



UvA-DARE (Digital Academic Repository)

Learning in Collaborative Moments

Practising Relating Differently with Dementia in Dialogue Meetings

Hoppe, S.; Vermeulen, L.; Driessen, A.; Roding, E.; de Groot, M.; Krause, K.

DOI

[10.3167/aia.2019.260302](https://doi.org/10.3167/aia.2019.260302)

Publication date

2019

Document Version

Final published version

Published in

Anthropology in action

License

CC BY-NC-ND

[Link to publication](#)

Citation for published version (APA):

Hoppe, S., Vermeulen, L., Driessen, A., Roding, E., de Groot, M., & Krause, K. (2019). Learning in Collaborative Moments: Practising Relating Differently with Dementia in Dialogue Meetings. *Anthropology in action*, 26(3), 10-22. <https://doi.org/10.3167/aia.2019.260302>

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.

Learning in Collaborative Moments

Practising Relating Differently with Dementia in Dialogue Meetings

*Silke Hoppe, Laura Vermeulen, Annelieke Driessen,
Els Roding, Marije de Groot and Kristine Krause*

ABSTRACT: In this article, we describe experiences with dialogue evenings within a research collaboration on long-term care and dementia in the Netherlands. What started as a conventional process of 'reporting back' to interlocutors transformed over the course of two years into learning and knowing together. We argue that learning took place in three different articulations. First, participants learnt to expand their notion of knowledge. Second, they learnt to relate differently to each other and, therewith, to dementia. And third, participants learnt how to generate knowledge with each other. We further argue that these processes did not happen continuously, but in moments. We suggest that a framework of collaborative moments can be helpful for research projects that are not set up collaboratively from the start. Furthermore, we point to the work required to facilitate these moments.

KEYWORDS: care, collaborative moments, dementia care, dialogical anthropology, diversity, professional backgrounds

From Giving Back to Learning Together

Giving back to the field is widely seen as good practice in anthropology. Ever since the crisis of representation and the reflexive turn of the 1980s, anthropologists are expected to explicate how they communicate their writings to those they have worked with (Marcus 2002; Peacock 1997). Central to the discussion about 'giving back' is how knowledge is seen and conceptualised (Low et al. 2010). It tends to feature as something that can be either handed over or facilitated. For example, Louise Lamphere (2018) describes how early 'action anthropology' is aimed to enable communities to make their own choices, and Wayne Werry (1992) argues that, instead of consulting experts, communities should be assisted with evaluating and creating their own knowledge. Paulo Freire describes this as the 'banking concept of education',

where 'knowledge is a gift bestowed by those who consider themselves knowledgeable upon those whom they consider to know nothing' (2009: 72). However, while acknowledging the transformative power of knowledge, this split tends to create another separation, namely between those who know and those who acquire this knowledge.

The separation between anthropologists and those they work with has long been problematised within strands of anthropology inspired by feminist thinking, science and technology studies, and disability studies. Dialogical anthropology stresses that the subject of study is unstable (Crapanzano 1990) and that anthropologists do not 'discover' knowledge by talking to and working with interlocutors, but co-create and co-perform it in the fieldwork process (Fabian 1990; Pool 1994). Strongly influenced by performance theory, dialogical anthropology does not



see knowledge as ‘lifted’ from interlocutors’ heads and then reported back to them, but as resulting from joining people in their reflections (Johannsen 1992). Thus, the boundaries between researcher and researched become problematised: interlocutors are not mere research ‘subjects’ but researchers who do their own theorising (Casas-Cortes et al. 2008) and ‘co-labour’ together with anthropologists (Cadena 2015). This approach resonates with feminist material semiotics, which insists that knowledge cannot be separated from how it is known, and which thinks of knowledge as a practice (‘knowing’) rather than as a noun (Haraway 1988; Pols 2014). The field of disability studies has been most articulate about the political implications of refusing to draw boundaries between researcher and researched, viewing collaborative research as a form of political action (Woelders et al. 2015). Similarly, within critical pedagogy, the distinction between teacher and student is dissolved, with students viewed as critical co-investigators (Freire 2009).

In this article, we draw on these very different traditions addressing the politics of knowing and learning together¹ to analyse what happened in the ‘dialogue evenings’ organised within the framework of the Partnership on Long-Term Care and Dementia in the Netherlands. The partnership was set up in 2012 by Anne-Mei The and was funded by the Dutch Ministry of Health, the Gieskes-Strijbis Foundation, the care organisation Cordaan, and the University of Amsterdam. Its goal was to improve care for people with dementia by combining theory and practise.² The researchers, who at that time were working towards obtaining their doctorates, therefore set up dialogue evenings around findings from their PhD projects in order to report back to practitioners and people affected by or interested in dementia.³

What happened during those meetings took the researchers by surprise. What started as conventional ‘reporting back’ transformed over the course of two years into learning and knowing together. In particular moments, the division between anthropologists giving information and interlocutors as audience dissolved. Moreover, the research team soon realised that they were not only learning together with the invitees, but actually practising new and different ways of relating to one another.⁴ While the format of the dialogue evenings fit well with some of the challenging characteristics of dementia – for instance, the need to acknowledge tensions and ambiguities – we believe that the outcomes are also relevant to other fields in which people from different positions come together. This article is inevitably a simplification of

the ‘messy social dynamics’ (Plows 2018: xiii) that characterised the dialogue evenings.

We argue that learning took place in three different articulations. We talk about ‘articulations of learning’ to indicate that we do not claim to grasp the totality of learning that occurred, but merely want to highlight specific expressions of multiple forms of learning.⁵ We define learning not in the sense of reaching a specific aim, but rather in the sense of practising and developing (Freire 2009). In this context, dialogue was an ‘epistemological relationship’ (2009: 17) in which listeners became co-investigators of knowledge and in which education developed into a collective process (Pradhan and Singh 2016), or, as one participant of the evenings phrased it, in which we ‘all becom[e] wiser’.

First, participants learnt to appreciate different kinds of knowing and learning. Instead of seeking answers, participants found themselves reflecting on the complexity of situations, and gaining an understanding of the diversity of positions therein. Second, they learnt to relate differently to each other as occupying particular subject positions in the field of dementia care. Both people with and without dementia changed how they viewed and talked to each other, as did family members and those from different professional backgrounds. Third, over time participants gained an understanding of the evenings, not in terms of providing or consuming knowledge, but in terms of practising new relations and generating new knowledge together, thereby taking ownership as a group.

