort?

When analysing John's stories and how he is holding his own, we have been inspired by how Frank sees stories as acting in people's lives. It is not just people doing things with the stories they tell. Stories do things to people. A key analytical concern in conducting DNA is to ask dialogical open-ended questions regarding the data material rather than following a prescribed formula (Frank 2010, 2012a). Which questions to ask varies depending on the type and aim of the research. In this study, we found it useful to ask the following open-ended questions: Which voices can be heard in John's personal stories? What cultural resources shape how John's story is told? How do the stories he tells inform people about who he is and how does his telling explore who he might become? (Frank 2012a).

Multiple drafts of the emergent analysis of John's stories were composed by the first author. These drafts were read by and discussed with the second author, who has extensive experience in doing narrative research (see, e.g. Synnes 2015; Synnes & Malterud 2019). Two of the drafts were read by an experienced third researcher. The discussions focused particularly on ethical aspects, alternative interpretations and different theoretical understandings.

Ethical Considerations

The Norwegian Centre for Research Data assessed the project. To protect John's privacy, his story is anonymised in accordance with guidelines for anonymising from Norwegian Centre for Research Data. Information or personal traits that could identify John have been rewritten. A written informed consent was collected from John at the start of his involvement with the research project. Formal consent was not acquired from his family, but they were informed that John had agreed to take part in this research project. At the start of each guided tour at the art museum, the participants were informed by the art educator that the first author was taking part in the tour as a researcher. Verbal consent was not sought before each interview, but the research context was mentioned regularly and talked about to re-inform John about the setting for the interview.

Methodological Reflections

The Research Context

John is an open-minded person who embraces new opportunities. One such opportunity was to take part in this research project. As a research participant, John reflected on his past and present life. He said he found the conversations meaningful because they gave him a chance to think and talk about things in a way he rarely did.

As noted in Keady et al. (2017), "the use of social research method(s) can stimulate memories, awareness and growth for all those involved in the encounter, including the person living with dementia him or herself" (p. 3). We are grateful for all we have learned from talking to John and thinking about his stories. Without giving a firm conclusion, our impression is that the participation in the research project played a role in John's striving to live a meaningful life in the best possible way.

Trustworthiness

According to Riessman (2008), there are no established criteria or procedures for validation or trustworthiness in narrative research. Riessman mentions two levels of validity – the story told by the research participant and the story told by the researcher (2008: 184). In our case, the validity or trustworthiness

of John's story is linked to how well it can represent John's experiences and meaning-making processes. We have tried our best to stay true to John's voice and to what we understood to be the points he wanted to convey in his stories. John read a tailored transcript of one of the first interviews. The first author also shared some initial interpretations with him in conversations she had had with him at the museum. Nevertheless, the analysis in this article is necessarily our story based on John's stories. As Riessman also states, trustworthiness in a narrative analysis is grounded in the story told by the researcher, in how reflexive and convincing the researcher presents the analysis. In this process, Riessman recommends, "reliance on detailed transcripts, attention to language, contexts of production [...] acknowledgment of the dialogic nature of narrative." In addition, the researcher should be open and reflexive regarding the methodological decisions and limitations of interpretations (2008: 195). We have tried to be open on how and under what conditions and contexts the stories of John were collected and how we have analysed them. We have strived to maintain an open dialogue between us and also discussed the case of John with other colleagues. One recurrent issue of discussion was our methods for data construction as John's illness progressed. Photo elicitation was a useful research tool throughout the research process. If the research were to be continued, we discussed adopting other image-based research methods. We also considered walking interviews in the museum space as a way of reviewing the paintings on the wall, but this was not possible due to restrictions at the museum.

The second author never met John but discussed each interview with the first author as the interviews took place. The fact that the second author never met John provided an analytical distance in the discussions of John's stories.

John's Stories: "I still want to be part of the world...where I belong"

This presentation of John's story is an attempt to look at how John is holding his own in his situation of living with Alzheimer's. First, we present the stories related to his need and efforts to stay active despite his illness. These stories are followed by narrations of what the participation at the art museum programme meant to John.

