

VULNERABLING PEOPLE: DEMENTIA AND THE MAKING OF EMBODIED AGENCY

ABSTRACT

In dementia research and care practice and there has been a turn to try to offer approaches that acknowledge the patient's personhood and agency and protect the rights of the vulnerable. Yet while defining people as demented or vulnerable, the focus is on the disabilities of and dysfunctions in the patient, and the strengths are left undiscussed, thus ignoring an important part of being a person. I move the focus from disabilities to strengths and call for more attention to be paid to other ways of interaction with vulnerable people. As an example, I consider 'making' as a form of creative interaction and how this applies to people living with dementia. My focus is on the phenomenological experience of the world. I argue that this offers a perspective that shows the value in embodied knowledge and making practices in a manner that acknowledges the agency and ability to interact with the world, even when other forms of interaction might not seem possible.

Keywords: agency, art, dementia, making, phenomenology, vulnerability

INTRODUCTION¹

Due to medical developments, people are living longer and consequently the illnesses and health problems are changing with the demographics of the population. The so-called 'disease of the century', Alzheimer's disease has gained special attention from the public and the media, and dementia research has increased drastically in the past 20 years (Leibing 2006: 241; Lock et al. 2006: 129). Dementia is named a burden, because it is costly for the state and as it affects strongly the lives of the patients and of their relatives, friends, and carers (Lock 2013: 12). In 2017 WHO declared dementia 'a public health priority' endorsing the Global action plan on the public health response to dementia 2017–2025

(WHO 2017). There is now an increasing concern to help people with dementia to live a life with meaning and dignity (ibid: Foreword).

In policymaking, medicine, and sciences the term 'vulnerability' is of great importance to ensure that people and groups that are more exposed to harm and unequal power relations are getting fair and secure treatment. It helps to acknowledge patient's susceptibilities so that the person can be supported to live in a secure environment and get the treatment needed. Also, the United Nations Agenda for Sustainable Development states that 'people who are vulnerable, including people with disabilities, older people and migrants, must be empowered' (ibid: 5), thus further connecting

the categorising to entitlements and possible rights. However, classifications, such as vulnerable and demented, are never completely straightforward and have serious implications on people's lives.

Older people and especially people living with dementia are generally considered to be highly vulnerable, sometimes even excessively so (Alzheimer's Society 2016). Vulnerability is both a term coined to ensure equality and support for people living in vulnerable situations and a label. Like any labels, 'vulnerability' carries powerful social and political meanings and assumptions. Indeed, as it is being used in current discourse, people do not want to be called vulnerable, because of the fear and embarrassment of being perceived as a burden. It labels the carrier as unable to do something and as weak in one way or another. It seems as if there was something wrong with the person's self. A pioneer in the research of dementia care, Tom Kitwood, notes how Western societies highlight individualism, even to the point where autonomy has come to be the central measure of personhood (1997: 9). This is problematic for the diagnosed, as with the idea of a person not being able to take care of him/herself come feelings of loss of autonomy and personhood. Thus, vulnerability is often perceived as an inherently negative trait, requiring intervention and help from the fully functioning parts of the society.

Truly, although we are trying to avoid thinking of the vulnerable as simply passive victims, dementia, for example, is often seen as something that just happens to people (Zarowsky et al. 2013: 5). However, it is important to keep in mind that people with vulnerabilities are constantly active agents. Vulnerability is often defined through the notions of lacking the power to do something and the power that other people have over the vulnerable ones (ibid: 7). The obligation to treat

people as equals is taken away through the categorisation of vulnerable and demented. The diagnosed are no longer seen as fully capable agents in society, they are not able to give consent, and their autonomy has been replaced by power-laden fostering relationships, where the vulnerable do not have any other right but to be helped and protected. Vulnerability is to a great extent about power-laden relations and encounters. It is not solely about people's abilities (or lack of them), but it is also about people's situations and relationships to others.

Following from Ingold's (2011: 174) argument that we are in a constant becoming with the world, an active term *vulnerabling* might be more suitable for research, treatment, and policymaking. Moving away from categories and nouns to verbs and processes (ibid: 175) could show that people are constantly negotiating their vulnerabilities in their surroundings and in relation to each other. People with dementia are vulnerable because their relationships to their surroundings is determined in ways that they do not themselves understand or agree with. *Vulnerabling* is a constant process of becoming and transformation, shaping and shaped by interactions. In the same way it is also important to see dementia as an active lived process. The term *dementing* has got its own strong stigma attached to it as it is seen as a one-way process of dying within, due to the medical definition. However, it is important to see it as relational and situational as well and as shaped by and *enacted* in interactions.