We further argue that learning together and relating differently did not happen continuously, but in moments. To think in moments acknowledges the limitations of the dialogue evening format, and allows us at the same time to think about the potential that comes with anthropological fieldwork. We draw on Kirsten Hastrup (2018), who uses the term ‘collaborative moments’ to describe her cross-disciplinary work. Hastrup explains how the very co-presence of different disciplines in the field changed her way of ‘being present’ and led to her ‘being affected differently’ (2018: 332) by what she and her colleagues from archaeology and biology were studying. Similarly, moments for us do not only have a temporal dimension, but are characterised by a certain degree of extraordinariness. The aim of this article is to explicate what these collaborative moments were like and what was necessary for their emergence.

We did not plan to write this article from the outset. Instead, we had to reconstruct events retrospectively by assembling notes and stories.⁶ In order to assess

how invitees experienced the dialogue evenings, we organised an extra meeting in which we shared our wish to publish an article about the dialogue evenings and informed participants that we would use material from the meeting and the evaluation [14 on Table 1]. Furthermore, we asked a colleague who was not directly involved in organising the meetings, Marije de Groot (fifth author), to conduct an email and telephone evaluation amongst participants. After completing a draft of the article, we hosted another dialogue evening in which we presented and discussed the article with regular participants [15], in line with our understanding of consent as a process (Dewing 2007). Participants agreed with the article’s content and further added to our argument.

In the following, we briefly describe the format of the dialogue evenings and then analyse three articulations of learning: learning to appreciate a different

kind of knowing, learning to relate differently, and learning to generate knowledge as a group.

From Reporting Back to Relating Differently

The Set-Up

The dialogue evenings took place in the centre of Amsterdam at the newly founded academic field lab involved in the partnership.⁷ In preparation, the organisers set up the PowerPoint presentation, arranged the chairs, and got the soup and sandwiches ready. At around 6:30 pm, the first invitees arrived. Invitees included people with dementia, family members, care professionals from different care organisations, care managers, social workers, spiritual counsellors, music therapists, physiotherapists, oc-

Table 1: Overview of Dialogue Meetings

Nr.	Date	Title	Summary
1	19-02-2015	Kick-off dialogue meeting	The first meeting started with elevator pitches of the research projects, followed by discussion, in sub-groups, of the research topics.
2	20-05-2015	Self-reliance and quality of life	Susanne van den Buuse’s presentation questioned the link made between self-reliance and quality of life for nursing home residents. Afterwards, cases were discussed.
3	01-10-2015	Searching, making and maintaining contact	Annelieke Driessen and Laura Vermeulen addressed questions of maintaining contact with the social and physical world in a life with dementia. The groups looked into normative interpretations and conflicting values around dementia.
4	28-01-2016	Suffering and dementia	Natashe Lemos Dekker and Silke Hoppe spoke to the theme of suffering. Responses to the presentation and personal and shared experiences with suffering were discussed in smaller groups.
5	19-05-2016	Written impressions	Paula Irik and Irene Kruijssen collected utterances of people with dementia, which they called ‘diamonds’. With participants they discussed how these ‘diamonds’ affect their readers.
6	29-09-2016	Daily wanting in dementia care	Annelieke Driessen presented what care workers deem ‘good’ in care encounters in which people with dementia want something other than their carers, providing examples from her fieldwork (Driessen 2017). Group discussions touched on the role of family members and the specificities of dementia care.
7	27-10-2016	The Dementia Social Trials	Hugo van der Wedden presented the applied work conducted by Anne-Mei The. He discussed how stories collected in ethnographic studies were transformed into interventions for a social trial in dementia care.
8	01-12-2016	‘Measuring’ versus ‘knowing’ in dementia care	Laura Vermeulen, Marjon van den Broek, Bart Niek van der Zedde and Titia Daniels discussed what ‘knowing’ may mean in the home setting of a person with dementia. Bringing together examples from their work in different disciplines, they explored with the group a case in which the outcomes of ‘knowing on the basis of experience’ and ‘measuring’ conflicted.

9	29-01-2017	Picturing dementia	Following the publication of a newspaper article written by Laura Vermeulen and Mart Vegt (Vermeulen 2016), which featured an othering picture, this evening addressed how people with dementia are depicted in images. Facilitated by Annelieke Driessen, Laura Vermeulen and Els Roding, participants experimented with drawings and text, and questioned how minority groups could be depicted without relying on stereotypes.
10	16-02-2017	End of life with dementia	Natashe Lemos Dekker and Mieka Vroom touched on trust, powerlessness and uncertainty at the end of life with dementia. The group explored how, without trying to find one single narrative, different realities can be acknowledged and given space.
11	16-03-2017	Tensions in life and work with dementia	Annelieke Driessen and Kristine Krause introduced a list of 'burning issues' in the lives of those who work and live with dementia. Seated in a circle, the group refined the list, added issues that were consequently prioritised, and discussed issues such as the tension between safety and freedom.
12	13-04-2017	Sharing experiences	Silke Hoppe presented on empathy and sharing experiences in the context of her research on early-onset dementia (Hoppe 2018a). The groups discussed how they reached understanding using the method of the Socratic dialogue.
13	23/24-06-2017	Dementia and the good life	During this two-day participatory conference, PhD candidates and dialogue evening participants held workshops together on the topic of their joint dialogue evenings project and PhD candidates' studies for a broad audience from the field. How is a good life with dementia done?
14	14-09-2017	Fireplace meeting	The conference was evaluated, and initial ideas for this article were discussed.
15	08-11-2018	The dialogue paper	After a presentation of the overall argument of this article, each group took up one part of the argument, discussing its validity and sharing additional reflections. Participants also decided they wanted to continue with the dialogue meetings, joining the PhD candidates in organising them.
16	11-01-2019	Mart's wish for euthanasia	This meeting was issued by Mart Vegt. With the support of Kristine Krause, Laura Vermeulen, Margriet de Zwart and Leny van Dalen, Mart told the audience of his wish for euthanasia. The audience asked questions and shared similar and alternative outlooks on life.
17	28-03-2019	Mutual dependency in care relations	Silke Hoppe discussed literature and personal experiences on the topic of dependency. For the first time, the dialogue meeting took place in a nursing home. Participants discussed their experiences with asking for and providing help.
18	11-04-2019	Do people with dementia speak 'Dementees'? Paradoxes of recognition	Kristine Krause, Irene Kruijssen, Paula Irik and Laura Vermeulen discussed how to open up spaces for equality without exacerbating differences. This question was explored, taking as a case Paula and Irene's plea to recognise utterances of people with dementia as a language in its own right.
19	23-05-2019	Silence and 'doing nothing'	Dominant imaginaries depict nursing homes as places where 'nothing' happens. Based on her fieldwork, Ilja Brugman invited participants to observe life on the ward and to reflect together on the many ways they had observed of making contact.
20	13-06-2019	Intimacy	Margriet de Zwart, Rita Slooten, Laura Vermeulen and Kristine Krause reflected together with participants on how boundaries in intimacy and sexuality change throughout the life-course and with dementia.

