A good life with dementia

Ethnographic articulations of everyday life and care in Dutch nursing homes

Driessen, A.-E.

Link to publication

Creative Commons License (see https://creativecommons.org/use-remix/cc-licenses):
Other

Citation for published version (APA):

General rights
It is not permitted to download or to forward/distribute the text or part of it without the consent of the author(s) and/or copyright holder(s), other than for strictly personal, individual use, unless the work is under an open content license (like Creative Commons).

Disclaimer/Complaints regulations
If you believe that digital publication of certain material infringes any of your rights or (privacy) interests, please let the Library know, stating your reasons. In case of a legitimate complaint, the Library will make the material inaccessible and/or remove it from the website. Please Ask the Library: https://uba.uva.nl/en/contact, or a letter to: Library of the University of Amsterdam, Secretariat, Singel 425, 1012 WP Amsterdam, The Netherlands. You will be contacted as soon as possible.
RAUM UND SATTELL MIR ZURÜCK!
ERLEDIGE DICH DIENSTLEISTUNGEN;
ABSTRACT
What can pleasure in the nursing home teach us about dementia and subjectivity? In this chapter I seek to challenge the assumption that the ‘fourth age’ involves the loss of subjectivity. In presenting dementia as a single pathway towards loss and decline, alternative pathways that provide more hopeful imaginaries become obscured. Drawing on ethnographic fieldwork in residential dementia care, I show how care professionals craft conditions that invite residents to take pleasure in, for example, dancing and bathing, and thus to become what I call ‘appreciating subjects’. Although residents do not craft these conditions themselves, they are active in accepting the invitations offered and enacting their appreciations. I argue that pleasure is a relational achievement, one that is contagious for those who let themselves be affected.

PLEASURE IN DEMENTIA CARE

Dementia is one of the most feared diseases of our times (Pin et al. in van Gorp and Vercruysse 2012, 1274). Emotionally charged metaphors, in both lay and medical discourse, are illustrative of this: they present people with dementia as sailing off into darkness or drowning in a sea of forgetfulness, as plants, vegetables, empty shells or even as ‘living dead’ (Hashmi 2008, 209–10; Moser 2008, 104; Gubrium and Holstein 2003, 216; van Gorp and Vercruysse 2012, 1277). Dementia has been described as implicating a loss of self. Selfhood, then, seems to be dependent on cognitive functions (Mitchell, Dupuis, and Kontos 2013; Moser 2011; Taylor 2008; Kontos 2004).

These fears culminate in the so-called ‘fourth age imaginary’ (Higgs and Gillearsd 2015). The ‘fourth age’ is collectively imagined as a terminal destination in life, marking the departure from a fit and healthy life to illness and dependency, in which people with dementia are seen as losing their subjectivity; they can no longer express themselves intelligibly, and are stripped of all possibilities to enjoy life (ibid., 14). In line with Higgs and Gillearsd, I argue that this imaginary is disabling in itself. In presenting dementia as a single pathway towards loss and decline, alternative pathways that provide more hopeful imaginaries become obscured (ibid., 72–77).

In this chapter I question these ideas about what dementia means for being a subject by presenting ethnographic data on moments in which pleasure occurs in dementia care. As we seem to expect these moments the least when thinking about dementia, I ask: what can taking a closer look at moments of pleasure teach us about the kind of subject someone with dementia may become? Rather than accepting that subjectivity relies on cognitive abilities that are lost to those with dementia, I understand the fourth age imaginary as a specific version of understanding dementia, which projects particular versions of life with dementia while excluding others. Based on my observations in care practices, my aim is to take a step towards ‘articulating alternatives’ (Moser 2005; Vogel 2017) to counterbalance the dominant understanding of cognitive decline as fatal to subjectivity.82

I describe the residents of the Dutch care home I studied who are living with dementia as ‘appreciating subjects’, rather than as people suffering from function loss. I demonstrate that they can take pleasure in dancing, bathing and daily care. My analysis of these situations suggests that pleasure is a relational achievement, comparable to the organisation of pas-

82 I explicitly do not wish to deny the potential political utility of pointing to the incapacities and needs of those affected (e.g. Comer 2007), or to contribute to what some have argued to be a burden of excessive obligations to be happy (Ahmed 2010).
sion as put forward by Gomart and Hennion (1999). I describe how care professionals\(^{83}\) craft the conditions that subsequently require residents’ active surrender before pleasure may occur. As residents actively let themselves be affected, others can become affected too. By virtue of its spread, pleasure is contagious. I thus demonstrate that a focus on pleasure brings people with dementia to the fore as appreciating subjects rather than subjects characterised by lack or as no subjects at all. This shift of attention from cognitive capacities to crafted conditions and enacted appreciations may itself help realise the potential of pleasure in the lives of those living with dementia.