In this article I challenge the focus on deficiency and loss when talking about vulnerable people or people with dementia (see Aaltola, 34–36 in this special issue). This focus has severe implications on people's views on self and personhood, as well as on how people interact with the diagnosed. In order to study the ways how people with dementia are in the

world with their disease and vulnerabilities, I propose to use Merleau-Ponty's (1962; 1974) and Gibson's (1966) theories on perception and experience. This approach shows that cognitive skills do not have to be the carriers of personhood, and that even people who are not able to form coherent sentences or recall names and events are active agents and have other skills that should be acknowledged. These strengths can be an important part of a person's identity and work as ways of communicating with the surroundings and other people, and to help negotiate vulnerabilities in new ways. Other authors (Mansfield-Loyne et al. 2016: 24) have suggested that often when talking about or working with people living with dementia, the attention is on the verbal abilities and abstract thinking that might be already deteriorating, while alternative forms of interaction are not considered. The phenomenological approach opens a platform to look at alternative forms of interaction, such as creative making practices, which recognise the skills and agency of the person as well as their ever-changing vulnerabilities.

There are various ways of knowing, thinking, and interacting. I argue that a phenomenological approach to 'making' offers a way to see the embodied knowledge and understand the different ways of thinking and perceiving the world (Philpott and Kane 2016: 243). In the creative process of making, sensation, memory, and perception become intertwined (ibid: 243). Thus, through making, one is entangled with the world both as a living and experiencing organism and as a cognitive agent (Varela et al. 1999: 238). When making things, the person is attuned to the environment differently, through a bodily process, and influenced by emerging affordances and multi-sensorial experiences inherent in the making process (Ingold 2000: 23; Ingold 2011: 162). In this article

I explore 'making' as a way of perceiving and interacting with one's surroundings, particularly focusing on two examples where people living with dementia engage in practices of making.

CONSIDERING WAYS OF MAKING: MUSIC AND STORYTELLING

I use the term 'making' instead of art when referring to creative activities. Art is a term that is often associated with artists who make objects, such as paintings, statues, or ornaments. However, this is only one, institutional, part of art. The American pragmatist, John Dewey, wants to emphasise how the meaning of art is connected not with the institutional ideas of creativity but with the body and senses of a person (Dewey 1934: 27). As Ingold writes, 'the creativity of making lies in the practice itself, in an improvisatory movement that works things out as it goes along' (Ingold 2011: 178). Both Ingold (2011: 216) and Dewey (1934: 27) highlight that art refers to a process of doing or making as embodied beings. Hence, when using the term making, I refer to art as the daily processes of creative making, which include embodied practice, interaction with one's surrounding, and emotional attention. What is being made does not matter, but that making is meaningful.

There are many successful projects that engage in creative forms of interaction with people who have dementia². Such projects have included approaches such as narrating, art, social encounters, and memory work (often while overlapping). Yet their possibilities and theoretical implications have rarely been explored further. In this article I especially focus on two examples, a film 'Alzheimer's: A True Story' (1999)³ and the *TimeSlips* storytelling project (Basting 2006; *TimeSlips*, 2018), in order

to consider how making, as a form of creative interaction, can offer a perspective of viewing vulnerability in a way that acknowledges the strengths and agency of people, even in the case of severe dementia. I have chosen these two examples from many possible ones, as they both portray the importance of creative activities in the lives of these people who live with dementia. Neither of the examples are what would be commonly perceived as practices of making, as they are about storytelling and music. Yet, following Dewey's definition on art, I see them both as processes of creative making and interaction.

The first example, 'Alzheimer's: A True Story' (1999), depicts the latter years of a lecturer and pianist Malcolm Pointon. Malcolm was diagnosed with Alzheimer's disease in 1991, and he and his wife Barbara decided to let filmmaker Paul Watson document their lives and the development of Alzheimer's disease for seven years. The film received a mixed reception and raised a lot of debate about whether it is unjust to portray Malcolm's life in the advanced stages of the Alzheimer's disease for the public without having edited out the humiliating and difficult parts. I will not go further into these debates, but they do show certain taboos that surround the representation of people with dementia. However, it is partly due to this portrayal of the difficulties that come with dementia and how hard it can be for the closest relatives, why I want to use this specific example. The film's portrayal of Alzheimer's disease and Malcolm reflects the general assumptions and stigma that is linked to the illness, while at the same time it shows Malcolm's frustrations, his connection to music, and his agency. This example is very specific, as it portrays only the story of one person, and only certain scenes of it. Yet this film portrays brilliantly, even though partly unintentionally, how making music can

be seen as social interaction and the challenges created when the activity is not meaningful.

