Artful Dementia Research Lab

Progress report 2017-2021



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1 Introduction

Artful Dementia Research Lab (ADLab) is hosted by the Centre for Women's and Gender Research at UiT and funded by UiT The Arctic University of Norway. The lab is led by Professor Ann Therese Lotherington and coordinated by Post Doctor Lilli Mittner, both at the Centre for Women's and Gender Research.

ADLab was established in October 2017. During the enablement period 2017/18 the lab had three active researchers: the project leader, the coordinator and PhD candidate Dragana Lukic. In January 2019 Professor Rikke Gürgens Gjærum joined the Lab, and in October the same year PhD candidate Karoline Dalby, and successively MA students and research assistants became part and the lab. This progression report accounts for the first four-years period of activities.

This report presents ADLab's research areas (Section 2), the timeline of activities from August 2017 to December 2021 (Section 3), and a self-evaluation of the overall progress (Section 4).

2 Research areas

Artful Dementia Research Lab

Conceptual work

A major challenge for innovation in the field of dementia care and research is a vocabulary steering our thoughts towards dementia as a deficit and a tragedy. Reconceptualization is therefore central to the broader work for social, cultural, and political change.

Situated art interventions

To understand in-the-moment experiences our researchers become part of the relations we study. We do this by conducting situated art interventions in various places involving people living with dementia and their companions.



Open research

We work to make our research as transparent as possible. Hence, we explore how to make qualitative and arts-based data openly accessible. We further investigate ethical dilemmas arising when people living with dementia are involved as equal citizens in research.

Innovation

To achieve societal impact of our research and increase awareness of the potentials for enacting dementia beyond human individual loss, we conduct analysis of policy documents and pair them with the knowledge created through the situated art interventions.

ADLab is both a research and intervention project. The Lab is founded on situated art intervention research with the creative and performative arts, and has two main goals:

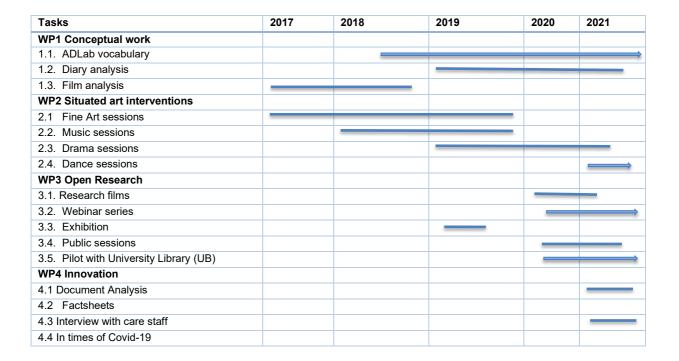
- (1) to advance knowledge on how to enact dementia beyond individual human loss
- (2) to increase awareness of how to create meaningful reciprocal relations between people living with and without dementia and promote research-based cultural change.

ADLab is currently organised along four work-packages (WPs) dedicated to:

- (1) Conceptual work
- (2) Situated art interventions
- (3) Open research
- (4) Innovation

In October 2019 ADLab developed an English webpage (www.uit.no/research/adlab) and an blog in Norwegian language (https://site.uit.no/adlablog/), to ease the communication with our English-speaking partners and the Community in Northern Norway, and to reach out to a broader audience. We update the web successively with research output, such as the ADLab webinar series, factsheets, and research films.

3 Timeline



4 Work packages

4.1 Conceptual work

ADLab challenges the vocabulary used in the dementia field (research, practice, and everyday life) to transform terminology and reconceptualise the prevailing understanding of the field. Theoretically this WP draws on research output from Prof. Ann Therese Lotherington on citizenship and feminist theory, empirically it draws on fieldwork

conducted in the ADLab. In addition, we work on transforming the disability GAP model towards a possibility GAP model. The conceptual work has just only started and will be continued in the consolidation phase of ADLab (from 2022 onwards).