**THE EMERGENCE OF APPRECIATING SUBJECTS**

I draw here on fourteen months of ethnographic fieldwork that I conducted in Dutch residential care. In what follows, I explain the contours of my fieldwork and how I have drawn on the insights of scholars working at the intersection of anthropology and science and technology studies to outline my approach to studying pleasure. Undertaking this methodological discussion leads us directly into the central ethnographic and analytical matter of this chapter: just how should we understand subjectivity anthropologically in the lives of people with dementia?

I follow Ingunn Moser in understanding subjectivity as ‘a location of consciousness, knowing, thinking or feeling’ (Moser 2005, 693), most adequately thought of in the plural (‘subjectivities’) to denote that subjects emerge differently when relationships are structured differently (ibid.). Subjectivity, on this account, is thus not an innate capability, but instead a set of ‘positions and possibilities for experience that emerge in embodied interactions’ (Moser 2011, 714). If subjects are not pre-given presences, but the outcome of heterogeneous processes, they cannot be the starting point for theorising; instead, they must be studied empirically. By focusing on practices, I resist fixing subjects or assuming that innate corporeal capacities for pleasure are necessarily lost with the progression of dementia. Instead I analyse how subjects are acting and enacted, how they **become** appreciating subjects in relational engagements with their sociomaterial environments.\(^{84}\)

---

\(^{83}\) I use the term ‘care professionals’, but mean this term to include people as diverse as care workers, volunteers, managers, receptionists and physiotherapists. Visiting family members sometimes helped in crafting conditions for pleasure.

\(^{84}\) The term ‘sociomaterial environments’ builds on the material semiotic tradition (Law 2009). Scholars in this tradition argue against separating the material from the social, and insist instead on studying their complex entanglement of things-in-becoming.
I use Emilie Gomart and Antoine Hennion’s work on passion as a form of attachment (1999) as a methodological starting point to studying pleasure empirically among those who may not be able to voice what they do (and do not) like. Drawing on their longstanding scholarly engagements with drug addicts and music amateurs, they argue that ‘active work must be done in order to be moved’ (ibid., 227). Music amateurs acquire skills to appreciate nuances in music, playing the same part over and over until the effect ‘arrives’. Likewise, drug users manage their dependence on heroin so as to remain prepared for pleasure.

Moving away from the question ‘who acts?’ – positioning the subject as the source of action – and asking instead ‘what occurs?’, Gomart and Hennion pay attention to what is done to help active dis-possession occur (1999, 225–26). This shift from ‘action’ to ‘events’ (ibid., 223) is helpful in seeking out pleasure among people with dementia as it allows us to see not only that action is distributed in networks and configurations, but also that objects may prolong and transform actions initiated elsewhere in surprising ways. It is no longer merely about doing, but also about what is ‘left and made to arrive’ (ibid., 222). Active and passive are blurred together. The attachment, ‘that which allows the subject to emerge – never alone, never a pristine individual, but rather always entangled with and generously gifted by a collective, by objects, techniques, constraints’ (ibid., 221), takes the form of actively submitting to self-abandonment.

This idea raises the possibility that people with dementia might still be involved in pleasurable moments and relationships, a possibility that empirical ethicist and ethnographer Jeannette Pols has argued for explicitly. Pols contends that, while residents of dementia care homes cannot always verbally express their attachments, they can make these known through their embodied ways of valuing something (2005, n.d.). These ‘enacted appreciations’, as Pols calls them, are both passive and active, and they can be verbal or non-verbal, and shared or rejected by others. Crucially, subjects are active in their own enactment. Pols invites us to consider subjectivity as ‘the possibility to appreciate and value – or resist and subvert – the subject positions one enacts [together with others]’ (Pols, n.d.).

The ethnography I present in this chapter explores conditions in which chances for subjects with dementia to appreciate and actively surrender to pleasure are collectively crafted. I take the arguments of Hennion, Gomart and Pols about appreciation and subjectivity as tools with which to attend empirically to how, in care practices, new subject positions are enacted by and for people with dementia and those around them. Between 2014
and 2015, I spent six months in the care home\(^85\) De Zonneweide,\(^86\) home to fifty residents, fifteen of whom were diagnosed with various forms of dementia. I spent another eight months on one of two dementia care floors (each consisting of two interconnected wards, home to twenty-two residents with moderate to advanced dementia respectively) of the nursing home De Parkhoeve.\(^87\)

