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Thinking with Dementia. An introduction to the series

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Thinking with Dementia

Edited by Krause, Kristine; Pols, Jeannette; Driessen, Annelieke and Yates-Doerr, Emily

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Stories about time shifted, folded and shared, the extraordinary ordinary, and keeping separate and being a-part.

★ September 10, 2018

Thinking with dementia. An introduction to the series

By Jeannette Pols, Kristine Krause, Annelieke Driessen and Emily Yates-Doerr

Fourteen stories

This series is a collection of fourteen stories that are written to ‘think with dementia’. Over the past three years, six PhD students from the anthropology department at the University of Amsterdam have conducted ethnographic research on dementia care in the Netherlands. When the PhD projects came to a close, we organised a workshop to bring our work on dementia in conversation with the work of other researchers.^[1] Some of our guests were specialists on dementia, but we deliberately put them in conversation with academics who were not dementia experts to find new ways of addressing the topic. We asked all involved to write stories that reflect on, make present, or imagine ways to live with dementia. During the workshop we re-wrote these stories, and after the workshop we re-wrote them once again, while collectively arranging them into the series that follows.

Some stories ask what the daily lives of dementia can teach us about mundane situations, the things we take for granted. Other stories explore the orienting force of time in our lives. Still others recount what it means to participate in conversations and encounters, what it implies to remember or reminisce, and how objects figure in these memory practices. The stories often focus on seemingly small details. In doing so, they concurrently address ‘big questions’, such as imagining a life ending with dementia, suffocating from despair in a life that becomes unmanageable, or drowning in an unbearable everydayness of life. The stories offer ways to speak about the unspeakable and find out what this is, as it is often hidden in



everyday routines and gestures, words and feelings. Crucially, they show what may happen when the everyday loses its self-evidence and what new things we can recover from this loss.

Uttering the inarticulate

By thinking *with* rather than *about* we do not discuss policy problems, medical research or other well-articulated issues. We set off from an ethnographic tradition, narrating events that have struck us, but for which we have to yet find words to articulate what they teach us. We make use of the genre of the story, since stories are semiotically open-ended things; things without fixed meanings that can take different directions, convey different moods, or stir different activities. What a story does overflows the comprehension of the author, and perhaps the reader too.

By design, our stories are not theoretical exposés, but take the shape of ethnographic accounts, poetic contributions, puzzling situations, or impressions. Individually, they provide no answers or arguments, but present thoughts and images, or convey feelings. They experiment with different styles in between matter-of-fact representations and poetic impressions. Our pieces are trying out the possibilities of story-telling and story-learning alike, giving us new ways to think with our lack of words.

An anthropology of care

In using stories to articulate new connections, this collection is part of a larger endeavour to open up matters of care that are in urgent need of careful words, especially when it is a struggle to find them. These stories are part of the larger project of an *anthropology of care* that aims to address topics that matter to those concerned, and in doing so make them matter to others as well. Stories contrast with other stories and trigger unexpected reflections. Much scientific investment is being made to find the cure to make dementia go away. Our project, we hope, is focused on interesting and helpful ways to respond to dementia in its everyday occurrence. In this way, it is less about cure-seeking than it is like a cooking pot: fusing particular tastes, smells and textures, and inviting new mixes of ingredients. We hope our readers will take what we have made here and add, adjust and spoon in new ingredients in new ways.

Organisation

Over the course of the workshop, we grouped our stories into three themes, and these three themes are what structure this series. Each thematic section is accompanied by a refraction that does not present theories we ‘knew all along’, but was written *after* the stories. We worked from the bottom up (although this turned out to be quite a challenge, with bookcases of theory ready to run with). These reflective readings are, out of necessity, reductions; or rather they are specifications of the richness of the stories, following some streams of thought rather than others. Our conclusions aim to find ways to make sense of the stories and to temporarily tame some of their ambiguities. But we also invite different specifications—those we cannot quite yet think, but may soon.

The first theme is *time*. This elusive concept takes concrete forms in our daily lives. But what happens when time stops being taken for granted? Thinking with dementia helps us to see how we bridge different asynchronicities in practice, folding different times and places

together. We do this without much trouble. But what happens when boundaries become more inflexible and connections between now and then become fragile? Is there still a possibility to create some shared reality?

The second theme is *daily life*, a key term in ethnographic studies about care for diseases that do not go away. It is a term that is at once simple to understand, and which evokes a lot of complexity when things start to falter. Or the reverse: it leads to a lot of difficulties when it is not, or no longer, problematised.

The third theme is *participation*, a notion that is per definition central to the social sciences. How are possibilities for participation altered when dementia comes into play? How do particular repertoires of participation change what it means to participate? What size do the worlds have we participate in, and how may we prevent them from shrinking, or becoming unshared?

