

# Palliative Care in the Public Eye

Insights & Strategies to  
Enhance Understanding &  
Engagement

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## EXAMINATION COMMITTEE

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## Curriculum Vitae

Marjolein Matthys holds a Bachelor's degree in Clinical Psychology from the University of Ghent (2008) and a Bachelor's and Master's degree in Cultural and Social Anthropology from the University of Amsterdam (2010 and 2012, respectively). During her Master's studies, she researched death confrontations as existential-dynamic conflicts in the lives of non-religious adults in the Netherlands, for which she was awarded the Annual Thesis Competition Award by the University of Amsterdam's Department of Anthropology. In May 2019, she joined the End-of-Life Care Research Group to investigate public perceptions of palliative care and develop a public awareness campaign to promote palliative care in Flanders. Marjolein's primary research interests include narrative and discourse theory, the anthropology of ethics, existential anthropology, and all aspects of interdisciplinary research that contribute to our understanding of the dynamics of meaning-making surrounding the end of life.

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- The dissertation can be consulted via:  
<https://biblio.ugent.be/person/802003160519>

# Project Summary

## Background and aim

While the need for palliative care is growing on a global scale, access and uptake are hindered by limited public knowledge and negative beliefs surrounding palliative care. A call for broad educational initiatives on palliative care, directed at the whole population, has therefore often been made. However, for these initiatives to be effective, they need to be built on a thorough understanding of public perceptions within the sociocultural contexts in which they are embedded. Furthermore, important lessons can be drawn from investigating the quality and discursive organization of meaning within publicly available information and communication on palliative care, as well as exploring how the public receives, interprets, and evaluates these various sources. Research on all of these aspects had been lacking, resulting in a clear lack of evidence-informed strategies and initiatives aimed at enhancing public knowledge, receptivity, and engagement with palliative care. This project set out to fill this gap and was driven by **two main research aims**:

- 1: To gain a deeper understanding of public perceptions surrounding palliative care within the sociocultural context of Flanders.
- 2: To co-creatively design a broad public campaign strategy to tackle unknown, misunderstood and stigmatized aspects of palliative care in Flanders.

## Methods

To reach these aims, five different studies were conducted. Overall, our approach brought together multiple methodologies, predominantly interpretative qualitative research, and was driven by social constructionist ontology and epistemology.



## Results

We found that while the general public in Flanders widely recognizes that palliative care is not just for older adults or cancer patients, the majority of the population is **unaware of several of its key roles**, such as enhancing day-to-day activities and managing serious illness-induced stress. Our research moreover revealed how negative perceptions of palliative care are often shaped by **confused understandings surrounding medical end-of-life practices**, in particular palliative sedation and euthanasia, and the personal values people adhere to in connection to this. Looking at the online information of palliative care, we found **discrepancies in descriptions and definitions of palliative care**, as well as **inter- and intra discursive tensions**, which together contribute to public confusion and potentially even stigmatization. Moreover, public campaigns on palliative care were **interpreted, evaluated, and engaged with in highly divergent ways**, with the observed differences not being separable from broader societal discourses (e.g., those surrounding aging) and structural factors (e.g., access to optimal healthcare). Overall, **our studies confirmed the importance of addressing public perceptions of palliative care by pointing to the existence of unknown, misunderstood, and stigmatized aspects within the Flemish context**. **Diversified strategies**, with a focus on increasing personal relevance, are needed to more effectively influence public understanding and engagement with palliative care. Moreover, **destigmatizing palliative care also involves destigmatizing persons with serious illness** and representing them in active and resilient positions is vital to this. Building on these findings, a comprehensive campaign strategy was co-creatively developed, incorporating six communication principles and six components.

## PROMOTORS

- Prof. dr. Benedicte Deforche (UGent)
- Prof. dr. Kenneth Chambaere (UGent)
- Prof. dr. Luc Deliens (VUB)
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## PROJECT GROUP MEMBERS

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