For the first ten weeks of fieldwork in each location I undertook at least three eight-hour shifts per week, helping care workers to make beds, accompanying residents to the living room or to the hairdresser, and serving food to residents. I observed and aided care workers in providing daily care tasks – such as getting residents up, washing and dressing them – and less regular activities, such as physiotherapy sessions, gym classes and the newspaper reading circle. I spoke to care workers, occupational managers, volunteers and family members about giving care and life with dementia. When busy work schedules allowed for it, I deepened these conversations in semi-formal interviews.\(^88\)

Later, I spent more time with residents independently from organizational schedules. Instead of interviewing them, I accompanied residents on their walks on the ward and occasionally outside, and sat with them in the coffee corner or at the dinner table. I provided residents with as many opportunities to become aware of my position as a researcher as the context permitted. Building on Pols’ (2005, n.d.) approach to enacted appreciations, I paid attention to whether residents seemed to feel comfortable around me. Taking enactments of discontent seriously, I withdrew from situations in which residents seemed to respond to my presence in an agitated manner.

---

\(^{85}\) In the Netherlands a distinction exists between *verzorgingshuizen* (residential care homes, also called *woonzorgcentra* [live-care centres] to emphasize the policy that seeks to give precedence to living over caring) and *verpleeghuizen* (nursing homes), the latter being home to people with a ‘heavier care need’ compared to the former. Here, I use the terms ‘care home’ and ‘nursing home’ to distinguish the two, and ‘institutional care settings’ to indicate both.

\(^{86}\) All names used for residential homes and interlocutors are pseudonyms.

\(^{87}\) At both locations, care workers and residents’ family members were informed of the study through leaflets and the newsletters of the institutions under study. The study was approved by the Ethics Committee of the Amsterdam Institute for Social Science Research. During and after the fieldwork period my fellow doctoral students in the Anthropology of Care research network at the University of Amsterdam and I organised ‘Dialogue Evenings’ [*Dialoogavonden*] throughout the duration of our projects. In these meetings we presented our (preliminary) findings to interlocutors and others who were interested, followed by an exchange of thoughts about these findings and their implications for work and life with dementia. For more information, see [http://partnershipforcare.uva.nl/activiteiten/dialoogwerkgroepen.html](http://partnershipforcare.uva.nl/activiteiten/dialoogwerkgroepen.html).

\(^{88}\) Interviews were transcribed and organised along with extensive field notes into themes using the qualitative analysis program NVivo. I obtained written informed consent from all interviewees.
Throughout the fieldwork, I attended closely to seemingly insignificant movements and occurrences, such as taking up an invitation to dance, forming a smile or sinking into a warm bath and relaxing, that I took to signal residents’ attachments (Hennion 2001, 2007, 2017). It is these moments that I focus on here as I describe care practices in which care professionals crafted conditions for pleasure. I argue that, in these practices, residents – and others – emerged as appreciating subjects.

**DANCING: AN INVITATION TO PLEASURE**

At the beginning of my fieldwork, the bi-weekly dance was still rather new in De Zonneweide. Care worker Joani and physiotherapist Leon had written up a plan for the event and gained the management’s approval, but staff attendance was low for a long time; many found it rather embarrassing to dance in front of their colleagues or silly to do so during work time. Out of enthusiasm, but also undoubtedly keen to get an extra pair of hands, Leon and Joani asked me to join. So, whenever I could, I attended the activity. Receptionist Tamara told me that whenever family members came in during the event, they always expressed their joy at seeing the residents and staff members dancing. Over time, Leon and Joani’s enduring enthusiasm resulted in the loyal presence of more and more staff, and some volunteers became regulars at the event. Some days the manager would join the crowd on the dance floor too. To me, the dancing activity became a symbol of how pleasure in dementia care could be achieved.

Twice a month, on Tuesday afternoons, Mr Zondag set up his music equipment in the entry hall. Mr Richard, a resident who I knew always looked forward to the event, helped to set aside the tables at which the tea club gathered every morning, and to arrange the chairs into a large circle. The music – ranging from jazz to foxtrot to Dutch folk songs – echoed invitingly through the corridors, reminding all that the dancing was about to begin. As the sounds began to fill the space, the home’s institutional aspects – the reception in the hallway, the restaurant and the coffee bar tucked away next to the back entry, the lift to the residents’ apartments upstairs – disappeared into the background.

When everything was ready, the care staff, the volunteers and I accompanied the residents to the chairs at the edge of what had now become a dance floor, and attempted to entice those hanging back to join in as well. Leon often did a round of warming-up exercises, after which he opened the floor for the hour to come. After some dancing, Joani and the restaurant staff served lemonade to everybody.
Mr Zondag, the in-house DJ, is himself a resident of De Zonneweide. He granted me an interview in his two-room apartment, between the shelves of self-made mix tapes and an impressive collection of LPs, a mere fraction of the music collection he used to have before moving into the care home. Although he never dances when he plays music for the event, he spoke of the pleasures of dancing in the present tense: ‘When you are there with two people on the dance floor … and it goes well, it gives you pleasure [dan geniet je\textsuperscript{89}]!’