4.2 Situated art interventions

ADIab has successfully collected unique data that helps to understand dementia in fundamentally new ways. The following four situated art intervention studies are part of this WP:

• Multisensorial entanglements

with focus on fine art activities that resulted in an exhibition at a residential care home (PI: Dragana Lukic)

Resonance

with focus on co-creativity related to sound and music (PI: Lilli Mittner)

Shorelines

with focus on applied theatre, not yet finished but it started with successful Kickoff event at the Bergsodden nursing home just before the corona lock down (PI: Rikke Gürgens Gjærum & Karoline Dalby)

• Connectivity room

with focus situation art interventions within non-medialized spaces such as museums, festivals, or libraries (PI: Rikke Gürgens Gjærum & Lilli Mittner)

Happy end

with focus on dance in collaboration with NextDoorProject

The interventions are specifically designed to give insight into subjective indicators of how to enact dementia beyond human individual loss. They enable us to analyze in themoment-experiences and mechanisms of how to connect meaningfully with people living with dementia through different creative, non-linguistically dependent activities.

4.3 Open research

The *Artful Dementia Film* (3.1) was generated from qualitative analysis of the Kick-off event for the Shorelines project in co-operation with technical support by the University Library, UiT (Terje Bergli and Tiia Grøn).

ADLab webinar series (3.2) is a format of scholarly conversations bringing together researchers from a variety of disciplines working on art & dementia. By making our conversations transparent and openly accessible we invite a broader audience to listen and take part in knowledge creation. All recording and data handling are declared with the panelists.

As part of the open research approach, we invited the public into residential care homes by means of an exhibition (3.3), and conducted a multisensorial art session as part of a general festival programme (3.4).

ADLab is a pilot project for Qualitative Open Data at UiT. Together with experts from the University Library the task (3.5) of WP3 is dedicated to the development of a consent forms making research processes with people living with dementia transparent within the community.

4.4 Innovation

This work package draws on the findings from an analysis of Norwegian dementia action plans (4.1). Results from WP1-4 further ground concrete and compelling suggestions for future art interventions promoting connectivity and fostering relations with people living with dementia. The objective of this WP is to justify the proposed cultural changes designed to contribute to rectifying remedial underestimation of people living with dementia and their ability to connect. Preliminary results stemming from WP4 are released in the form of recommendation and fact sheets along the project's development (4.2). Further, we conducted interviews with care staff (4.3) will enable us to measure effects of situated art intervention research. The material will be analyzed in 2022. We also had to adapted the Shorelines study due to the pandemic which resulted into new and unexpected results (4.4).

5 Concluding remarks

ADLab has, in its implementation phase, refined its work dynamics and achieved good results in a short period of time. The cooperation between researchers has been prolific. It has facilitated data collection and boosted the influence of the project beyond the University. ADLab has already provided data and assistance for three local nursing homes and the local dementia action week and searches to reach further out into society and intervene into current societal structures and cultural practices.

6 Output 2017-2021

6.1 Articles and book chapters

- ⇒ Lotherington, A. T. and Obstfelder, A.U. (submitted). "Enacting citizenship through writing: An analysis of a diary written by a man with Alzheimer's disease"
- ⇒ Lukić, D. (submitted). "Toward a multisensorial apparatus in dementia art research: exploring intimate entanglements in co-creative sessions."
- ⇒ Dalby, K., Mittner, L., & Gürgens, R. (fortcoming). Consent as an aesthetic process.

 Nordic Journal of Arts, Culture and Health.
- ⇒ Gürgens, R., & Mittner, L. (in print). Research innovation: Developing arts-based research methods to make sense of micro-moments framed by dementia. *Nordic Journal of Art and Research*.
- ⇒ Mittner, L. (2021). Resonating moments. Exploring socio-material connectivity through artistic encounters with people living with dementia. *Dementia*, 20(7). https://doi.org/10.1177/14713012211039816
- ⇒ Mittner, L., Dalby, K., & Gürgens, R. (2021). Re-conceptualizing the gap as a potential space of becoming: Exploring aesthetic experiences with people living with dementia. *Nordic Journal of Arts, Culture and Health*, *3*(1–2), 62–73. https://doi.org/10.18261/issn.2535-7913-2021-01-02-06
- ⇒ Mittner, L., & Gürgens, R. G. (2021). Situating an Art Intervention with People Living in a public space: Notes from the field. *Nordic Journal of Arts, Culture and Health*, 3(1–2), 115–121. https://doi.org/10.18261/issn.2535-7913-2021-01-02-11
- ⇒ Lukic, D., & Mittner, L. (in print). Significance of diffractive methodology: Multiple ontologies of Alzheimer's disease and other dementias within multisensorial cocreative entanglements.

