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## Thinking ahead: supporting family caregivers of nursing home residents with dementia in advance care planning

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# List of publications

## Peer reviewed publications

- 2021 Physicians' perceived barriers and proposed solutions for high-quality palliative care in dementia in the Netherlands: qualitative analysis of survey data. Bavelaar L, van der Steen HTA, de Jong H, Carter G, Brazil K, Achterberg WP, van der Steen JT. *J Nurs Home Res.* 2021;7:23-31.
- 2021 Nederlandse vertaling en eerste stappen in validatie van de PPEET om burger- en patiëntenparticipatie te evalueren. Bavelaar L, van Tol LS, Caljouw MAA, van der Steen JT. *TSG Tijdschr Gezondheidswet.* 2021;99:146–153.
- 2022 Developing country-specific questions about end-of-life care for nursing home residents with advanced dementia using the nominal group technique with family caregivers. Bavelaar L, Nicula M, Morris S, Kaasalainen S, Achterberg WP, Loucka M, Vlckova K, Thompson G, Cornally N, Hartigan I, Harding A, Preston N, Walshe C, Cousins E, Harrison Dening K, De Vries K, Brazil K, van der Steen JT. *Patient Educ Counsel.* 2022;105:965-973.
- 2022 Interventions to support family caregivers of people with advanced dementia at the end of life in nursing homes: A mixed-methods systematic review. Gonella S, Mitchell G, Bavelaar L, Conti A, Vanalli M, Basso I, Cornally N. *Palliat Med.* 2022;36(2):268-291.
- 2022 Guidance for family about comfort care in dementia: a comparison of an educational booklet adopted in six jurisdictions over a 15 year timespan. Bavelaar L, McCann A, Cornally N, Hartigan I, Kaasalainen S, Vankova H, Di Giulio P, Volicer L, Arcand M, van der Steen JT, Brazil K, and the mySupport study group. *BMC Palliat Care.* 2022;21:76.
- 2022 Change in advance care plans of nursing home residents with dementia and pneumonia: secondary analysis of RCT data. Bavelaar L, Visser M, Schlicksupp P, Tilburgs B, van der Maaden T, Achterberg WP, van der Steen JT. *J Am Med Dir Assoc.* 2022;23(10):1741.e19-1741.e26.
- 2022 A Family Carer Decision Support Intervention for people with advanced dementia residing in a nursing home: A study protocol for an International advance care planning intervention (mySupport study). Harding A, Doherty J, Bavelaar L, Walshe C, Preston N, Kaasalainen S, Sussman T, van der Steen JT, Cornally N, Hartigan I, Loucka M, Vlckova K, Di Giulio P, Gonella S, Brazil K. *BMC Geriatr.* 2022;22:822.

### **Conference proceedings**

- 2020 Developing Country-Specific Question Prompt Lists About Dementia Palliative Care for Family Caregivers. Bavelaar L, van der Steen J, Nicula M, Morris S, Kaasalainen S, Achterberg W, Brazil K. *Innov Aging.* 2020 Dec 16;4(Suppl 1):786.
- 2021 Development of an Early Career Research Committee and Online Mentorship Programme as part of the mySupport Study. Fitzgerald S, Danielle J, McCann A, Di Sante E, Bavelaar L, Nicula M, Gonella S, Harding A, O Connell S, Vlckova-Horakova K, Fox S. *Palliat Med.* 2021;35(1\_suppl):1-243. (p100, Abstract number: E-18).
- 2022 Methodological issues and challenges in designing and conducting research at the end of life: Findings of qualitative and textual evidence from researchers' perspective. Vlckova K, Gonella S, Bavelaar L, Mitchell G, Sussman T. *Palliat Med.* 2022;36(1\_suppl):3-122. (p17-18, Abstract ID: OA01:04).
- 2022 What matters to users? Evaluation of the look and feel and content of a family booklet on comfort care in advanced dementia: A mixed-methods study assessing users' preferences. Dijkstra E, Bavelaar L, van der Steen JT, Sizoo E. *Palliat Med.* 2022;36(1\_suppl):3-122. (p61, Abstract ID: P02:53).
- 2022 Change in advance care plans in nursing homes when people with dementia experience pneumonia: secondary data analysis of RCT data. Bavelaar L, Visser M, Schlicksupp P, Tilburgs B, van der Maaden T, Achterberg WP, van der Steen JT. *Palliat Med.* 2022;36(1\_suppl):3-122. (p77-78, Abstract ID: P03:36).