cupational therapists, policy-makers, journalists, social scientists and anyone else with an interest in the evening's topic. Amongst the participants, ranging from 20 to 30 on different evenings, were first-time attendees as well as regulars. The organisers tried to make the invitees feel welcome by greeting them with a cup of soup, involving them in a chat and introducing participants to each other.

Most evenings followed a similar format: At 7:00 pm, the speaker(s) of the evening – one or two researchers, sometimes together with a colleague or person from the field – gave a short presentation (see Table 1 for an overview). The topics were inspired by the researchers' projects, and included work in progress. With input from the evenings, this work developed into articles on independence and self-reliance (Van den Buuse 2016) [2], empathy (Hoppe 2018a) [12], free will and 'wanting' in daily dementia care encounters (Driessen 2017; Driessen et al. 2017) [6], end of life (Lemos Dekker 2018) [10], and stillness and remaking worlds (Vermeulen 2018) [8].

While particular topics drew people with specific interests, we realised that the format and the space created for exchange was far more important than the topics themselves. During the presentations, questions and feedback were explicitly welcomed, but the in-depth dialogue began after the break in smaller groups, each led by one of the organisers, in which material from the presentation was discussed. In these groups, '[a]ll [had the] right to speak and all [were] also equally responsible for listening' (Pradhan and Singh 2016: 265). In a concluding plenary, each group shared their insights with the others. The evening usually closed with an announcement of the programme for the following months and a thank you to all participants. Some evenings had more experimental formats; for example, during the evening in which we explored the impact of images, we sorted images for text and wrote text to go with images [9].

Learning Together through Complexity

While the PhD candidates initially assumed that they would have to simplify issues and avoid the anthropological reflex to complexify phenomena (Law 2004), the invitees made them realise that complexity was exactly what they valued. Dementia case manager Iris Oosterhoff said in one of the first meetings: 'I don't want bullet points, I want the mess'.⁸ She explained that simplifying was something she did every day at work, where she had to take quick decisions and provide answers, whereas dementia

care in her opinion is about tensions and ambiguities. During the telephone evaluation, Iris explained how the open exploration of topics in the meetings appealed to her:

It was about the process and not about the outcome. And this is very important, because once one focuses on the outcome one cannot explore topics freely anymore. Considering the research questions together in an open-ended manner during the evenings invited us to engage in an open dialogue and gain new insights into the process. . . . We need more of this exploratory listening and dialogue in dementia care.

The organisers tried to facilitate this open exploration of topics in the group work using a method called 'Socratic dialogue'. The approach is to analyse a situation from different angles so that people can place themselves in the situation without judging its different articulations (Kessels et al. 2008). Through this process, participants worked at gaining a deeper understanding of others' stories, experiences and perspectives, which, according to music therapist Anna Leeuwen, led to more respect.

An example where this worked particularly well was the discussion of conflicts in care. After a general discussion, nursing home carers brought in a case. They shared how conflicted they were because a client wanted to wear comfortable jogging pants, while his wife wanted him to wear a new pair of trousers. After listening to their story, Margit Tempelman, a psychiatrist in a managerial position, said that even though she was aware of the complexity of their work, this story brought home to her how torn care workers can feel when facing competing demands under constant time pressure. Other respondents confirmed that becoming aware of the difficulties of other groups was very valuable. As Anne Vermeij, a policy and innovation officer in a care organisation, outlined in the evaluation: 'Our perspective was broadened by being close to patients and family carers. Learning about and becoming more aware of their experiences helps one to stay closer to their needs in one's daily work'.

During the evening when we discussed a draft of this article, spiritual counsellor Astrid Lange pointed out that the format of the dialogue evenings was congruent with the content. Not-knowing and the need to come to terms with ambiguity are typical features of dementia as a complex condition for which there is no treatment. Similarly, the dialogue evenings were not directed towards solutions, and thus allowed for mess, not-knowing and ambiguity (Greenstein et al. 2015). One could say that participants learnt 'doing

complexity' together, which they felt was an unrecognised aspect of their work.

Learning to Relate to Each Other in New Ways

Another articulation of learning was to practice relating differently to each other and to dementia. The dominant image in Dutch society of a person living with dementia is not of someone with whom you could learn together. It is typically of a bed-ridden person receiving institutional care (The 2017), who comes to embody 'the other' in relation to the dominant paradigm of 'active ageing' (Higgs and Gilleard 2015). The dominant discourse on prevention thereby neglects the actual needs of people living with dementia and their carers (Pols and M'charek 2016; The 2017).

The dialogue meetings provided a safe place where daily life issues could be shared. People with dementia and nursing home care workers were engaged with as people to learn from. As many pointed out in the evaluation, the very co-presence (Hastrup 2018) of people from different backgrounds changed the narratives and ways of relating. Differences in education and social status or competition between representatives of different organisations were, for the duration of the evening, often replaced with an emphasis on equality. According to spiritual counsellor Astrid Lange, the dialogue evenings produced non-hierarchical moments in which participants encountered each other as people and not in terms of their roles. Thus, the value of the group was that it offered 'an alternative paradigm to the accepted social order' (De Mendelssohn 2000 qtd. in Vice and Gildenhuis 2016: 103).