But how does this pleasure occur? Consider, to begin with, the music. Mr Zondag’s collection holds numerous well-known tunes from the 1940s and 1950s with which residents can sing or sway along. In our interview, Mr Zondag described his memories of the ballrooms he and others from his generation frequented in their youth:

Whenever you hear that music after years and years, then I think ‘Hey! This one was played when I was in [the Dutch province] Drenthe, when the Netherlands was liberated [in 1945], when the English came and they threw a dance night and we sat there in the room and this music was being played,’ and then I still see those few Englishmen dancing with the villagers in that school room. And that suddenly comes to mind, that comes to the fore of my memory.

The music does work: it actively evokes memories of the past and stirs up emotions associated with it.\textsuperscript{90} And it moves bodies. Here, it is not the loss of the ability to recall words and memories that is foregrounded, but rather a body that remembers. The music entices listeners to dance.

That does not mean it is easy. Some steps have been forgotten. Legs simply refuse to move as fast as the beat. Energy levels fade mid-song. Hips and knees are too stiff for dancing. Ballroom dancing as it was done in the Netherlands when these residents were young – in pairs, following sequences of steps, with ‘dancing poses’ – is no longer possible for them. So, to help pleasure occur, Joani and Leon have trained their colleagues and volunteers to adjust their own bodies, ideas of what dancing is, and

\begin{flushleft}
\textsuperscript{89} The Dutch verb \textit{genieten} translates as ‘to enjoy oneself’ or ‘to get a great deal of pleasure (out of)’. The noun \textit{genot} translates as ‘enjoyment’ or ‘pleasure’. I predominantly used ‘pleasure’ as its translation as it opens up a register that automatically includes the bodily.
\textsuperscript{90} A testimony to the positive effects of music on people with dementia is the documentary \textit{Alive Inside} (Rossato-Bennett 2014) in which people with dementia are given a music player with a personalised playlist. For a Dutch account of music, familiar objects and reminiscence for people with dementia, see Carpentier 2017. A welcome comment in this report is that memories that come up during reminiscence are not always positive.
\end{flushleft}
the environment in ways that enable dancing together. As De Zonneweide is home to many more women than men, and female care workers outnumber their male colleagues, first to go is the presumption that a pair consists of a man and a woman: female care workers danced with female residents too. Then, instead of taking a classical dancing pose, care professionals and residents hold one another’s lower arms for stability. Steps are smaller and slower; chairs are always nearby. Those unable to walk dance while standing in front of their chairs. Those unable to stand dance while seated, by moving their arms, legs or feet. With these adjustments, residents do not lack abilities. Instead, they have potentials that can be realised if the right conditions are in place.

Sometimes Leon and Joani introduce other formations altogether. The circle, for instance, affords different ways of relating to one another and allows for surprising situations: when Joani holds out her hand to Ms Koning, she takes it, unsure on her feet. Her other hand finds Leon’s hand, who in turn holds Ms Rose’s hand. I am standing between Ms Rose and Joani, and in this little circle we all find stability. We move carefully to the left, then to the right, sometimes pushing and pulling carefully to indicate the need to change the pace. The circle opens to include Ms Steiner, who tripped, fell and broke her arm a few days earlier. Before, she could walk by herself, but now she is on painkillers and therefore sitting in a wheelchair at the edge of the dance floor. Mr Richard takes the wheelchair and turns Ms Steiner as well as he can within the circle that we have formed. Both laugh. Then we all do. Ms Steiner drums the beat of the music on the armrests of her chair and she smiles with her eyes wide open now that she is included in our dance. Ms Rose suddenly says, radiating with joy, ‘I like it!’ [‘Ik vind het leuk!’], emphasising the ‘leuk’ as if she is herself surprised by it. Ms Jacobs sits on a chair in the circle, but firmly refuses my request to dance with her. She says, ‘I am not a dancer’. Yet in her chair she seems unable to stop wiggling her feet to the music. Dancing does not give Ms Jacobs pleasure, but something else may do just that; the music may still entice feet to wiggle.

People with dementia are different from Gomart and Hennion’s drug users and music lovers, as residents with dementia do not generally craft conditions for pleasure so intentionally by themselves. But the argument that conditions must be established, prepared and organised remains helpful to understand how pleasure occurs, nevertheless, on the dementia ward. Care professionals, and a few residents who are able to help, including Mr Richard and Mr Zondag, arrange heterogeneous elements such as music equipment, LPs, chairs and lemonade in ways that appeal to resi-
dents’ sensitivity to music, touch and togetherness. Moreover, not just any conditions are crafted, but those that resonate with the past of this particular group of people, evoking memories and feelings.