My second example is *TimeSlips*, a project and method started by Anne Basting in 1996, which eventually developed into a corporation that spread to 15 countries. *TimeSlips* is a storytelling method that is specifically aimed to offer a 'simple revolution in elder care by infusing creativity into care relationships and systems' (*TimeSlips* 2018). It is meant to improve 'well-being through creativity and meaningful connection' with others (*ibid*). The method is based on free-form storytelling activities, which are organised in groups with people who have dementia and directed by a facilitator. The facilitator has a picture that he/she uses to encourage the participants to tell a story together. The participants take turns telling something about or giving a description of the event or the person in the image. The story does not have to be linear or structured and sometimes it might take a poetic form. The participants are free to participate as they want, without being judged. I have chosen this example, as even though storytelling and life story approach is often used as a method to work with older people, it is seen as problematic with people who have dementia due to decreased cognitive skills. *TimeSlips* is, however, specifically designed this in mind, moving away from the traditional narration towards a more creative and flexible making of a story in a collaboration with others.

Both of the examples show how communication and making is possible even for people who live with severe forms of dementia. Dewey (1934: 24) argues that art is in the very process of living: living beings are in interaction with their surrounding world, becoming what they are through this interaction. Making is part of everyday interaction and communication (*ibid*: 13) and thus I argue that it has the

potential to affect the ways in which dementia is viewed and vulnerabilities are negotiated in everyday life, whether for better or worse.

CATEGORIZING 'DEMENTED'

The medical classification practices, definition of dementia, and common ideas about people living with dementia go very closely hand in hand. Medical Dictionary defines dementia as

an acquired Organic Mental Disorder with loss of intellectual abilities of sufficient severity to interfere with social or occupational functioning. The dysfunction is multifaceted and involves Memory, Behavior, Personality, Judgment, Attention, spatial relations, Language, abstract thought, and other Executive Functions. The intellectual decline is usually progressive, and initially spares the level of Consciousness. (Medical Dictionary 2018: Dementia)

The process of Western medical categorising is often based on standard profiles of disease, in this case, 'demented'. These are matched with certain characteristic that are observable and countable in the system, such as cognitive skills (Hoogeveen et al. 2004: 25). Diagnosing a person with dementia, and especially when dividing it into types of 'early, moderate, advanced, severe, and end-stage' dementia, leads to restructuring and categorising ideas of life, personhood, and value (Kaufman 2006: 23–24). This kind of categorisation is part of an instrumentalisation of the bodies and selves, distinguishing the 'disabled' or 'vulnerable' from the 'normal' people (ibid: 26–27; Martin et al. 1988: 146,160). Yet what is often forgotten is that dementia is not a disease per se, but an umbrella term for certain kind of symptoms (Alzheimer's Research UK 2018; Kitwood

1997: 21). There are various forms of dementia, caused by a wide range of factors, and these *dementias* are lived in different life situations by different people (Sabat 2001: 9; Dementia UK 2018). Yet in our classification practices people living with dementia are defined as belonging to one more or less coherent vulnerable group.

The definition highlights the decrease in one's cognitive abilities. Because the attention is on the losses, a person living with dementia is seen as disabled and even unable to make his/her own decisions. Dementia is considered one of the worst diseases in relation to loss of autonomy, as an ability to act independently in everyday life is deteriorating, putting the diagnosed into a very vulnerable position (Alzheimer's Society 2016). A specialist in memory research and neuropsychology, Steven Sabat, argues that 'such an assumption and the nature of the interaction between the afflicted and the healthy which occurs as a result, will have potentially profound effects on the behavior of the afflicted' (Sabat 2001: 10). When calling people demented, they are limited to being a dysfunctional part of the society. The diagnosed become a burden, and in some cases lose their agency and even rights (Kontos et al. 2010: 166). The person becomes 'vulnerabled', defined as lacking agency, one whose main role is to be cared for. This is even to such an extent that the stigma outweighs the benefits of being diagnosed. For example, according to a study done in UK, 56 % of people postpone getting diagnosis at least by a year, due to fears of stigma and loss of independence (Alzheimer's Society 2016).