- ⇒ Lukić, D; Lotherington A. T. (2020). Fighting symbolic violence through artistic encounters: searching for feminist answers to the question of life and death with dementia: Confortini, C.C; Vaittinen, T. (eds) *Gender, Global Health, and Violence: Feminist Perspectives on Peace and Disease*, Rowman & Littlefield, 2020. Post-print open access: https://hdl.handle.net/10037/16911
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- ⇒ Lotherington, A. T. (2019). Artful Dementia: Feminist Theory Applied. https://criticalgerontology.com/artful-dementia
- ⇒ Lotherington, A. T., Obstfelder, A., & Ursin, G. (2018). The Personal Is Political Yet Again: Bringing Struggles between Gender Equality and Gendered Next of Kin onto the Feminist Agenda. *NORA Nordic Journal of Feminist and Gender Research*, 26(2), 129–141. https://doi.org/10.1080/08038740.2018.1461131
- ⇒ Ursin, G., & Lotherington, A. T. (2018). Citizenship as Distributed Achievements: Shaping New Conditions for an Everyday Life with Dementia. Retrieved from https://munin.uit.no/handle/10037/12510
- ⇒ Bartlett, R., Gjernes, T., Lotherington, A.-T., & Obstefelder, A. (2016). Gender, citizenship and dementia care: a scoping review of studies to inform policy and future research. *Health & Social Care in the Community*. https://doi.org/10.1111/hsc.12340

6.2 Conference presentations, poster & workshops

- ⇒ Webinar «Kunst og kreativitet i helhetlig omsorg» del 2. (2021, November 24). https://www.youtube.com/watch?v=BJxGNy4LDSs
- ⇒ Mittner, L. (2021). Don't mind the gap dance with dementia!. Nordic Arts & Health Research Network meeting 7th 8th June 2021 (online)
- ⇒ Dalby, K., Mittner, L. & Gürgens Gjærum, R. (2020). Verksted: Hvordan er vi sammen? Situert kunstintervensjon som mulighetsrom for mennesker som lever med demens. *Kunst og velferd. En konferanse om kunstens plass i velferdsstaten* 23.-24. april 2020, Oslo

- ⇒ Mittner, L., Lukić, D., & Lotherington, A. T. (2019). Workshop on Feminist Art Interventions | Shaping Spaces of Possibility through Co-Creative Action. Kjønnsforskning NÅ! Tromsø 13-15 Novembre 2019
- ⇒ Mittner, L., (2019). Situert kunstintervensjon som mulighetsrom. Aktiv deltakelse for mennesker som lever med demens. Aktive eldre og aktiv aldring 7. norske kongress i aldersforskning, Fornebu 24-25 Octobre 2019
- ⇒ Lukić, Dragana; Mittner, Lilli; Lotherington, Ann Therese (2019). Exploring transformative powers of the arts for societal change: reimagining life with dementia through co-creative artistic encounters. *The Museum for All People: Art, Accessibility and Social Inclusion*, Madrid. 2019-04-02 2019-04-05 2019.
- ⇒ Mittner, L., Lukić, D., & Lotherington, A. T. (2017). The Role of the Artist in Arts-Based Dementia Care. *Poster at the 27th Alzheimer Europe Conference "Care today, cure tomorrow" 2017-10-02*. Berlin.
- ⇒ Lotherington, Ann Therese; Obstfelder, Aud; Zuiderent-Jerak, Teun; Jerak-Zuiderent, Sonja (2017). Artful Dementia: Experimental Arts Interventions for Gracious Living. *Dimensions of Ageing A Multidisciplinary Seminar*. The Norwegian University Center in St. Petersburg, 26-28 September 2017