The felt absence of hierarchical relations was particularly evident in the positions of people with dementia during the evenings. All but one evaluator especially appreciated the way in which Mart Vegt and Eric van Neure took up their roles during the evenings, reversing the dominant view of people with dementia as pitiful and needy. They enabled this through their open way of communicating. Eric, for instance, often introduced himself with his infectious sense of humour – 'I am Eric, and I have Alzheimer's, so I might have forgotten that I've met you before' – making it easy for everyone to connect with him. He often added that he is dedicated to 'delightful decline'.⁹ By articulating his condition in this way, without denying the difficulties, he created space for practising new ways of relating to dementia. Participants not only gained more understanding, but were able 'to do things differently' in relationships (Vice and Gildenhuis 2016: 117).

Participants also learnt to relate differently to dementia care. Mart, for instance, was introduced to the group by Laura Vermeulen. He had very negative views on nursing homes and regarded care workers as incompetent and even corrupt and care managers as not committed to their work. Listening to care workers' stories, however, altered his view. He could appreciate their hard work more, as he told Marije and Laura. Eric and Mart did not inhabit a position at the margins, but rather took a central position in discussions, and their presence was crucial in creating the evenings' atmosphere.

At another meeting, Mark Smit, one of the PhD candidates, facilitated a group in which Evelyn Vos, whose father lives in a nursing home, met Frank Mulder, her father's physiotherapist [6]. They had never met in person before, but realised that they were speaking about the same man when sharing issues in one of the small groups. Guided by the opening presentation on 'wanting' (Driessen 2017; Driessen et al. 2017), for Evelyn it was an eye-opener to hear Frank speaking about the challenges of his work. Evelyn concluded that possibly she wanted her father to do *too much*. Meeting in a space outside of an institutional care setting made them both relate differently to one another.

While we argue that during the dialogue evenings people from different subject positions met on an equal footing, we also point out that people's different subject positions were fluid and intertwined – a family member of a person with dementia was also a care worker, and a researcher was also the child of someone living with dementia. As we argue below, we consider this fluidity a resource for mutual learning. Participants also became co-organisers of a conference that was put on at the end of the first series of evenings, and they co-authored the conference report.¹⁰

Learning through Taking Ownership

Allowing complexity and relating differently were two articulations of learning. Both enabled participants to take ownership of the meetings by re-formulating 'knowledge about' as 'knowing together' (Freire 2009). This became apparent when, in the last months of the two-year trajectory, something like a group began to evolve. Participants told Marije de Groot in the telephone interviews that they looked forward to seeing each other again. Regular participants felt appreciated by other attendees for simply being present and offering their views. They remembered points that others had raised and started to

build up an informal repository of insights and lessons learnt. In one meeting, the organisers had to improvise because the researcher scheduled to present was sick. They suggested choosing from a list of 'burning issues' [11], which included topics such as the friction between accepting or interfering in a care situation (letting somebody mess around with food or assisting with feeding), whether to care for enjoyment in the moment or for continuity with pre-dementia preferences (enjoying meatballs while having been a vegetarian), and the tension between safety and freedom (letting people wander around) (Driessen et al. 2017). When Annelieke asked for a vote, music therapist Anna Leeuwen raised her hand, pointed to some issues, and said: 'We have worked on those already,' expressing a 'we' in possession of shared knowledge. Other participants joined to take charge and suggested different wordings of the list, thereby re-authoring it. The withdrawal of the central speaker of the evening necessitated a different way of facilitating and simultaneously made a sense of group ownership emerge.

The boundaries between organisers and participants were further blurred as many evenings were planned and facilitated together by a researcher and somebody from their research. Co-presenters included family members, care managers, care workers, spiritual counsellors, physiotherapists, and people with dementia. In a session on end of life, for instance, a daughter presented her thoughts on the death of her mother before the researcher joined in with more general remarks [10]. In another evening on imaginaries around dementia, the researcher presented points which she had prepared together with Mart, one of the participants with dementia [9]. Finally, ownership was taken even more when participants decided that they wanted to continue organising evenings even after the research projects were finished [16–20].

Fostering Collaborative Moments

Enabling Elements

Crafting this space in which people learnt together without looking for straightforward answers and practised relating in new ways did not emerge by itself. In making people feel welcome, many things were mobilised. Prior to the start of each meeting, the organisers carefully prepared the group exercises and ensured a good mixture of stories and visual material. A space was initially provided by the university, and later by the field lab. Crucially, this

space included a kitchen in which snacks, soups and sandwiches could be offered to participants, who came after a long work day and a cycle through rainy weather. Eating together fostered informal conversations and inclusion (Krause and Driessen 2017).

Preparing for the evenings required work, knowledge input, money and infrastructure. The evenings themselves relied on the quality of the relations the researchers had built up during fieldwork and on the willingness of their interlocutors to take part. The organisers evaluated each meeting and accommodated lessons learnt in the next one. These included recognising how chairs and tables could support interactions (placing chairs in a circle invited group members to take over responsibility for the discussion), or how to strike a proper balance between general and personal knowledge in opening the meetings.

The make-up of the group was also subject to care. Bringing people of diverse backgrounds together was possible because the researchers knew most of the participants from their research. Both the academic field lab and the researchers helped to recruit people by circulating invitations via their mailing lists, via Twitter and via word of mouth, and participants brought others along.

Relating to each other in new ways became possible because participants dared to open up. The basis for this openness were the shared experiences of the continuing changes and losses associated with dementia. As participants pointed out during the feedback session on this article [15], dementia is particular because it invites a continuous process of learning. Against this background, the core group of invitees who were part of the dialogue evenings from the start dared to share their stories about their work, their families and their private lives. Some invitees had begun to trust the researchers during interviews and expanded their 'fieldwork trust' to the others and to the dialogue evenings. At the same time, the relations between some of the researchers and their interlocutors became stronger because of the evenings.