Diagnosing and categorizing people is a process that involves an ambiguous negotiation of their vulnerabilities. On one hand, being categorised as vulnerable activates relational responses: the person can access help, get a broader support network, and gain understanding and knowledge about dementia.

This happens while, on the other hand, the person's social relations, roles, and interactions will be transforming. Patients are defined in terms of their disabilities and vulnerabilities in relation to others. In the classifying process of considering whether a person has dementia, the focus is on the lack of cognitive abilities that is often associated with the standard and universal profile of dementia (Hazan 1980: 30–31; Sabat 2001: 10). Following from the categorisation, the loss of some abilities of cognitive thinking and verbal communication is also the loss of the personhood and agency. Yet with this kind of view, the embodied experience of living with dementia, of being in and interacting with the world, and even different ways of remembering, knowing, and perceiving are left unaccounted.

PERCEIVING AND PRODUCING EMBODIED KNOWLEDGE

In Western societies cognitive skills are valued to such an extent that that it could be said that we live in a 'hypercognitive society', where mind and cognition are overvalued, and other abilities neglected (Post cited in Hughes 2014: 71). The general disposition to value the mind over the body, emphasises the loss of cognitive skills, especially memory, and further indicates that the person with dementia is 'dying within' (Kontos 2003: 160; Leibing 2006: 259). I propose to use a phenomenological approach, which focuses on perception and experience, as a move away from this focus on mind and cognition and mind-body divide. According to this, one does not perceive the environment with the mind but with the whole body and all the senses together, through active engagement in and with it (Gibson 1966: 5). Merleau-Ponty argues that phenomenology offers an 'account of space, time and the world as we "live them"

(Merleau-Ponty 1962: vii). For him, the idea of being in the world is gained through embodied experience (Merleau-Ponty 1974: 201). We can only learn about our surroundings and about ourselves by actively living in the world and experiencing it. By taking a phenomenological approach I want to emphasise the experience, and not the category, of dementia. It is important to see people with dementia as perceiving and experiencing agents. This is something that is inherently part of being alive and a person. I argue that a person's agency and personhood does not depend on cognitive abilities but is connected to various ways of interacting with one's environment.

Phenomenology focuses on experiencing the world through living in and interacting with it. According to Gibson (1966: 5) the body is a 'perceptual system'. One does not perceive the world with the mind, but through active engagement in the world and through the intertwinement of the senses (ibid: 5). Gibson points out for instance how babies learn to experience the world through moving, listening, touching, and tasting. They should not be seen as new machines that receive data and learn to make sense of it, but instead they are actively experiencing and perceiving (ibid: 5–6). Perceiving what we see is only possible through movement in the environment. When I am looking at a building, I perceive it as three-dimensional because I have experienced the world three-dimensionally, through having moved in it. Knowing is 'the movement of a person from one context to another', as it is through movement that one perceives (Harris 2007: 1). A focus on embodied practices and experience acknowledges the body with its limitations. A person with illness or disability might not perceive the world in the same ways as the healthy do, but they still perceive to their fullest.

Another problem with a sole focus on cognitive abilities when talking about dementia is the ways in which value is attached to abilities to remember and recall memories. Personhood is shaped by one's experiences, and these past experiences reside in our memories. The abilities to narrate these memories in a coherent manner is seen as tied to the person's sense of self, leading to an idea that when these abilities are lost the person's sense of self is also becoming vague (Kontos 2006: 195). Indeed, life stories might be a significant part of one's identity, but identity is certainly not limited to them. Memories and experiences do not reside in the mind waiting to be recalled, but they are embodied in ourselves (Hallam and Ingold 2007: 11; Kontos 2006: 215). By focusing on experience instead of solely cognition, I am moving towards a more context related approach, where one's memory is embodied and in constant change. Memories are not intangible nor linear but constantly changing, depending on the context. This is even more so with people that have dementia. A person's memory, who lives with dementia, varies greatly from one moment to another, depending on the surroundings, mood, and senses. It can be that at one point a person struggles to remember where he/she is and what year it is, while half an hour later he/she is aware of it. Memory is situational and not only tied to cognitive skills, but also to the constant interaction with the surroundings. Merleau-Ponty refers to an embodied memory and knowledge, which cannot be formulated without the bodily effort made (1962: 144)⁴. For almost any action in the world, we need a seemingly infinite amount of knowledge about the world and ourselves, and this knowledge and experience is in our embodied memory (Varela et al. 1999: 148–149). Perceiving the world or knowledge are not merely cognitive actions so

that they would be happening in the mind, but they are constant processes happening as the person is interacting with his/her surrounding (ibid: 148–149).

