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PhD in Medical Sciences
2020-2021

INVITATION to the Public defence of

Annelien VAN DAEL

To obtain the academic degree of '**DOCTOR OF MEDICAL SCIENCES**'

Advance care planning, dementia and nursing homes

The defence will take place on **Monday, 29th March 2021 at 4 p.m.**

and will be organised **online** accessible through the following link:

Join Zoom Meeting

<https://us02web.zoom.us/j/87019697805>

Meeting ID: 870 1969 7805

Passcode: 905872

Summary of the dissertation

Worldwide, every three seconds there is a new case of someone with dementia. As it is likely for people living with dementia to lose their decision-making capacity and their ability to communicate as the dementia progresses, advance care planning (ACP) is considered to be important. ACP is defined as 'a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care'. Especially in nursing homes, where it is estimated that more than 65% of the people with dementia die, the uptake of ACP is low.

The aim of this PhD thesis was twofold: 1) To describe current evidence concerning ACP for people living with dementia and to examine to what extent ACP and end-of-life decision-making have changed over time among people with dementia; and 2) To evaluate the ACP+ intervention, an intervention program to improve the implementation of advance care planning in nursing homes in Flanders.

We found that ACP is important and acceptable for people with dementia and practiced more over the years. However, training and education for all parties involved is needed to further increase the uptake of ACP. We found ACP+ to lead to a significant improvement in self-efficacy in ACP of care staff, but no improvements in their ACP knowledge. These results underline the difficulties of changing ACP practices in the complex setting of nursing homes, but also hallmark first important steps towards improved care for this vulnerable population.

Curriculum Vitae

Annelien was born on the 17th of May 1990 in Rotterdam, the Netherlands. She obtained her high school diploma (VWO at Lek & Linge in Culemborg) in 2007. Being unsure about the next step, she chose adventure and spent half a year in Australia and half a year working at the cardiology ward of the Rivierenland hospital in Tiel. The latter is where she found her interest in the care for older people. While obtaining her bachelor's (2011) and master's degree in Clinical and Health Psychology (2013) from Utrecht University, she worked as a care assistant at a nursing home for blind older people in Wolfheze. In 2013 she started as a research assistant at the geriatrics department of the Radboud University Medical Centre in Nijmegen, further exploring her interest for older people, dementia and quality of care. In September 2016 Annelien started as an Early Stage Researcher (ESR) at the End-of-Life Care Research group (VUB), within the EC Marie Curie Actions funded project INDUCT (Interdisciplinary Network for Dementia Using Current Technology), focusing on advance care planning. She was supervised by Prof. Lieve Van den Block and Prof. Lara Pivodic and worked in close collaboration with Dr. Joni Gilissen, Prof. Luc Deliens, Prof. Robert Vander Stichele, Prof. Chris Gastmans. During her PhD-trajectory, Annelien also had the opportunity to work with Prof. Claire Goodman, Prof. Frances Bunn and Dr. Jennifer Lynch of CRIPACC research group of the University of Hertfordshire (UK). Currently, Annelien works at ZonMw, the Dutch organization to promote quality and innovation of healthcare research. Annelien is married to Jos and the proud mother of Gijs (~2017) and Olivier (~2019).