The open exploration of topics was further enabled by the kind of material presented. In the evaluation, invitees said that the ethnographic vignettes taught them to see 'layers of reality' that they were previously unaware of. Marijke Schoonhoven, policy officer in a care organisation, explained in the evaluation that learning about the daily lives of people with dementia in Laura's presentation [8] taught her how much support was already in place in people's neighbourhoods. Supporting people to maintain

these relationships could be more helpful than offering 'day care' in another part of the city, she realised. But participants also valued the theoretical input that the researchers offered in the beginning of most sessions. Initially, some of the organisers felt uncomfortable about this part, because they felt that it created distance and hierarchy. Over time, however, the organisers realised that the theoretical input did some other work than just representing content. Overviews of research findings or reflections from literature prepared a common ground for discussing cases and for personal explorations in smaller groups. It offered a mode of thinking which allowed cases to be discussed not so much as examples that had to be judged but as ways to convey what they taught participants about the session's central theme. This became apparent during a meeting on 'understanding' and 'measuring' [8]. In the discussion, some participants wanted to evaluate cases according to notions of 'good care'. Bringing attention back to the evening's introduction, in which normative evaluations were questioned, participants were able to explore different perspectives rather than evaluate them. The balance between general and personal knowledge enabled a non-judgemental atmosphere in which participants felt safe to share worries and concerns.

Furthermore, the organisers invested in making the dialogue evenings accessible for everyone. They worked on their relationship with each participant and made sure that people felt welcome and appreciated (Mckillop and Wilkinson 2004). On the one hand, this meant catering for particularities. Laura made phone calls ahead of time to organise transport, or travelled together with Eric and Mart. On the other hand, ensuring that everyone felt welcome meant allowing for positionings to stay fluid throughout the meetings. It helped that participants with dementia were very explicit about how they wanted others to relate to them. Eric, for instance, voiced that he wanted people to respond to his needs as intuitively as possible (Vermeulen 2016). The stories of participants with dementia were often seen as inspiring, something that posed the danger of reproducing 'inspiration porn' (Young 2014): the tendency to objectify disabled people for the benefit of people without a disability (Grue 2016). In order to counter this danger, people with dementia often spoke not only as 'experiential experts', but also in other roles. Eric, for instance, spoke as a son when retelling how his father had died, and Nella Sterre talked about experiences with intimacy in her early twenties. Another way in which we countered the separation

between people with and without dementia was to encourage participants to think with their own possible futures with dementia, and not just with experiences they had as professionals or family members.

Challenges

Facilitating the dialogue evenings was not all easy and positive. As the focus of the evenings slowly shifted, the PhD candidates had to learn along the way. Too much of a dialogical format, they discovered, also had a downside: some participants stopped attending because they sought the kind of knowledge transfer that the meetings were slowly moving away from. In addition, while most people valued the space for reflection and dialogue, others were reluctant to share personal experiences and did not like the parts of the programme that felt like a 'compulsory confession' to them.

This divide became bigger when new participants joined in larger numbers in 2019. In order to cater for newcomers who were not yet familiar with the shared learning that had taken place, the organisers realised that it was crucial to strike a balance between presenting general knowledge (analytical work, an overview of findings, or a literature review) and personal stories. This, in turn, required more preparation work when a topic was not owned by the researchers, but issued by a co-presenting participant. This challenge became obvious during a session on intimacy initiated by participants [20]. In preparation of the meeting, the organisers identified 'boundary work' as connecting the personal examples brought in by a woman with dementia and two carers. None of the presenters, however, had done research on the topic, and there was little preparation time. Hence, there was only a brief mention of the topic, and no general introduction. While the session was appreciated by participants, the organisers and presenters felt insecure when moderating the discussion; one reason for this was that it had not been possible to link personal stories through an analytical focus.

It was particularly difficult to prepare presentations suitable for people with such different backgrounds. Although the question of how to do justice to the different experiences of those in the room was an ongoing concern, it was not possible to completely include everybody. While the organisers were happy that Eric and Mart could participate, the evenings were less accessible to interlocutors living with more advanced dementias. Initially, this was also due to the location of the meeting. When meetings were held at nursing homes in 2019, the organisers realised that the length of the sessions and the predominantly dis-

cussion-based format allowed people with advanced dementias to participate in the sessions' socialities, but less so in their substantive explorations.

Another challenge was group members' eagerness to give people with dementia space to talk. This meant that family members were possibly silenced when it came to expressing the difficulties they encountered. In her research on early-onset dementia, Silke Hoppe, for instance, learned a lot about the pain and difficulties of family members caring for a loved one with dementia (Hoppe 2018b). Finding it inappropriate to discuss this in the presence of people with dementia, she chose instead to problematise talking about suffering [12].

We do not claim to have achieved full inclusivity in the dialogue evenings. Rather, we aim to show how moments of inclusion became possible, and how they could be hindered. Who was included and excluded was thus constantly shifting. The point perhaps is to continuously aim for more inclusivity, while acknowledging that full inclusion is impossible.

Conclusion

While the organising team started the dialogue evenings based on the widely shared assumption that knowledge can be handed over to, or discovered by, invitees, they learnt together with the participants that creating room for complexity and making space for a diverse group of people resulted in talking and relating differently to each other and allowing moments to emerge 'where new understanding may occur . . . and unexpected connections emerge' (Hastrup 2018: 321). New understandings and connections were forged in moments when people who were situated very differently within the field of dementia care began to relate to each other outside of their established positions. In these moments of 'knowing something with others' (De Maré 1985 qtd. in Vice and Gildenhuis 2016: 119), not only did the dichotomy between researcher and researched collapse, but also those between 'carers' and 'cared for', 'informal' and 'formal' carers, and formal carers and managers. To reach these learning moments, participants engaged in analytical labour together while becoming 'jointly responsible for a process in which all [grew]' (Freire 2009: 80). One could argue that learning together and practising relating differently to each other was actually a way of doing dementia care differently. In this sense, we practised social learning as defined by Mark Reed and colleagues (2010) as a change in understanding that goes beyond

the individual and which is situated in a wider social context.

We have drawn on the notion of moments to highlight three different articulations of learning, which we have proposed to see as collaborative work. We suggest thinking in moments because the research projects were not set up collaboratively from the start, but something like collaboration happened in the restricted time frame of the dialogue evenings. 'Thinking in moments', 'partnership' and 'collaboration' could thus be conceived not as closed constructs or conditions, but as vulnerable, momentary achievements. As Janelle Taylor argues, they can become 'boundary objects' (Star and Griesemer 1989 qtd. in Taylor 2018: 1) that are loose enough to allow people to connect with the project according to their needs and preferences, but also robust enough to maintain a shared point of reference. In many cases, the ideal of collaboration might not be realisable (see Heckler and Russell 2008), but we argue that *collaborative moments* can be enabled with some work and with the luck to have inspiring, committed participants.