6.3 Factsheets

- ⇒ Artful Dementia Research Lab. (2021a). *Digital Data Handling within ADLab*[Factsheet 2/2021]. https://zenodo.org/record/5565094#.YXejUNZBx Q
- ⇒ Artful Dementia Research Lab. (2021b). How to engage in knowledge creation in ADLab? [Factsheet 1/2021]. https://zenodo.org/record/4638965#.YXejBNZBx Q
- ⇒ Artful Dementia Research Lab. (2021c). Bergsodden Residency Creating Dance with People Living with Dementia During an Two-Weeks Art Residency. https://doi.org/10.5281/zenodo.5729715

6.4 ADLab sessions

- ⇒ HappyEnd Residency, Bergsodden 8. November to 18. November 2021, Harstad
- ⇒ StoppMotion, Bergsodden 7. Decembre 2020, Harstad
- ⇒ Churchlab, Trondenesdagene 27. October 2020, Harstad
- ⇒ ADLab på Bergsodden 12. februar 2020, Harstad

6.5 Multimedia

- ⇒ Rolland, T. (2021, January 5). *Barn lager kunst sammen med eldre i*Harstad. https://www.youtube.com/watch?v=9fxwvs6hRTo&ab_channel=UiTNorgesar

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- ⇒ Mittner, L., Grøn, T., & Bergli, B. (2021, January 21). *Artful Dementia Film 2021*. Zenodo. https://doi.org/10.5281/zenodo.4455781
- ⇒ Dalby, K., & Rolland, T. (2020). På labben: UiT Harstad—Karoline

 Dalby. Forskningsdagene, Forskningsrådet. https://youtu.be/JmiQLer1YkQ
- ⇒ Rolland, T. (2020, November 19). *Vil endre synet på demens gjennom kunst og kultur*. https://www.youtube.com/watch?v=wCNM8lkqtsw&feature=emb_logo&ab_cha nnel=UiTNorgesarktiskeuniversitet

6.6 Outreach

- ⇒ UiT The Arctic University of Norway (2921) *Åpen vitenskap ved UiT / Open Science* at UiT [Video]. https://www.youtube.com/watch?v=A cZouTefbo
- ⇒ Mortensen, M. (2021, January 18). Møtet mellom de demenssyke og barna overrasket: Mye bedre enn forventet.
 NRK. https://www.nrk.no/tromsogfinnmark/hjertegodt-mote-med-demensrammede-og-skolebarn-i-harstad-1.15313702
- ⇒ NRK. (2021). Dokumenterer kreativt samarbeid i nord. https://tv.nrk.no/serie/distriktsnyheter-nordnytt/202101/DKTR98010721/avspiller#t=10m58s
- ⇒ Flydal, L. O. (2020). Demens stenger ikke for skaperkraft. *Vårt Land*. https://www.vl.no/religion/2020/11/16/demens-stenger-ikke-for-skaperkraft/
- ⇒ Rolland, T. (2020). Vil endre synet på demens gjennom kunst og kultur. *Forskning.No*. https://forskning.no/demens-helsetjenester-kunst/vil-endre-synet-pa-demens-gjennom-kunst-og-kultur/1776792
- ⇒ Filosofisk samtale på Skarven, 22 februar 2020, Tromsø
- ⇒ Dalby, K. (2020). <u>Skape øyeblikk sammen med mennesker med demens.</u> Harstad Tidende
- ⇒ Mittner, L., Lukić, D., Lotherington, A. T., Dalby, K. & Gürgens Gjærum, R.

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- ⇒ Lotherington, A. T., & Obstefelder, A. (2018). Kreative og utviklende liv med demens. *Nordlys. Nordnorsk Debatt*. Retrieved from https://www.nordnorskdebatt.no/kreative-og-utviklende-liv-med-demens/o/5-124-43770