From a phenomenological viewpoint, 'making' is perceiving, while at the same time it is an enactment of one's embodied memory. It is interacting with one's surroundings, whether it is with the environment or other beings. It directs one's attention literally to the thing at hand in a manner that multiple senses are being used and the environment is explored. The different senses, then, are inherently intertwined in one's body, creating a combined perception, which is shaped by one's attention (Gibson 1966: 55). Ingold compares making to being alive and to wayfaring. He writes that the 'perceiver-producer is thus a wayfarer, and the mode of production is itself a trail blazed or path followed. Along such paths, lives are lived, skills developed, observations made and understandings grown' (Ingold 2011: 150). Through making, the person both perceives and produces at the same time, in active engagement with the surrounding and others in it (ibid: 150). In this engagement with one's surroundings one does not just produce art and objects, but also relationships, memories, and knowledge. Through making, people are perceiving and living with their surroundings. It is a way of interacting.

Next, I look at the two examples that emphasise the interaction with one's surroundings and other beings in the processes of making. The examples demonstrate how people with dementia are capable of meaningful interaction and how making can shape ways of becoming for people living with dementia and their relationships to others. I explore how exploring other forms of interaction can help to recognise a person's agency and abilities and

question the vulnerabilities and/or disabilities that are often taken for granted in the case of dementia sufferers.

ALZHEIMER'S: A TRUE STORY

As the first example I use a film that portrays the latter parts of lecturer and pianist Malcolm Pointon's life. Malcolm was diagnosed with Alzheimer's disease in 1991, and he and his wife Barbara decided to let filmmaker Paul Watson document their lives and the development of Alzheimer's disease for seven years. The result of the filming was the movie 'Alzheimer's: A True Story' (1999). The film portrays how dementia is often a heavy burden as it exemplifies the hardships that Alzheimer's disease cause Malcolm and his relatives and friends. It also depicts an Alzheimer's patient gradually losing his personhood. Malcolm's wife struggles with his condition and shares her thoughts: 'On the surface, he looks as though he was the same person, but you know inside that there is something that's eating him away and depriving me of the person I knew and loved' (Alzheimer's: A True Story 1999, t. 9:03).

The movie especially highlights the infantilisation that Malcolm experiences and how everybody struggles to take him seriously. 'As a child would anxiously search the house for his mother, so Malcolm spends his time looking for Barbara' (ibid: t. 28:00). Malcolm is compared directly to a child in the film, while indirectly the film moves between Malcolm's childhood photos and his current state with Alzheimer's disease. At the same time, people would unintentionally talk to Malcolm in a manner that ignores his agency. 'I'm going to take you for a walk' (ibid: t. 20:20), might seem like a statement of a fact to another person. Yet it removes some of Malcolm's agency. One does not take a person for a walk but goes for

a walk with him. Such use of language goes unnoticed and unquestioned, and yet none of us would like to be talked to in that manner. The film shows how a person with dementia loses more and more his personal freedom and agency. The more Malcolm becomes vulnerable through the progression of dementia, the more he gets infantilised by his surroundings, highlighting the negatives of vulnerability. Malcolm becomes defined by the disease and his own agency and personhood is forgotten. In a substantial way the film shows practices of infantilisation and acknowledgement of his increasing vulnerability, while the moments of creativity and active agency are only momentary.

Still, what comes most distinctively out of the film is the sense of music, and how besides all the difficulties with communicating and doing even the most basic tasks, Malcolm still maintains his personality and his sense of music. Long after he had lost his ability to talk and perform many other cognitive tasks, Malcolm could still play the piano, or make music with his mouth, or by tapping the plates. The film shows how music embodies emotions and interaction. An especially striking scene is when Malcolm starts tapping the plates, taking turns with his son, and finding a common rhythm and harmony (ibid: t. 15:40). He is making music with listening, moving, and interacting with his environment and with his son. Malcolm kept his musical abilities, he was able to make music, play the piano, and communicate with people through music. The music offered him a platform to be an active agent and to express himself when other forms of interaction were not possible.