Dementia as an inspiration?!

We invite readers on a journey of ‘tasting stories’ that link, more or less obviously, to dementia. We attempt to put dementia on the agenda in a way that provides inspiration for ethnographers and others interested in, or engaged by, dementia—and those who are just encountering the topic. If dementia is indeed becoming a part of so many lives, it is high time that we reflect on what this actually means to those lives, how ethnographic work may respond and relate to these lives, how to represent and study them, and even how dementia may help ethnographers to think differently about other fields of study. So yes, in this collection we dare to take dementia as an inspiration! We invite you, the reader, along on this path that is full of surprises; to wander with us, and add to our project of thinking with dementia.

The workshop ‘Thinking with Dementia’ that gave rise to this publication took place in June 2017 at the University of Amsterdam. This collection is the outcome of joint and indivisible work. Kristine Krause and Jeannette Pols developed the idea for this project in conversation with members of the Long Term Care and Dementia research group (Susanne van den Buuse, Annelieke Driessen, Silke Hoppe, Natashe Lemos Dekker and Laura Vermeulen). Kristine and Annelieke developed a workshop format based on stories, organised the workshop, and took care of the conditions for this publication. Contributors commented on each other stories and discussed the issues which are now assembled in the refractions. Jeannette helped to organise and chair the workshop, and is responsible for re-writing the mostly rather scattered notes that the participants wrote up in groups, into four refractions. Emily Yates-Doerr gave invaluable feedback and brushed up some of the Dutch- English and took care of the publication of the collection with Somatosphere. We thank Kim Lewis and his team for the design of the website sphere, and Zoe Goldstein for editing the papers. We are grateful to the research priority area Social Science and Global Health of the University of Amsterdam for sponsoring and financing the event of the workshop and publication.

[1] This workshop followed on from a conference entitled ‘Living well with dementia: How do we do that?’, which was organised in Amsterdam to explore dementia and the good life, with people living with dementia, caregivers, care professionals, medical professionals, managers, artists and interest group representatives. For the conference proceedings, see Amsterdam Care

Collective (2018) <http://www.medanthrotheory.org/read/10021/dementia-and-the-good-life>.

Annelieke Driessen conducted ethnographic research in three nursing homes in the Netherlands as part of her PhD project in the Anthropology of Care Research Group at the University of Amsterdam, the Netherlands. Her thesis “Doing Dementia Differently” explores ways of living with dementia as they are crafted in everyday life and daily care practices on the ward. Her publications include “Pleasure and Dementia: on becoming an appreciating subject” (*The Cambridge Journal of Anthropology* 36 (1), 2018) and “Sociomaterial will-work: Aligning Daily Wanting in Dutch Dementia Care” (in *Care in Healthcare: Reflections on Theory and practice*, Palgrave Macmillan, 2017). Annelieke is currently working as a Research Fellow at the London School of Hygiene and Tropical Medicine, UK. As part of the research team involved in the Forms of Care project, she studies ‘active non-interventions’ as a form of care at the end of life.

Kristine Krause is Assistant Professor at the University of Amsterdam. Her research interests include political subjectivity 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 working on a book covering these subjects as they pertain to the Ghanaian diaspora in London and is developing new research on care outsourcing to Eastern European countries.

Jeannette Pols is appointed as Socrates professor ‘Social Theory, Humanism and Materialities’ at the Department of Anthropology, program ‘Health, Care and the Body’, at the University of Amsterdam. She is Associate Professor and Principal investigator at the section of Medical Ethics of the Academic Medical Centre in Amsterdam. In 2017 Pols was appointed as a member of the Advisory Board for the Government on health care: RVS (Raad voor Volksgezondheid & Samenleving). The core of Pols’ research is empirical ethics, which studies ‘normativity in practice’. She formulated three research lines for the Socrates chair, to which she was appointed in 2012: 1) the analysis of ethical and aesthetic values in sociomaterial care practices; 2) the articulation of actual and preferable subject positions of people with chronic disease and other technology users; and 3) conceptualizing practical knowledge of patients and their caregivers.

Emily Yates-Doerr is an anthropologist who studies how nutrition science shapes food systems and health care in Guatemala. She is an assistant professor at Oregon State University and the University of Amsterdam. She is the author of the book “[The Weight of Obesity: Hunger and Global Health in Postwar Guatemala](#)” (UC Press, 2015) and a co-editor of the book, “[The Ethnographic Case](#)” (Mattering Press, 2018, 2019) which experiments with a [novel form of peer-review](#) and which initially ran as a Somatosphere series. Follow her on Twitter at [@eyatesd](#)

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