Second, building on Hastrup (2018), we find it helpful to think with collaborative moments, instead of talking of collaborative research, to describe what emerged within the dialogue evenings. We know very little about what happened outside the meetings, nor do we pretend to have actually improved dementia care by facilitating the evenings. But for the restricted time frame of the evenings, family members and care professionals were experts thinking with each other and many of those present experienced relating differently to one another. Thinking in terms of moments rather than in fixed formats allows us to highlight these temporary, vulnerable achievements and to acknowledge the limitations of the dialogue evenings whilst thinking about the potential that comes along with anthropological fieldwork.

Third, in agreement with Alaka Wali (2006: 6) we think that there was an 'underlying spirit . . . of working, learning, and moving toward positive social change together' (qtd. in Lassiter 2008: 73), which nurtured the emergence of collaborative moments. During the meeting in which we discussed a draft of this article, one invitee stated that he always kept something from the energy of the evenings and another participant chose the term 'magic' to describe such shared moments. Thus, using the concept of moment also allows space for the out-of-the-ordinary, or for 'transgressive occasions', as described by Hastrup (2018: 318).

In this article, we identified various enabling elements that made collaborative moments possible: the

specific quality of the fieldwork relationship, particular discussion materials, organisations that could offer a space and a network, funding that enabled us to offer food and refreshments, and a research team studying the same topic and sharing tasks and responsibilities. There were, however, also restrictions, such as the fact that doing the dialogue evenings did not count for completion of the PhD projects and that funding from the university stopped once the PhD funding ended. We nevertheless see a clear role for academic anthropology emerging: it is easy to be critical of the university as an ivory tower that does not produce solutions for real-world problems or to see the university as applying the ‘banking concept of education’ (Freire 2009; Greenstein et al. 2015). Also, with current budget cuts, it might be hard to invest ‘time and resources in activities that might not be immediately translatable into measurable outcomes, such as getting to know one another and building trust’ (Greenstein et al. 2015).

We believe, however, that letting people from the field partake in our luxury of having time to see more complexity instead of less – and not having to solve it – can be an important contribution of the university. Thus, we would argue that in order to become applied, anthropologists do not have to simplify issues; rather, they have to provide space and time for people to think by themselves. In so doing, academic work can become a place to practice relating differently. In this new way of relating, knowledge can be produced jointly and frictions can be held together.

Acknowledgements

First and foremost, we want to thank all participants in the dialogue evenings for their openness, their engagement and for sharing their thoughts on this article. We would like to thank five participants in particular. Irene Kruijssen, Paula Irik, Margriet de Zwart, Eric van Neure and Mart Vegt’s commitment to the dialogue evenings has been crucially supportive in our organising of the evenings. We are grateful for the comments on the article that we received from Susanne van den Buuse, Natashe Lemos Dekker and the Writing Care Group at the Anthropology Department of the University of Amsterdam. The dialogue evenings on which this article is based were funded by the Dutch Ministry of Health, the Gieskes-Strijbis Foundation, the care organisation Cordaan, and the Research Priority Area Global Health, University of Amsterdam. The location for the dialogue evenings was kindly provided by the Ben Sajetcentrum.

SILKE HOPPE is a PhD Candidate at the Long-Term Care and Dementia Partnership at the Anthropology Department of the University of Amsterdam. Her dissertation research focuses on the experiences of people with early-onset dementia and their families in the Netherlands. E-mail: s.c.hoppe@uva.nl
ORCID: <https://orcid.org/0000-0002-7438-4153>

LAURA VERMEULEN is a postdoctoral research fellow at the University of Amsterdam and programme coordinator at the Ben Sajet Centre. She conducts an applied study on network approaches in community care. For her doctoral thesis she draws on critical phenomenology to study stillness and responsiveness in the lives of community dwelling people with dementia. E-mail: l.h.vermeulen@uva.nl
ORCID: <https://orcid.org/0000-0002-7908-5304>

ANNELIEKE DRIESSEN (PhD, 2019) is a Research Fellow at the London School of Hygiene and Tropical Medicine as part of the Forms of Care project team, where she conducts an ethnography of palliative care and ‘active non-interventions’. Her doctoral research explored the enactment of ‘interesting subject positions’ for people with dementia in everyday life and care in Dutch nursing homes.
E-mail: annelieke.driessen@lshtm.ac.uk
ORCID: <https://orcid.org/0000-0001-5627-1684>

ELS RODING is a Research Degree Student at the London School of Hygiene and Tropical Medicine. She is interested in the organisation of care and forms of collaborating with ‘the field’. Her previous projects were about dementia care and occupational physicians. In her doctoral research, funded by the Wellcome Trust, she studies care and time in pressure ulcer prevention and management.
E-mail: els.rodin@lshtm.ac.uk
ORCID: <https://orcid.org/0000-0001-8293-1674>

MARIJE DE GROOT worked as a Research Assistant in Medical Anthropology and Global Health, with a main focus on elderly people being tired of living and their wish to die. In addition, she has published on social egg freezing in the Netherlands and as a co-author on community health in Uganda.
E-mail: marijedegroot88@gmail.com
ORCID: <https://orcid.org/0000-0001-6424-9436>

KRISTINE KRAUSE is Assistant Professor in the Anthropology Department at the University of Amsterdam. Her research interests include political subjectivities and health, citizenship, and care. She has published

on transnational therapy networks and the intersections of medicine and religion in global Pentecostalism. Currently, she is developing new research on care outsourcing. E-mail: k.krause@uva.nl
ORCID: <https://orcid.org/0000-0003-1339-0450>