Looking at Malcolm playing the piano brings the discussion to the acknowledgement of one's agency and skill in the making process. Often, the diagnosis of dementia seems to create almost automatically a boundary between past

agency and the current traces of that agency. The embodied knowledge that severely demented people have is seen as 'sedimentation of previous individual preferences', the only thing left from their 'real', rational agency (Dekkers 2009: 260). Kontos (2003: 156) argues that such ideas show us the assumptions that people have of the development of dementia and loss of agency going hand in hand. However, this kind of debate is rendered obsolete when we look at embodied experience and knowledge. A pianist does not have to look where each key is when playing, nor do I have to look at my keyboard while I am writing this. It does not mean that the action is instinctive. One knows where the keys are and what happens when you press them. These are our embodied memories, which are created from previous embodied experiences of interaction with our surroundings.

The importance of music for Malcolm has been well portrayed because his relationship to music is characterised as active engagement with his surroundings. For Malcolm, it seemed to be music that often brought up memories and coherence, and made him engage more with his surroundings, for example, when he started composing rhythms with his son on the plates. Yet it is clear that this action was not instinctive, but a playful and engaging interaction between two people in a certain setting (Alzheimer's: A True Story 1999: t. 15:40). Memories are an important part of any interaction, and yet no interaction should be seen as a trace of the past, but as an active engagement with the present. Music is not a backdoor to our mind, but a way of interacting with the world, with the memories and body. The engagement with music is an active process and expressed through emotions and movement. Listening to music is rarely a passive activity, but an active one, as one reacts to music with singing, moving, and remembering. This can be seen clearly in the

ways in which Malcolm's engagement in playing the plates seemed to be even more meaningful than many times when he played the piano.

The story demonstrates how the process of making can have different levels of meaningfulness for the person. At one point in the film Malcolm shows his frustration with the activities he was offered, which, even though playing music is pleasant for him, were too basic for his experience and skills with piano: 'I am angry because I sit down or whatever it is, I am allowed to play things that are not very good' (ibid: t. 24:43). He also comments on the therapist who would come to play piano with him: 'But she has got no sense of music' (ibid: t. 23:11). Indeed, the film does give an impression that this is partly the reason Malcolm did not enjoy this organised activity. This contrasts with how at another point in the film he endeavours to make music with his son by playing the plates at the dinner table, an event that he seemed to enjoy greatly. Kitwood points out this difficulty of finding creative and meaningful solutions for individual people, without imposing false ones, and notes that it requires skill, imagination, and knowledge about the person and his or her past (Kitwood 1997: 83). It requires acknowledgment of the person's skills, memories, and agency. Playing music acknowledges Malcolm's agency, opening a platform for other forms of interaction. Yet at the same time the label of dementia and seeing him as vulnerable lead to the belittling of his abilities. Malcolm's passion for music is not only an echo from his past self, but it is part of who he is, and for a talented pianist art therapy that does not recognize his talent will lead to belittling his personhood and agency. The case of Malcolm shows that people with dementia are able to contribute to society, but that the contribution is highly connected to their social interactions, which are shaped by the current ideas of vulnerability and dementia.

TIMESLIPS—A COLLABORATIVE WORLD OF MAKING

My second example is *TimeSlips*. It focuses on creative and collaborative narration with people living with some forms of dementia. Narratives have been used to understand and communicate the lived experience of dementia, as this practice considers people's own life histories and lets them narrate and present their own identities as they want. Indeed, it has been praised for showing the person behind the patient (Clarke et al. 2003: 698) and opening up understandings of how people relate to and cope with dementia (Bond cited in Li and Orleans 2002: 228). However, narrating is greatly built on one's linguistic memory and social relations, meaning that often people living with dementia can struggle with it. Li and Orleans note that when we ask people to tell about their memories, we are at the same time making them face their own declined ability to remember (ibid: 243). Basting also argues that often older people are encouraged to talk about their past, as if there was no meaningful present to talk about (Basting 2006: 193). There is a risk of creating a stereotype of older people as being stuck in the past, without a sense of future, 'stepped out of the flow of time' (Degnen 2007: 231). Another problem with many narrative approaches is that narratives are often seen as coherent and linear, even though, as Degnen notes (ibid: 223, 231), it is normal that older people structure their stories very differently than, for example, a 40-year-old would. Yet *TimeSlips* project has moved away from the traditional life story and linear narratives approach and is focusing more on the creative and interactive sides of storytelling.