This does not mean, however, that residents are entirely passive – that is, simply waiting for others to arrange their enjoyment. Consider Leon’s reflection on ways of relating in dancing:

Look, one should never force anyone. You wouldn’t like it either if someone leads you in a forcing manner. But you should, in fact, invite [the resident] to move, and sometimes it may just be that someone starts to move by him/herself and then it is nice that you can move along. That is the principle of ‘following while leading and leading while following’ [leidend volgen en volgend leiden]. When I dance with somebody and what I want does not happen, then I go along with that, and then you lead again and that’s fun.

Leon offers an important insight here: taking pleasure cannot be achieved through force, only through invitation. Music entices the body to move. The care professional or volunteer extends a hand and the stability for a dance. The crafted conditions offer a subject position in which pleasure is a possibility, yet to become an appreciating subject requires residents’ acceptance and a positive appraisal of those conditions, and in turn attention to such appraisals by others: the resident accepts the hand, steps onto the dance floor, moves along and leads. Residents thus are ‘active-passive’ in just the same way as Gomart and Hennion’s drug users and music amateurs. Almost paradoxically, it is when they actively surrender to the conditions crafted by others that they become positively attached to what seized them.

When the dancing carer is receptive to the resident’s moves and goes along with these, dancing becomes dancing together. When residents enjoy themselves, it affects their dance partners and bystanders too. If the care workers let themselves be affected, they too emerge as joyful subjects. By virtue of its spread, pleasure is contagious.

Leon suggests that this experience of dancing together can transform relationships between residents and care professionals:

I feel [that] one becomes more equal. The way I see it is that I am making contact which is somehow more real. And with ‘more real’ I mean, there is a person sitting in front of you, not only a patient or a resident. There is a person! [‘Er zit gewoon een mens!’] That is what … dancing
does. Yes, whether they are in a chair [dancing to] the music, or just
dancing freely as it were, or together, in an ‘open embrace’ of course,
yes, then it is people sitting in front of me, more so than usual.

For Leon, dancing makes it easier to see someone as a ‘person’ rather than
merely a ‘resident’; through dance, people gain subject positions that allow
for individuation and connection.

Dance as the medium of interaction allows people with dementia to
invite care workers into a different subject position too. They can be more
than ‘mere’ caregiving professionals. For Joani, dancing is a way to encoun-
ter residents in a different role to her usual one as a care worker:

[It is like] being put in another role by the person with dementia, for
instance, a mother, a friend or a daughter. During the dance, the meet-
ing of two people, in whichever role, is [of] central [importance]. They
are now no longer in a hierarchical relationship.

Azucena Guzmán-García, Elizabeta Mukaetova-Ladinska and Ian James
have made a similar point with regard to Latin ballroom dance classes and
people with dementia, stating that care workers value ‘hav[ing] a break in
a fun way with residents’ and ‘interact[ing] in another context apart from
cleaning and feeding’ (2013, 532). Enjoying a dance together enacts rela-
tionships that are different from one person helping another. Joani even
feels that dancing can facilitate the provision of daily care in the longer
term, because the friendlier, warmer affect towards each other remains.

Pleasure, jointly achieved through invitations extended by music and
chairs and with people moving together, in self-abandonment to condi-
tions crafted with care, may not bring perfectly rational, independent cog-
nising agents into being, but it does facilitate the emergence of relational,
appreciating subjects nevertheless.

**BATHING: SURRENDERING TO CRAFTED CONDITIONS**

In dancing, sociality is instrumental to transforming relationships and
giving rise to unexpected subjectivities. How is pleasure different in a set-
ting attuned to one single person? The practices related to bathing in De
Parkhoeve illustrate how one-on-one situations can have similar effects.

It was care worker Bram who showed me the bathtub in the ‘snoezel-
ruimte’, a multisensory environment. Snoezelen, a form of therapy developed
in the Netherlands in the 1970s, relies on the use of a variety of sensory
stimuli, such as lights and colours, music and sounds, scents and differ-
ent tactile materials. Bram regards it as his main task to bathe the clients with ‘heavier care needs’. He contends that bathing can add a lot to nursing home life: ‘People can take tremendous pleasure in taking a bath. … Clearly they are sitting in the living room all day and there are activities. But you can really see that a one-on-one activity like this has a lot of added value [meerwaarde].’