Notes

1. We draw from different theoretical traditions that might not necessarily align easily but that share similar political points. This corresponds with the varied approaches of the authors.
2. The partnership was directed by Robert Pool and Anne-Mei The: <http://partnershipforcare.uva.nl/>. The dialogue evenings developed from a course entitled 'Voices Out of Order', in which anthropologists and practitioners discussed the challenges of caring for, and doing research with, people who do not produce coherent narratives. The mixed group that emerged called itself the 'Amsterdam Care Collective' (2018) and co-organised a large closing conference titled 'Dementia and the Good Life' (www.medanthrotheory.org/read/10021/dementia-and-the-good-life). At the university level, the group was led by Jeannette Pols and Kristine Krause.
3. The organising team consisted of PhD candidates Silke Hoppe, Laura Vermeulen, Annelieke Driessen, Natashe Lemos Dekker, Susanne van den Buuse and Mark Smit; assistant professor Kristine Krause; and Master's student Els Roding.
4. We use the term 'invitees' to refer to those invited for the evenings. We use 'participants' to refer to both the invitees and the organising team. We do not speak of people with dementia separately, because we think that this incorrectly establishes them as different from the others.
5. Stuart Hall (Hall and Grossberg 1996: 141ff.) and Donna Haraway (2004: 83) both use the term 'articulation' to denote the joining of disparate and unequal connections.
6. This included notes of members of the organising team who did not co-author this article.
7. The Ben Sajatcentrum (www.bensajetcentrum.nl/ben-sajet-werkplaatsen) aims to improve links between academia, education and care-providers.
8. All invitees' names are pseudonyms, except for Eric and Mart (though Mart's last name is a pseudonym). With permission from the presenters, we did not anonymise the names used in the table.
9. In Dutch: 'vrolijk verval'. In 2018, a documentary on Eric's life came out on Dutch television (see www.maxvandaag.nl/programmas/tv/een-poging-tot-vrolijk-verval). For a short film featuring Eric's approach, see www.youtube.com/watch?v=CNPJo4YrL2M&feature=youtu.be.
10. www.medanthrotheory.org/read/10021/dementia-and-the-good-life.

References

- Amsterdam Care Collective (2018), 'Dementia and the Good Life: Collaborations with the Field', *Medicine Anthropology Theory*, www.medanthrotheory.org/read/10021/dementia-and-the-good-life, accessed 24 August 2019.
- Cadena, M. de la (2015), *Earth Beings: Ecologies of Practice across Andean Worlds* (Durham, NC: Duke University Press).
- Casas-Cortes, M. I., M. Osterweil and D. E. Powell (2008), 'Blurring Boundaries: Recognizing Knowledge-Practices in the Study of Social Movements', *Anthropological Quarterly* 81, no. 1: 17–58, doi:10.1353/anq.2008.0006.
- Crapanzano, V. (1990), 'On dialogue', in *The Interpretation of Dialogue*, (ed.) T. Maranhao (Chicago: University of Chicago Press), 269–291.
- De Maré, P. B. (1985), 'Large Group Perspectives', *Group Analysis* 18, no. 2: 79–92, doi:10.1177/053331648501800203.
- De Mendelssohn, F. (2000), 'The Aesthetics of the Political in Group Analytic Process – The Wider Scope of Group Analysis', *Group Analysis* 33, no. 4: 438–458, doi:10.1177/05333160022077506.
- Dewing, J. (2007), 'Participatory Research: A Method for Process Consent with Persons who Have Dementia', *Dementia* 6, no. 1: 11–25, doi:10.1177/1471301207075625.
- Driessen, A. (2017), 'Sociomaterial Will-Work: Aligning Daily Wanting in Dutch Dementia Care', in *Care in Healthcare: Reflections on Theory and Practice*, (eds) F. Krause and J. Boldt (New York: Palgrave Macmillan), 111–133.
- Driessen, A., I. van der Klift and K. Krause (2017), 'Freedom in Dementia Care? On Becoming Better Bound to the Nursing Home', *Etnofoor* 29, no. 1: 29–41, <https://www.jstor.org/stable/44318093>.
- Fabian, J. (1990), 'Presence and Representation: The Other and Anthropological Writing', *Critical Inquiry* 16, no. 4: 753–772, doi:10.1086/448558.
- Freire, P. (2009), *Pedagogy of the Oppressed*, 30th ed. (New York: Continuum).
- Greenstein, A., C. Blyth, C. Blunt, C. Eardley, L. Frost, R. Hughes, B. Perry and L. Townson (2015), 'Exploring Partnership Work as a Form of Transformative Education: "You Do Your Yapping and I Just Add