The project is aimed at 'nurturing creative expression among people with Alzheimer's

disease and related dementia' (Basting 2006: 180). The project differs from most other narrative approaches, because of its 'free-form style of storytelling' and the narrators can experiment with their stories and ideas freely in a group (ibid: 182). Indeed, it is a collaborative form of making, in which the participants actively engage with the world. Storytelling is a good example of an active engagement in the world and interacting through making. However, language, cognition, and talking are often seen as being so central to it, that it excludes some people. Yet Basting argues that *TimeSlips* recognizes a person's contribution in the storytelling even if he or she would not be able to participate verbally in it, as one's gestures and sounds are incorporated as well (ibid: 182). The project thus avoids some of the pitfalls of other narrative approaches, as it is more flexible in its linear and linguistic form, making it easier for people with dementia to participate. This kind of approach does not limit people's participation as it offers an inherently inclusivist approach. Ideally, participants are not judged for what they can or cannot do but are rather encouraged to participate and to be an active part of the process. Unfortunately, in many activities in care homes the residents have no agency in the planning of their day nor their recreational activities. According to Basting, the *TimeSlips* project helps people with dementia to gain back part of active agency in their lives and shows the possibility for people with dementia to participate in something great and meaningful (Basting 2006: 193).

Storytelling and music include always movement, rhythm, and making. In *TimeSlips* one example called 'memories' highlights the interactivity and the rhythm that is part of the process of making.

.../Back in the sixties/ She's 35–40 yrs old/ young/ 13/ Western days/ humming, 'As I walked down the streets of Laredo'/ Getting ready to drive cars/.../Chicago/ its a good sized wheel/ She can /Do it/ Annie! (lines 6–12 and 27–31, Jenny and group of men cited in *TimeSlips* 2018)

This story, which is connected to a picture, is constructed in a poetic form, the men adding their comments and ideas into one stream of thought joining memories and feelings. The story is created together, everyone finding their way to contribute, reacting to the picture and to each other. 'She's 35–40 yrs old/ young/ 13' (*TimeSlips* 2018): the men exchange their ideas, giving multiple voices to the poem and recognising the different ways of perceiving. Basting writes that creative storytelling supplies a social role, one with value, that allows for the integration of past and present, and that acknowledges the strengths and potential of the present lives of people with Alzheimer's disease and related dementia. It offers storytellers an avenue for self-expression that frees them from the demands of memory and rational language (Basting 2006: 193). It is an example of a collaborative making process, where storytelling has a clear bonding effect on the groups, and where the making of a story happens in constant interaction between people with dementia, who recognise each other's agencies. Making is a way of interacting and a form of becoming with one's surroundings, and at the same time it is very social process.

MAKING AND VULNERABLING

In the previous parts I have taken a phenomenological approach to making and ideas of dementia. I have used two examples to demonstrate how making is a way of interaction that makes

understandable the agency of vulnerable people. In the final part of this article, I want to come back to the processes of defining the vulnerable and demented and highlight the importance of interaction in this. Through my examples I have outlined the problems with the categorisation based on cognitive abilities, and how I consider dementia patients as active agents who are able to make things and relate actively to their environment. However, how are dementia and vulnerability relational processes?

One does not become vulnerable or demented in just one day. It is a process of becoming with one's surroundings and this process is constantly changing and ongoing. Using Ingold's approach of 'becoming' with one's surroundings (Ingold 2000: 23; Ingold 2011: 12, 162), I want to highlight that we are all connected to each other in one way or another, we depend on each other and our surroundings, and we are all changing with these whether we want it or not (Hughes 2014: 73; Ingold 2011: 162). Erinn Gilson ties vulnerability to the idea of becoming by looking at becoming as 'nonvolitional affective transformation that occasions new ways of feeling, thinking, and relating' (2014: 139). Thus, becoming entails vulnerability, as with the transformation comes the exposure to risks. Furthermore, people with dementia are in a constant process of becoming vulnerable, as in every interaction there is a potential to transformation and new ways of becoming. The ways of feeling, thinking, and relating are constantly changing, and even more so for people with dementia. According to Gilson, vulnerability is neither solely a deficiency nor loss. Vulnerability is a constant relational process with openness and possibility to transformation. This transformation may be painful and disturbing, but it is not inherently negative, nor should the experience of vulnerability be seen as such (ibid: 145).

Vulnerability and dementia are not events or categories that can be stamped on a person, but inherently relational and situational and part of active engagement and interaction with one's surroundings and others. The fears and ideas connected to dementia shape the ways in which the diagnosed person receives the diagnosis and interacts with it and with others. The diagnosis shapes to a great extent people's interactions with each other. Therefore, with being a highly vulnerable patient one is entitled to care, but also exposed to patronising treatment.