### **Manuscripts**

Methodological issues and challenges in designing and conducting ethical research at the end of life: findings of qualitative and textual evidence. Vlckova K, Gonella S, Bavelaar L, Mitchell G, Sussman T.

Changing and shifting tasks from physicians to nursing staff in advance care planning with family caregivers of nursing home residents with dementia: mySupport case study. Bavelaar L, Visser M, Billekens PFA, Geerds PL, Achterberg WP, Brazil K, van der Steen JT.

The impact of the mySupport advance care planning intervention on family caregivers' perceptions of decision-making and care for nursing home residents with dementia: pretest-posttest study in six countries. Bavelaar L, Visser M, Walshe C, Preston N, Kaasalainen S, Sussman T, Cornally N, Hartigan I, Loucka M, Di Giulio P, Brazil K, Achterberg WP, van der Steen JT.

# Portfolio

PhD student: Laura Bavelaar-von Oerthel  
Primary thesis advisor: Prof.dr. W.P. Achterberg  
Other thesis advisors: Dr.ir. J.T. van der Steen  
Dr. M. Visser  
Research programme: 31201 Geriatrics in primary care

## Courses and training

- 2019 Ethics in Dementia
- 2019 Kwalitatief onderzoek in de praktijk van de gezondheidszorg
- 2020 BROK Course
- 2020 Children, young patients and family involvement in the design of clinical research
- 2020 Developing a Dissemination Strategy for Health Research
- 2020 Research Integrity
- 2021 PhD Introductory Meeting
- 2021 Basic Methods and Reasoning in Biostatistics
- 2021 Regression Analysis
- 2021 Supervising working groups
- 2022 TTT: Coach de coach – Leidse Lijnen
- 2022 the mySupport Early Career Mentorship Programme

**Presentations**

- 2020 UNC-ZH Jubileumtour, online. Workshop presentation
- 2020 GSA 2020 Annual Scientific Meeting, online. Oral presentation
- 2021 31<sup>st</sup> Alzheimer Europe Conference, online. Oral presentation
- 2022 12<sup>th</sup> EAPC World Research Congress, online. Poster presentation
- 2022 26<sup>th</sup> Nordic Congress of Gerontology, Odense. Symposium presentation.

**Teaching activities**

- 2022 Workgroup teacher (Collaboration, Health promotion and Leadership) of 3<sup>rd</sup> year medical students, LUMC

# Curriculum Vitae

Laura Bavelaar-von Oerthel was born on November 14<sup>th</sup>, 1993 in Leiderdorp. She attended secondary school in Leiden at the Bonaventuracollege where she obtained her Gymnasium diploma in 2012. In addition, Laura received her Pre-University College diploma in 2012. Leiden University offered this program for students who would like a scientific challenge besides their secondary school curriculum and already gain some experience in academia. As part of the Pre-University College programme, Laura conducted a study into metacognitive skills as her ‘Profielwerkstuk’ under supervision of dr. Marcel Veenman, which was published in 2014 (Learn Individ Differ). This introduction into research in psychology sparked her interest and after secondary school, Laura started her study Psychobiology in Amsterdam in 2012. In 2015, Laura graduated cum laude and with honours. The research Master Brain and Cognitive Sciences at the University of Amsterdam was a natural follow-up to her education. Laura was granted access to the selective Master’s and graduated cum laude in 2017. In 2018, Laura started a PhD position at the University of Amsterdam. She worked on the Human Brain Project at the Cognitive and Systems Neuroscience lab, but then decided to change direction. Throughout her education at the University of Amsterdam, Laura had worked as a food assistant at the Alrijne Hospital in Leiderdorp. The care setting and interaction with patients, often older people, inspired Laura to change paths from fundamental neuroscience to person-centered care research. She started working as a junior researcher on the mySupport study in 2019 and was subsequently supported in expanding the study into a PhD research project at Leiden University Medical Center, in the Department of Public Health and Primary Care. During her time as PhD student, Laura participated in various committees and organized a Department outing, served as secretary to the mySupport study’s Early Career Researchers Committee and hosted and organized a symposium on ‘*New and emerging models of Advance Care Planning for Older Persons*’ and two-day mySupport study consortium workshop. In her free time, Laura volunteers at Zero Waste Groene Hart.

# Dankwoord

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Ten slotte wil ik mijn vrienden en familie bedanken die mij perspectief en balans brachten. En mijn lieve man, Lars. Voor alles.

*Vergeet me niet en vergeef me lief,  
Wanneer ik niet meer ben wie jij ziet.*

*Denk dan aan hoe het was.*

[Wat Als – Joe Buck]