The first author met John at the local art museum. John was one of seven persons with dementia who took part in the dementia-friendly

guided tour that day. The theme of the art tour was “Edvard Munch and emotions.” When the group sat down for coffee and biscuits after the tour, John said: “This made me happy. I was touched by Munch. All the things he managed to achieve.” Before he left the museum, he signed up for the coming tours. Previously, when John received the Alzheimer diagnosis, he suffered from a depression:

I got the diagnosis after... after I lost my job. After all, they are not interested in people who cannot “handle things” [he laughs] in such a setting. At that time, I was also very depressed. The depression was worse than having Alzheimer’s. The depression was incredibly tiring for a few weeks. But I don’t go around thinking about Alzheimer’s in the same way.

John is questioning what it means to be “an Alzheimer’s” because he does not feel like one; he feels like himself:

I have an ... Alzheimer’s [he hesitates]. I have an illness. But it’s not something I think about all the time because I have a solid layer over it, in a way. My personality and everything I am, exceeds, overrides that I happen to have an Alzheimer’s diagnosis, I think. I can do a lot with that myself, right. I don’t ... I can do other things [he laughs] than think about Alzheimer’s. My personality is much stronger than the Alzheimer’s [...] I am myself, really. Quite frankly, I think it is a strength.

John does not want the Alzheimer’s to absorb his whole being:

I want to go out of ... what shall I say ... “the dementia room” [he laughs]. I want to step out of that room ... I don’t want to be “an Alzheimer’s.” It may sound very silly saying it like that [he laughs]. But I feel like ... in a way ... embracing the whole world. I do not want to be an “Alzheimer’s” the whole time, to be honest [he laughs]. I am often tired of it. It does not overpower me in any way, but I think that ... I was sitting in a room at [the hospital]. Some nurses were sitting around the same table. I said: I don’t want to be an “Alzheimer’s” 24/7 [he laughs while talking]. That is not ... that’s not my personality. It’s not me, you see. I’m just a person with that diagnosis.

What is particularly striking about John’s commitment not to be an Alzheimer 24/7 is his feeling that his personality overshadows the impact Alzheimer’s has on his sense of self. His strong sense of himself is crucial in his stories as it seems to motivate his efforts to carve out a different life with Alzheimer’s than the one he knows of. John seems dedicated to staying as connected to the world as possible:

I was thinking to myself: Okay, I've got dementia, but I'm not going to be an idiot. [He's laughing]. No! I am going to ... I am not going to resign. I am not going to sit here to rot. I am not going to just sit and look around. I will rather join in, take part. Yes, I still want to be part of the world...where I belong.

John tells of an episode at the doctor's office, where he felt that his decision to stay connected to the world seemed to be challenged. John is participating in a creative group activity where he has been a member for several years. At the doctor's office, the doctor told him that he should tell the organiser of the activity that he has Alzheimer's. John disagrees:

I told the doctor: I'm not going to. I'm not going to tell the leader that I have an Alzheimer's diagnosis. For me, that will be totally wrong. For me, that does not work at all. I didn't want him to know, really ... So I decided that I was not going to tell him. I felt the doctor's opinion was that the leader should know. But for me, that was not the way to go. I didn't tell him. That's how it ended [he laughs]. I am still taking part in the [activity] ... as a regular member. That's how it is.

In this encounter with his doctor, it sounds as John feels that the doctor is displaying an overbearing attitude towards him. John does not want to tell the leader – perhaps because he fears negative consequences. He wants to decide for himself who to tell. Previous research has found that persons with dementia often experience discomfort about disclosing their condition due to the stigma associated with dementia (Xanthopoulou & McCabe 2019). John's way of dealing with the illness at this particular moment appears to be to keep part of his life as ordinary as possible for as long as possible. He actively seeks out experiences that are not “part of the Alzheimer's,” as he says. To be in the activity as a regular member may be one way for John to uphold the sense of self he would like to have. He seems to interpret the doctor's suggestion as an expression of things that keep him in the “dementia room.” He wants something that can nourish him outside of the world of Alzheimer's.

John regularly attends the organised activity and visits the local art museum, and he also stays active in other ways. He exercises and visits the local library. He is also interested in politics. To keep record of the issues that interest him, he has created an archive of news clippings that he uses as a form of external memory. He turns to the archive as a resource in conversations:

It's a bit strange what I'm doing. Creating an archive with news clippings [he laughs]. I do it mostly for myself, though. I do it because I want to participate in the world.