Bram takes about one hour to bathe a resident. He helps residents to wash themselves, and gives the male residents a shave. Indeed, during the bathing activity it is easier to attend to individual preferences than during the dancing activity. Bram chooses personalised music based on what he knows about a resident’s past and what they respond well to. He combines ‘body-pleasing aspects’ (Twigg 2006, 122–123; 138), such as warm bathwater, with dimmed, coloured lights that move slowly, like a kaleidoscope, across the ceiling and along the walls. He may, so he tells me, also ‘do a bit of physiotherapy: let [the bathers] move their legs, if they can still do that, or move their arms’. Lastly, he offers the bather breakfast in the tub – coffee or tea, and a sandwich of choice, or what the staff knows that this particular resident likes to eat – which he places on a table that stretches across the tub. After the bath, the bather can sit in the adjacent room for a bit longer, if desired, with a cup of tea or coffee, while Bram cleans the bath, refills the tub and begins to bathe the next resident. The first bather often stays to listen to the music of the next.

Bram has by now bathed all residents at least once. Now he picks residents based on whether he thinks they find it enjoyable: ‘Everybody who likes it can be bathed again, others of course do not [have to bathe again]’. As with the dancing, the residents’ receptiveness is a prerequisite for pleasure; the occurrence of pleasure cannot be forced, but must be invited by the warmth of the bath, or by one’s favourite sandwich – which, in an unusual mixing of practices, can be enjoyed in the tub.

One Monday morning I encounter Bram by the tub, and he tells me that he is about to bathe Ms Velthof. He has communicated to the team that he will get Ms Velthof out of bed once the bath is ready for her. We go to her room together, and find her awake but unwilling to get up. She says that she wants to die. Bram jokes that he cannot arrange that for her: “The

---

91 Importantly, Bram works only a few hours per week, and when he does, he is an ‘extra’ to the scheduled care staff. One-on-one bathing sessions lasting one hour per resident would otherwise be much harder to realize.

92 Similar points have been made elsewhere. Pols’ study on washing in nursing home care highlights how washing may be pleasurable (Pols 2006); Vogel and Mol’s ethnography on eating and weight loss illustrates how food may invite pleasure (2014); and Brijnath’s ethnography on dementia in India demonstrates food and eating to be political and pleasurable (2014, 116–36).
Ministry of Justice does not allow for me to do this. But he has a bath waiting for her, he says. Ms Velthof gets up and walks along, meanwhile still commenting on ‘how stupid everything is’.

Once in the tub she seems less discontented. She talks about how fascinated she is by not being able to remember the most recent past. ‘How long did you say I have been here for? Two months? It really feels like I have been unconscious for the past two months.’ She wonders if she has eaten at all during those two months. I tell her she has been awake, but that she has memory problems. This she knows, she says. Then she asks if she has spoken at all during those months. ‘A lot!’ I say, and I tell her some of the things she said. She and I both laugh. She tells Bram to ‘scrub her properly, because of the dirt that accumulated over two months’. Now we all laugh. Bram gives her a washcloth, so that she may wash herself while he scrubs her back. She does not repeat the death wish she expressed before, but takes the washcloth. By the time she receives a cheese sandwich – her favourite, she says – she is chatting away energetically. The mix of eating and bathing gives the situation a special feel. These conditions help batters to acquire a body that is sensitive (Despret 2004; Hendriks 2012), a body that can appreciate warm water, the smell of soap, personalised music, conversation and food offered. Ms Velthof surrenders herself to the conditions Bram has created in the snoezelruimte: she asks for a back scrub, talks at length, and laughs. Her joy affects me too: I talk and laugh with her.

If residents let themselves be affected, pleasure may come in different forms. It may come in the form of particular embodied memories, as Bram told me once, while we were cleaning the tub:

This is the generation that bathed in a tub at home, or who did not have a bathroom at all. Then there was a bucket with water. I may ask a resident: ‘How did you bathe yourself when you were little? What did you experience then?’ There is a lady who really goes back to her childhood years – she will squat on her haunches in the bath; she really turns in circles like a little child, with little dolls.

Or it may come as pure relaxation, as Bram recounts after just having bathed Mr Knoop: ‘He loved it. He slept the whole time.’ ‘Oh, that sounds relaxed!’ I say. Then I hesitantly add, ‘Is that a good thing?’ ‘In his case, it is’, says Bram, and he explains that Mr Knoop spends much of his time lying in bed, somewhat restless. His sleeping in the bath signals that he was able to let go of some of his restlessness. As with dancing, there is
an active-passive engagement here. The act of relaxing, letting oneself be affected by the water and music, is required for pleasure to occur. This became most visible when a resident did not do so, as was the case with Ms Robijn. When Bram hoisted her onto the lift chair and started lowering the chair into the tub, she did not relax into the water but kept screaming ‘poo, poo, poo’. She moved her body away from the water to the best of her abilities. Bram later reflects on what happened in our interview following the occurrence:

Initially … she did not want to cooperate93 … but then, at once, the situation turns and then … you see how she beams and how she changes in her behaviour. … She [usually] really likes being in the tub. But now she came from the toilet. In her experience she is still straining. She was not; she was done. She has a prolapse [a medical condition of intestines protruding through the rectum]. So she pushes … a part of her intestines out, so perhaps that feels like straining. But then she stays in that [experience] of defecating. And then she says that: ‘poo, all poo, poo’. … And then it is really difficult to distract her.