People living with dementia are often going through enormous changes in their lives due to their symptoms. Yet along with the practices of infantilising and stigma of patienthood and vulnerability, the agency and actions of the person become even more suppressed. It is necessary to start highlighting and paying more attention to the ways of interacting that can maintain and enhance agency and action. Indeed, when looking at vulnerabling, and not just vulnerability, we can come to see it as a process that can go both ways, as something that is not inherently negative, but which enables other ways of perceiving and interacting. Kontos argues that the 'intelligibility of the body is essential to the continuity of our being' and that we should recognise this in order to acknowledge the embodied agency that vulnerable people have (Kontos 2003: 167). A way to recognise the role that each interaction plays in the formation of 'vulnerability' or in the formation of the experience of living with dementia could be identifying the skills and agency that individuals have. Working with these skills can help to find new means of interacting, and with it understand other forms of knowing and experiencing. *TimeSlips* is one example, where through making, the people with dementia can express their skills and perceptions in a meaningful way, as well as

connect with other participants positively and constructively. Looking at making as a form of interaction with people who have dementia can help to see what they have to offer to their surroundings and to themselves, but also has the potential to theorise vulnerability in new ways.

CONCLUSION

In this article I have explored how in the classifying process of vulnerabling, of becoming 'demented' and consequently, ethically 'vulnerable', the emphasis is on the disabilities and losses, while many important skills are left unaccounted. Yet the strengths and skills that people have are an important part of one's personhood and work as ways of communicating with the surroundings and other people. Diagnosing, categorising, and interacting are all tied together, and this should be remembered, as it has severe implications to the ways in which people perceive dementia patients. With the diagnosis of dementia, the person becomes a burden for the society and the label becomes repeatedly a defining factor for one's personhood and life. Yet, following Kitwood, even though dementia does shape a person's life vastly, it does not make the person. Vulnerability and dementia are relational and situational categories, which are in a constant change. I have argued that dementia should not be seen in the light of one's disabilities but as a relational process, and that by focusing on the strengths and on creating meaningful forms of interaction with one's surrounding it is possible to better understand people living with dementia, as well as acknowledge their agencies and skills. Yet the verbal and cognitive skills might be deteriorating, thus limiting the possibilities for meaningful encounters.

The phenomenological approach, which ties together body and mind and puts the

embodied experience and memory as central to all forms of interaction, can offer new ways of interacting, which consider the different forms of strengths and vulnerabilities. Following Ingold (2011) I have suggested making, as a form of interaction, to explore the different ways of knowing and interacting. The examples examine the meaning and value of the making process for people living with dementia. The *TimeSlips* project breaks the norms of narrating and shows that everyone is able to contribute to creative social interaction and to the creation of something great meaningful together with other. On the other hand, 'Alzheimer's: A True Story', shows some of the stereotypical ideas associated with dementia, such as loss of personhood and agency and becoming a child again. However, it also portrays how Malcolm maintains his love for music and his agency. No matter how severe the dementia, people continue to have strengths, and exploring these in the care practice and more generally can create new opportunities and understandings⁵. This kind of interaction would have its limitations, and yet it could offer a way to create more equal social relations, which recognise the agency of the vulnerable.

NOTES

- 1 This article is based on my dissertation *Dementia and Making of embodied agency – How a making based approach can help us to understand the importance of embodied experience of the person living with dementia, and can help us to see them as active agents?* MRes in Anthropology, Art and Perception in the Department of Social Anthropology, University of St Andrews, 2016 (Unpublished).
- 2 Some examples include but are not limited to: Collective Encounters (collaborative theater, Liverpool); Age of Creativity (art practitioners working with older people, Oxfordshire); Alive Inside (music and dementia, aliveinside.org); Music and Memory (musicandmemory.org);

Dementia Friendly Cinema (Alzheimer's Society; Tyneside Cinema).

- 3 The film has been known widely also under the name 'Malcolm and Barbara – A Love Story' (1999), and in 2007, after the death of Malcolm, another television program was aired as 'Malcolm and Barbara: Love's Farewell'
- 4 Merleau-Ponty used type writing as an example, as one does not have to think where the letters are to type (1962: 144).
- 5 The author is currently working on a PhD research project at the Queen's University Belfast (2018–2022). The work-in-process thesis title is: *The Art of Caring: New Opportunities for Creative Practitioners in the Ageing Economy*. It is funded by the AHRC through the National Productivity Investment Fund and is done in partnership with Age NI.

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