I don't want to be thrown off the merry-go-round. It probably sounds a little ridiculous, in and of itself ... but ... I'd rather be in the world.

Not having a job was a recurring topic in the conversations with John during the first year of his participation in the research:

What I don't like is that I have nowhere to go, a job. I don't have a job at the moment. I really want to try to get a job. When you get Alzheimer's, it's almost like you're not allowed to work at all. Suddenly, you're out of it. It pisses me off because I think there are many Alzheimer's who can manage some types of jobs.

I've been at home quite a lot. But there is something about it ... It is something about being an "Alzheimer's." I don't quite know what is ... I don't **feel** like an "Alzheimer's." I don't. What I feel is ... I feel ...well ...I feel a little useless I am not doing anything for anyone else. Do you understand? I'm at home folding towels [he laughs] ... it's okay, but it does get a little too monotonous. I want to do something different. I want to do something that has value for others.

His yearning for a job says something about John's aspirations to not only participate but also contribute to society. This might relate to cultural expectations of productivity in society. As a community member, John wants to add something of value to others on a societal level. As far as we know John did not get a job, but his visits to the art museum seem to play an important role in this desire to participate in the world as a member of a community.

The first time John came to the art museum, he encountered Edvard Munch's art from the end of the 19th and the beginning of the 20th centuries, including "Sunday at Åsgårdstrand," "By the Deathbed (figure 1)," "Jealousy" and "Women at the Bridge." John felt emotional after the tour. Of all the art he has encountered on his visits to the art museum over the last 2 years, it is Edvard Munch's art that made the strongest impression on him.

I was very intrigued by him [Edvard Munch]. I was actually proud, proud of what he did. All this about death and life that I felt he captured. He opens himself up completely, in a way. He takes it in so deeply. And then he manages to convey it in a painting. It is really amazing. I was touched by him.

John felt a special bond to Edvard Munch because Munch's art connected to his own experiences. In his paintings, John discovered things from his own life. The paintings opened doors into his own mental archive of images, emotions and stories. It was as if they reached out to him.

There is something that comes from the painting. It comes to me. It says something to ... yes, to me. You see the painting, and then it immediately brings something out in you.

One of the life experiences that came to John in the encounter with the art was the loss of his father as a young boy:

It was like ... I felt like I was a kid again, you know? Because I was ... when my father died ... I was a young boy. I drew a lot when I was a kid. When he died I drew the cross everywhere ... I must have done it to get it out of my system. I was so young... still ... I realized I had to do it somehow. I've been thinking about that lately, since we started talking [John and first author]. I kind of ... how did I manage ... how did I manage to get through that period? I was good at school, so I didn't have any problems at school, but I was vulnerable. I had no father. I had to live through such things. How did I survive all that?

It is this feeling of vulnerability that especially draws John to Munch's paintings. Munch's paintings, he says, depict vulnerability.

In people's constant effort to "hold one's own," they need resources and allies, Arthur Frank writes (2012b: 3). Stories can be such companions to us (2012b). By companion stories, Frank means "the collection of stories that accompanies a person through his or her life, guiding decisions of how to act and, perhaps most important, guiding what the person finds it worthwhile to pay attention to" (Frank 2012b: 4). We argue that some of the paintings John encountered at the art museum, especially the paintings by Edvard Munch, became his companions in this way. They seemed to give him a feeling of togetherness - as if they gave him an opportunity to reflect upon losses in life, but they also gave him a sense of connectedness with his past and existential belonging.

He recognised his own vulnerability and seemed to find comfort in the painting. In front of the painting "At the Deathbed," (Munch 1895, Figure 1) which depicts Munch's sister dying with family members standing around the bed, John reconnected with a similar experience. He has also lost close relatives. This was not a negative experience, he said. The paintings accompanied him in his recollections.

Figure 1. *At the deathbed*, Edvard Munch 1895, oil and tempera on canvas.
Photo: Dag Fosse / KODE



Single images are by some literary critics considered low in narrativity compared to written or oral narration because they lack a way of depicting a story's chronology of events in time, which is considered essential in narrative (Schöttler 2016). The narrative potential of single images is to a large extent dependent on stories that the viewer already knows. Single images *evoke* stories familiar to the viewer rather than present a whole story (Varga & Raney 1988). The paintings by Edvard Munch are, thus, not finished stories told or written down; rather they invite the active observer to construct a story in his or her imagination (Schöttler 2016).