As long as Ms Robijn felt that she was on the toilet, to her the bath was ‘infected’. For very good reasons, she could not make herself available to the pleasure of taking a bath. Whether a resident can surrender to the conditions crafted thus depends also on what has happened before. Sometimes situations like this do not change at all, and the bath is better called off. In this case, however, when Ms Robijn’s foot touched the water, she suddenly stopped screaming. Bram slowly eased the lift down into the water. Ms Robijn seemed to surrender to the warm water, an act of giving up control and allowing the water to affect her. She enacted her appreciation by chatting away, eating a sandwich and moving her arms to the music like Bram. Such moments of change can be very touching. Bram recounts another such situation: ‘I have a resident who has severe aphasia. … I turn on [his] music – and then I can hear him hum every now and then. Those are special moments to me: somebody who in effect never speaks, and who can then hum to his favourite music’. Bram takes pleasure in residents’ pleasure; it affects him positively. Here, too, pleasure is contagious.

93 Care professionals frequently used phrases like ‘the resident did not want to cooperate’ or ‘the resident is difficult’ to describe situations that were indeed challenging. In this phrasing, residents are people who should comply with what care workers want rather than people with motives that are worth inquiring about. Spatial constraints keep me from challenging this phrasing here. I leave it as it illustrates that an active relaxation is required for pleasure to occur.
PLEASURE IN DAILY CARE

These examples of dancing and bathing demonstrate that pleasure is a sociomaterial and relational achievement that requires collective investments. As daily care is often characterised by low staff levels and little time per resident, my focus on dancing and bathing could give the impression that pleasure can only be achieved in ‘special events’ or when there are plenty of staff. However, pleasure occurred in daily care practices too, despite the very real time constraints. Andrea, one of the occupational therapists at De Parkhoeve, in a lengthy conversation about snoezelen which she allowed me to record, said:

You cannot conceive of ADL [activities of daily living] as just washing and dressing, but indeed it is also the start of somebody’s day. … One can also use ‘snoezelen’ in [daily] care work. For instance, by using a body lotion, you know? … Music can really help [residents] to relax, or they start singing along, which allows attention to be directed away from the less-pleasant things of ADL. Then people are less cross or less anxious. [The care workers] do that so beautifully: ‘this is her music, her music from when she was young.’ And if you attend … closely [to what] somebody thinks is pleasurable music … then that helps in starting the day [well].

Andrea points out how important it is to create pleasure in daily care. In situations like this, a little initial investment of time in pleasure costs no more time overall, and sometimes even less, than attempting to get a task done in other ways. Pleasure facilitates care routines. Instead of forcing residents, pushing through their ‘resistance’, as care workers sometimes called it, they invested in creating conditions that could facilitate residents’ passing into pleasure, in an effort to come to a shared desire of what was to be done (cf. Driessen 2017). These efforts require attention to whether the resident values what is offered to her: does the resident like the music? How is she responding to it in this moment?

Daily care, then, need not be in opposition to bathing, dancing and music. Precisely the merging of these ‘special’ practices with the doing of daily care aided in the process of getting care done pleasantly. Leon holds that when he uses music and dance in physiotherapy, ‘people connect [him] to something positive’, which helps the session. Ms Dirks screamed when anyone tried to wash her hair or her feet in the shower, but let Bram wash her hair and cut her nails when she was in the bath. Similarly, Ms Berg, who clenched her fists tighter and tighter over time, could relax her
hands enough to let Bram clean the skin between her fingers without the usual ‘fight’ and pain that this would normally cause. When Ms Postema was offered breakfast while bathing, practices that usually happen separately, she ate better than usual. When care worker Linda turned on some music, Ms Wijers, who had initially not wanted to get up, quite literally danced out of bed. When given a cup of hot chocolate just after waking up, Ms Veenstra could usually be enticed to get up and join the other residents for breakfast. And, as it is nicer to aid residents with daily care tasks when they are enjoying it, by investing in pleasure the encounters can become more enjoyable for care professionals too.