- in My Stuff"', *Disability Studies Quarterly* 35, no. 2, doi:10.18061/dsq.v35i2.4653.
- Grue, J. (2016), 'The Problem with Inspiration Porn: A Tentative Definition and a Provisional Critique', *Disability & Society* 31, no. 6: 838–849, doi:10.1080/09687599.2016.1205473.
- Hall, S. and L. Grossberg (1996), 'On Postmodernism and Articulation: An Interview with Stuart Hall', in *Stuart Hall: Critical Dialogues in Cultural Studies*, (ed.) S. Hall, D. Morley and K.-H. Chen (London: Routledge), 131–150.
- Haraway, D. (1988), 'Situated Knowledges: The Science Question in Feminism and the Privilege of Partial Perspective', *Feminist Studies* 14, no. 3: 575–599, doi:10.2307/3178066.
- Haraway, D. (2004), 'The Promise of Monsters', in *The Haraway Reader*, (ed.) D. Haraway (New York: Routledge), 63–124.
- Hastrup, K. (2018), 'Collaborative Moments: Expanding the Anthropological Field through Cross-Disciplinary Practice', *Ethnos* 83, no. 2: 316–334, doi:10.1080/00141844.2016.1270343.
- Heckler, S. and A. Russell (2008), 'Confronting Collaboration: Dilemmas in an Ethnographic Study of Health Policy Makers', *Anthropology in Action* 15, no. 1: 14–21, doi:10.3167/aia.2008.150104.
- Higgs, P. and C. Gilleard (2015), *Rethinking Old Age: Theorising the Fourth Age* (London: Macmillan Publishers).
- Hoppe, S. (2018a), 'A Sorrow Shared Is a Sorrow Halved: The Search for Empathetic Understanding of Family Members of a Person with Early-Onset Dementia', *Culture, Medicine and Psychiatry* 42, no. 1: 180–201, doi:10.1007/s11013-017-9549-4.
- Hoppe, S. (2018b), 'Burning Down the House: When Crisis Becomes Daily Life in Early-Onset Dementia', *Somatosphere*, 24 September, <http://somatosphere.net/2018/burning-down-the-house-when-crisis-becomes-daily-life-in-early-onset-dementia.html/>.
- Johannsen, A. M. (1992), 'Applied Anthropology and Post-Modernist Ethnography', *Human Organization* 51, no. 1: 71–81, doi:10.17730/humo.51.1.t62123516285r644.
- Kessels, J., E. Boer and P. Mostert (2008), *Vrije ruimte praktijkboek: Filosoferen in organisaties* [Book of practice: Philosophising in organisations] (Amsterdam: Boom uitgevers).
- Krause, K. and A. Driessen (2017). 'Soep doet goed! Werkplaatsen om samen te denken, te spreken . . . en te eten' [Soup does good! Work places to think, speak and eat together], in *Goed leven met dementie* [Good life with dementia], (eds.) A.-M. The, R. Pool and J. Pols (Amsterdam: Ban Sajat Centrum), 85–89.
- Lamphere, L. (2018), 'The Transformation of Ethnography: From Malinowski's Tent to the Practice of Collaborative/Activist Anthropology', *Human Organization* 77, no. 1: 64–76, doi:10.17730/1938-3525.77.1.64.
- Lassiter, L. E. (2008), 'Moving Past Public Anthropology and Doing Collaborative Research', *NAPA Bulletin* 29, no. 1: 70–86, doi:10.1111/j.1556-4797.2008.00006.
- Law, J. (2004), *After Method: Mess in Social Science Research* (London: Routledge).
- Lemos Dekker, N. (2018), 'Moral Frames for Lives Worth Living: Managing the End of Life with Dementia', *Death Studies* 42, no. 5: 322–328, doi:10.1080/07481187.2017.1396644.
- Low, S., S. Merry, M. Goodale, C. Lutz, J. Peacock and D. Price (2010), 'Engaged Anthropology: Diversity and Dilemmas: An Introduction to Supplement 2', *Current Anthropology* 51, no. 2: 302–326, doi:10.1086/653837.
- Marcus, G. E. (2002), 'Beyond Malinowski and after Writing Culture: On the Future of Cultural Anthropology and the Predicament of Ethnography', *Australian Journal of Anthropology* 13, no. 2: 191–199, doi:10.1111/j.1835-9310.2002.tb00199.x.
- Mckillop, J. and H. Wilkinson (2004), 'Make It Easy on Yourself: Advice to Researchers from Someone with Dementia on Being Interviewed', *Dementia* 3, no. 2: 117–125, doi:10.1177/1471301204042332.
- Peacock, J. L. (1997), 'The Future of Anthropology', *American Anthropologist* 99, no. 1: 9–17. <https://www.jstor.org/stable/682128>.
- Plows, A. (2018), *Messy Ethnographies in Action* (Wilmington, DE: Vernon Press).
- Pols, J. (2014), 'Knowing Patients: Turning Patient Knowledge into Science', *Science, Technology, & Human Values*, 39, no. 1: 73–97, doi:10.1177/0162243913504306.
- Pols, J. and A. M'charek (2016), 'Responsible Innovation: The Case of Alzheimer Diagnostics', in *Emerging Technologies for Diagnosing Alzheimer's Disease: Innovating with Care*, (eds.) M. Boenink, H. van Lente and E. Moors (London: Palgrave Macmillan), 205–224.
- Pool, R. (1994), *Dialogue and the Interpretation of Illness: Conversations in a Cameroon Village* (Oxford: Berg).
- Pradhan, J. K. and S. Singh (2016), 'Learning to Learn from the Other: Subaltern Life Narrative, Everyday Classroom and Critical Pedagogy', *Prose Studies* 38, no. 3: 261–270, doi:10.1080/01440357.2017.1290601.
- Reed, M. S., A. C. Evelyn, G. Cundill, I. Fazey, J. Glass . . . and L.C. Stringer (2010). 'What Is Social Learning?', *Ecology and Society* 15, no. 4, www.ecologyandsociety.org/vol15/iss4/resp1/.

- Star, S. L. and J. R. Griesemer (1989), 'Institutional ecology, "Translations" and Boundary Objects: Amateurs and Professionals in Berkeley's Museum of Vertebrate Zoology, 1907-39', *Social Studies of Science* 19, no. 3: 387-420, <https://www.jstor.org/stable/285080>.
- Taylor, J. S. (2018), 'What the Word "Partnership" Conjoins, and What It Does', *Medicine Anthropology Theory* 5, no. 2: 1-6, doi:10.17157/mat.5.2.526.
- The, A.-M. (2017), *Dagelijks leven met dementie: Een blik achter de voordeur* [Daily life with dementia: Looking behind the curtain] (Amsterdam: Uitgeverij Theoris).
- Van den Buuse, S. (2016), 'Conflicting Interpretations of the Concepts 'Self-Reliance' and 'Resident Control' after their Introduction in a Dutch Nursing Home', *Irish Journal of Anthropology* 19, no. 1: 12-18.
- Vermeulen, L. (2016), Mensen helpen met dementie: Hoe moet dat eigenlijk? [Helping people with dementia: But how?] *Het Parool*, 21 September, <https://www.parool.nl/columns-opinie/mensen-helpen-met-dementie-hoe-moet-dat-eigenlijk~b7005232/?referer=https%3A%2F%2Fwww.google.com%2F>.
- Vermeulen, L. (2018), 'Folding Time: Walk-Talking Joint Moments in the Nursing Home', *Somatosphere*, 17 September, <http://somatosphere.net/2018/folding-time-walk-talking-joint-moments-in-the-nursing-home.html/>.
- Vice, H. and A. Gildenhuis (2016), 'Reshaping Social Identity: A Qualitative Report on Experiences in an Interracial Median Group', *Group Analysis* 49, no. 2: 101-123, doi:10.1177/0533316416639206.
- Wali, A. (ed.). (2006), *Collaborative Research: A Practical Introduction to Participatory Action Research (PAR) for Communities and Scholars* (Chicago: Field Museum).
- Warry, W. (1992), 'The Eleventh Thesis: Applied Anthropology as Praxis', *Human Organization* 51, no. 2: 155-163. <https://www.jstor.org/stable/44126722>.
- Woelders, S., T. Abma, T. Visser and K. Schipper (2015), 'The Power of Difference in Inclusive Research', *Disability & Society* 30, no. 4: 528-542, doi:10.1080/09687599.2015.1031880.
- Young, S. (2014), "'I'm Not Your Inspiration, Thank You Very Much', *TED*. www.ted.com/talks/stella_young_i_m_not_your_inspiration_thank_you_very_much, accessed 24 August 2019.