To John, some of the paintings, indeed, evoked stories and life experiences. Munch's paintings could, thus, be seen as important companions to John in a continuous assemblage of fragments from his own life story, the suggested narratives in the paintings and the personal life of Edvard Munch

Figure 2. *A warning shot* by Christian Krogh (undated), oil on canvas. Photo: Dag Fosse/KODE



himself. At the art museum, John not only finds consolation and companionship but also wants something more from the art experience. He wants to immerse himself in the imagery, which becomes apparent when he refers to the painting "Vådeskudd" [A warning shot] by the painter Christian Krogh (Krogh undated, figure 2). In the painting, a man is looking around a corner, but we cannot see what he is looking at. Johns says:

I would like to see what is behind that corner. Behind the corner there is a landscape with a lot of exciting things that I would like to see. I want to break that barrier. I want ... I want it to be part of me. I want to get into it.

I want to step into the painting, so to speak. I want to get inside the painting. I think that is ... lovely [he laughs]. I kind of think ... hurrah [he laughs, Mark² also laughs]. Here I can just relax. And that's not a dramatic thing. There are dramatic things in the pictures, but it is not ... it is not dramatic for us as a person in a way. I don't feel it that way. The painting doesn't scare you, it's ... there's something about ... you have to go into it to see...that you are vulnerable in a way.

By immersing himself in the paintings, it is as if he finds shelter or creates some distance from the illness.

I feel relaxed [in front of the paintings in the museum]. I feel like I ... I can just simply surrender. I get into such a relaxed state. I feel I can get away with anything [he laughs]. It provides me with that opportunity. In a way, there are no limits to what it can do to me ... I am very happy that I am allowed to do that.

The programme at the art museum provided John with a space where he could relax, be himself and immerse himself in the art. He used his participation in the art programme, along with participation in other arenas and engagements, to remain an active citizen despite the Alzheimer's diagnosis.

Discussion

In this discussion, we would like to highlight three aspects of John's storytelling that say something about how John is "holding his own." First, we will highlight how John's strong sense of himself is a resource in his efforts to claim his place in the social world. Second, we discuss how he calls upon various narrative resources to shape an alternative narrative of dementia. Third, we focus on the importance of cultural participation for persons with dementia.

An Agent of His Own Life

Alzheimer's is threatening John's sense of self by disrupting his taken-for-granted world, but John does not feel he has lost himself. On the contrary, he expresses a strong sense of himself. Persons with dementia do not

² As mentioned in the 'Methods' sections, one of the interviews was conducted with John and another man. Mark is a pseudonym.

necessarily experience an inherent "loss of self" (Beard et al. 2009). Rather they, as John does, strive to "incorporate a 'manageable disability' into their existing identities" (p. 227). John acknowledges that he has Alzheimer's. Yet, he does not talk about the illness as an enemy to be battled at all costs but as something he tries to get used to.

Alzheimer's is challenging his connection to himself and the world, but he is expressing a commitment to stay as connected as possible. He continues doing the things that make him happy, such as participating in the organised creative group activity and visiting the library. John embraces new opportunities, such as going to the art museum and joining a research project. He finds a way to stay engaged in the social world by creating an archive of news clippings. He is consciously seeking out experiences that can lead his life onto a more positive path (Mattingly 1998). Furthermore, John is creatively engaging with the cultural resources available to him. At the art museum, he encounters art and listens to stories about the art and the artists. These visual and verbal stories act as narrative resources he uses to understand and expand his own narrative.

Narrative Entanglements: Resources and Restrictions

In listening to John's story, we can find traces of different cultural narratives. In parts of John's story, a big threat to him holding his own appears to be the prevailing tragedy narrative of dementia that informs negative attitudes towards persons with dementia. This anticipated loss of identity in the tragedy discourse follows expectations of loss of self and loss of agency (Dupuis et al. 2016). Such a view degrades a person with dementia to a "nonperson" (Lindemann 2014: 18) and confirms the perception of a person with dementia as "socially dead" (Dupuis et al. 2016: 358) and "fading away" (Whitehouse & George 2008: 22).