CONCLUSION

Pleasure occurs in a place where it is not usually expected: dementia care. The work of achieving pleasure here is distributed across a heterogeneous configuration: volunteers, care professionals and resident DJs come together to entice and invite residents, crafting the conditions for residents’ – and their own! – pleasure by arranging chairs, music and lemonade, and helping residents to make themselves available to what is offered to them. I have argued that active-passive surrender is required for the occurrence of pleasure. If residents let themselves be affected, they may corporeally remember steps from younger years, enjoy the togetherness and the touch of dance, forget the unpleasant toilet experience and sink into the warm water of a bath. Pleasure, then, may be observed in its many different forms: accepting a dance, smiling with eyes wide open, wiggling toes, humming and squatting, and also opening clenched fists and relaxing into sleep. I have furthermore insisted that pleasure does not just occur in ‘special events’ in institutional care settings, such as the dancing and bathing. Rather, the pleasure of music and dance, the joy of massages with a well-scented body lotion, or laughing together can be part of daily care too. As such, pleasure can facilitate care routines and, moreover, transform relationships. The elderly who were previously ‘mere’ care receivers, ‘cross’, or ‘thwarting’ the plans of their care-givers, are granted

---

94 To put ‘care for pleasure’ in the foreground, as I have done in this article, runs the risk of making those who provide daily and hands-on care for people living with dementia responsible for crafting conditions for pleasure. While care workers’ abilities are crucial for bringing about pleasure, it remains important to attend to concerns about workload, the immense everyday work that caregiving encompasses, and the environments in which care staff work. Recall that only when care workers felt safe enough to dance in front of their colleagues did they commit themselves to the activity. Precisely because people cannot be forced to enjoy themselves, facilitating and stimulating care workers in doing activities they too feel comfortable in is as important as the work that follows.
positions that are more positive; each becomes a ‘person’, a person enjoying a bath, a dance or a nap. Likewise, the care professionals become dance partners, people of equal standing, associated with something positive. My ethnography shows the importance of the relational conditions that invite the active surrender to pleasure and give rise to appreciating subjects. In this respect, this ethnography has relevance to debates on the concept of personhood (e.g. Kitwood 1993, 1997) and subjectivity in dementia and the critique that these debates ignore relational aspects of care (Baldwin et al. 2007, 181; Nolan et al. 2002). I have demonstrated that subjectivity, which I have here taken as enacted appreciations (Pols 2005, n.d.) within particular subject positions, emerges in the right conditions. In dementia care, these conditions are frequently crafted by care professionals, family members and other people involved in the care of people with dementia. What is good depends on the conditions that invite pleasure as well as one’s appreciation of them. Enacting appreciation should thus not be thought of as exclusively reliant on cognitive ability. Instead, the appreciating subject comes to the fore as embodied and collectively achieved in particular configurations. Pleasure is a relational achievement, one that is contagious for those who let themselves be affected. This ethnography of pleasure leads us away from all too easily assuming that subjectivity is dependent on cognitive capacities per se. I suggest this is a lesson about pleasure more generally: one needs conditions and invitations to be able to take pleasure in something. Although opportunities to craft the conditions that make pleasure possible may present themselves less clearly and less frequently to those diagnosed with cognitive impairment than to those who are not, everyone is ultimately dependent on such external conditions that invite one to actively surrender. This, finally, offers a lesson for ethnographers as well. Appreciations may be missed by those not receptive to them. I propose that ethnographers can learn from dementia care the art of becoming sensitive to subtleties of enacted appreciations, such as the wiggling of feet at the side of a dance floor, of lines relaxing on a face as somebody sinks into a warm bath. Attending to these subtleties,  

 Attending to these subtleties can also be learned from the method of the so-called miMakkus clowns as described by Ruud Hendriks, who are specialists in interacting with people with dementia. Hendriks uses Vinciane Despret’s (2004) work on the craft of learning to be affected to argue that ‘becoming a clown … means acquiring a body that is learning to become sensitive to the other, a body with which you learn to distinguish with increasing subtlety between differences in how the other person relates to the world, attentively, physically, and sensorily’ (Hendriks 2012, 469, emphasis original). The clowns’ method involves communicating in non-linguistic and non-cognitive ways: they slow their pace down, stop assuming that meanings are shared, and go along with the rhythm, intensity and mood of the other person.
so as to be able to articulate them as alternatives, requires ethnographers to become active-passive too. It requires that we let ourselves be led by those we study and affected by what occurs, much like care professionals when they dance with residents, ‘following while leading and leading while following.’ Just like a dancing care professional who sometimes leads and sometimes follows the dancing resident, the ethnographer attends to changes in intensity, direction and mood, at times taking the lead and at times letting herself be led. Doing research, too, depends on crafting conditions for research participants, conditions that extend invitations and in so doing make subject positions available to them beyond what is collectively imagined to be possible. If we expect a damaged subject characterised by cognitive disability, deficits and decline – such as that embedded in the fourth age imaginary – we may only reproduce particular versions of life with dementia, while blocking more interesting ways of living with, and indeed relating to, people with the condition.