John talks about feeling trapped in the "dementia room," which we understand as a metaphor for the tragedy narrative discourse. John's effort to hold his own seems to be a struggle between finding ways to enrich his life against forces trying to keep him in the "dementia room." John's actions can be seen as motivated by a desire to create an alternative story "while in the midst of acting" (Mattingly 1994: 812). At the art museum, he participates in the conversations about the art and consciously seeks to immerse himself in the imaginary world of the paintings. He creates

an archive of news clippings to support him in conversations with other people. We regard John's telling as a narrative that points his life in a more hopeful direction (Mattingly 1994, 2007). John wants his life to be more than a life as "an Alzheimer's." His telling can, thus, be understood as a search for a counter-narrative to the tragedy narrative of dementia. Counter narratives are "stories which people tell and live which offer resistance, either implicitly or explicitly, to dominant cultural narratives" (Bamberg & Andrews 2004: 1). The tragedy narrative of dementia can have a strong hold on the lives of persons with dementia because stories that already exist prescribe which future stories will be told and not told about dementia. Stories are not just something people shape and tell in retrospect; they also shape our future lives (Frank 2010). Telling and action are, thus, intertwined. His stories provide guidance for John's subsequent actions, and these actions, again, influence and become part of his storytelling. Hence, the stories John tells intertwine with the experiences he seeks (Mattingly 1998: 20).

Part of John's counter-narrative might also be seen in light of how Frank (2013) understands a quest narrative in illness. Frank (2013) describes the quest narrative as stories that search for alternative ways of being ill (p. 117). The storyteller is proactive and strives through the illness; he perseveres. The illness is reframed as a challenge that might help the narrator grow as a person (2013: 128). John's stories might be interpreted as a quest in his search for a meaningful life after losing his job, suffering from depression and receiving the diagnosis. The quest is about living a meaningful life as long as he lives. By using some of the narrative resources in a quest narrative, John is enabled to uphold a story of his life as moving forward. The narrative gives him a sense of direction; he "discovers alternative ways to experience suffering" (2013: 119).

In John's stories, we also find fragments of alternative stories about life with dementia - stories like the ones told by dementia activist Kate Swaffer (2016). In her book *What the Hell Happened to My Brain* (2016), Swaffer talks about how she refused to subscribe to what she calls the "prescribed disengagement" narrative that she felt was the only option after she received a diagnosis of semantic dementia. According to Swaffer, reinvesting in life is the best prescription for living a full, active life with dementia because the "prescribed disengagement" framework takes away hope and diminishes the power a person has over his/her life

(2016). John's narrative can be read as a continuous negotiation between the tragedy narrative and the living-well-with-dementia narrative, represented by Swaffer. This ties into what Steeman et al. (2007) found in their study of the experiences of persons with dementia living with the illness. The researchers discuss the living-well-with-dementia narratives expressed by many of the participants in the study as an expression of the struggle between feelings of worthlessness and remaining someone of value. The feeling of worthlessness and the wish to participate in society are of particular concern to John.

The Importance of Cultural Participation

There is an increasing amount of research looking into the relationship between citizenship and dementia (Bartlett & O'Connor 2010; Birt et al. 2017; Dupuis et al. 2016; Hughes 2019; Kelly & Innes 2013; O'Connor & Nedlund 2016). In a previous article (Lea & Synnes 2020), we argue that dementia-friendly programmes at art museums, such as the programme in which John took part, can be a way for persons with dementia to perform and practice their cultural citizenship, understood as the possibilities a person has "to be co-producer, or co-author, of the cultural contexts (webs of meaning) in which one participates" (van Hensbroek 2010: 322).

Cultural citizenship as conceptualised by Boele van Hensbroek raises awareness about the importance of giving persons with dementia the possibilities to be "co-producers" or "co-authors" of cultural meaning-making processes. Through the lens of cultural citizenship, persons with dementia are active agents, positioned in the centre of cultural processes that they are part of. By sharing interpretive control, the art educators at the museum gave John and other participants the opportunity to be co-authors of the meanings of the art works (Lea et al. 2020). This was done in a way that helped John connect with his resources rather than remind him of his losses. This opportunity to take part in cultural meaning-making processes seemed to be important to John in his efforts to hold his own. It gave him a place and a space to continue shaping his own life in the world as a fellow citizen.

The notion of cultural citizenship expands the concept of "citizenship" in dementia studies by highlighting the role of art in supporting persons

with dementia's connection to wider cultural discourses. As citizenship is closely linked to a person's rights as members of a community, the idea of cultural citizenship also draws attention to persons with dementia's cultural rights, which is enshrined in article 27 of the Universal Declaration of Human Rights (United Nations 1948).

Strengths and Limitations

It is neither possible, nor is it our aim, to generalise John's story to all persons with dementia taking part in an art programme at a museum. Neither was John chosen as a representative case, nor was it our aim to evaluate the dementia-friendly programme. Our objective has been to highlight different aspects of John's experiences to learn more about the complexity of personal experiences that can emerge from participating in an art programme at an art museum.

It is uncertain how the results from this case study would apply to other participants in dementia-friendly programmes at other museums. The readers can, however, learn from a case based on their familiarity with other similar cases. Such recontextualisation may lead to modifications of old generalisations (Stake 1995). The results of the study can, thus, be discussed in terms of transferability rather than generalisation. In our discussion, we have contextualised John's stories in a way that we hope provide insight into how his stories can have wider relevance. It can of course be argued that John is a unique case. But, we argue that John's effort to hold his own is a challenge shared with other persons with dementia in the early stages of the illness. The progression of an Alzheimer's illness differs from person to person, but we believe that others could experience growth and learning in a similar way, if supported and given the same opportunities. As with many initiatives directed at persons with dementia, the programme at the museum was not meant to be a long-term engagement for the participants. It was John himself who wanted to commit over time, as did a few others. John's long-term commitment was strengthened when he joined the research project where he was given the opportunity to reflect on his experiences in depth. This says something about the value of developing long-term art programmes for this audience group.

Possible Implications for Practice and Research

Our research shows the value of doing longitudinal studies in the field of arts and dementia. A central challenge is adopting a flexible research approach that can accommodate the increasing disabilities inflicted by the illness, as well as keeping in focus the person's capacity to grow, learn and connect. This is a challenge shared by both researchers, and art institutions and arts facilitators.

As part of the effort to strengthen the evidence base in the field of arts and dementia, there has been a growing research interest to better understand how and why visual art interventions work (Camic et al. 2016; Shoesmith et al. 2020; Windle et al. 2014, 2018). Our findings especially support Windle et al. (2014, 2018), who suggest that one of the two key conditions for effective arts programming is a provocative and stimulating aesthetic experience, in an inspiring environment (2014). Our research deepens the understanding of what aesthetic encounters over time can mean to a person with dementia by demonstrating how they support his efforts to stay connected to himself and the world around him. It also underscores the importance of paying attention to the components of aesthetic experiences, and the importance of aesthetic education in dementia care. Stimulating aesthetic experiences trigger mechanisms that may lead to persons with dementia's quality of life and social connectedness (Windle et al. 2014).

Closing Remarks: An Open End

DNA is grounded in an ethical commitment to representing others as un-finalised (Frank 2005, 2012a). This means that a research article can never claim the last word about a research participant.

...the research report must always understand itself not as a final statement of who the research participants are, but as one move in a continuing dialogue through which those participants will continue to form themselves, as they continue to become who they may yet be. (Frank 2005: 966-967)

Understanding research as a dialogue means respecting John's capacity and scope for change. In the case of John, we see this study more as an

opening than an end. It is not an attempt to limit John's future by implying what can be expected of him. In a different setting, at a different place and time, John might tell other versions of the stories or completely different stories. In the same way, our analysis of John's stories is just one of many ways to understand his storytelling. This means that others might interpret John's telling differently than we did. John's story does not represent an end. It is a contribution to an ongoing dialogue about ways in which lived experiences of dementia are interlinked with the wider cultural and social context.

In this article, we have attempted to show that John, in his efforts to "hold his own," is mobilising both internal resources (his strong sense of himself) and external cultural resources (narrative resources and cultural arenas and practices). Through his storytelling, he is challenging the dominant negative narrative of life with dementia. As noted by Loseke (2007), socially dominant stories "simplify the complex world" (p. 661). We need more nuanced stories about life with dementia. We need stories that can fashion new and more complex narratives, more responsive to the experiences of people with dementia. We especially agree with Hydén et al. (2014), who emphasise the need to learn from persons with dementia themselves about how to live a satisfactory life with the illness. Over time, such stories expand the cultural resources available to persons with dementia.

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