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978-1-108-84350-8 — Dementia and Society

Edited by Mathieu Vandenbulcke , Rose-Marie Dröes , Erik Schokkaert

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# Dementia and Society

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## An Interdisciplinary Approach

Edited by

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## Preface

As the population grows older, dementia becomes more noticeable in our society. Most of us sooner or later have to deal with dementia in our close environment or personally. Although there are some promising reports of decreasing incidence, prevalence is on the rise, especially in low- and middle-income countries. Surveys tell us that cognitive decline is the biggest concern among older adults. Both the unfamiliar realm of dementia and the prospect of losing one's cognitive abilities are terrifying. Most people fear to lose themselves and their dignity. People are afraid of not being taken seriously anymore, of being pushed aside in society. Such feelings express the imminent degradation of the very essence that a society stands for. The word 'society' comes from the Latin word *societas*, which is derived from the noun *socius*, meaning ally or friend, and describes a bond between people. Society is about living together as prosperously as possible. Of course, by the nature of their condition, persons with dementia are at higher risk of losing connection with the community they belong to and vice versa. To mitigate the risk of alienation and to safeguard the well-being of humans with cognitive impairment and their caregivers, society must consider how its policy and organization can best be tailored to the needs of people with dementia. This requires deep reflection on a range of topics: What defines dementia? Does the meaning of dementia depend on the perspective taken? How is dementia perceived in our society? Do portrayals of dementia affect persons living with dementia? How is dementia experienced and how does it affect relationships with others? What determines quality of life for persons with dementia? Can people with dementia still have a meaningful life? How to create a supportive and safe environment, when to decide on future care decisions and how to organize and finance care? Obviously these questions can only be answered by bringing

together expertise from different disciplines, which was the set-up of this book.

### Metaforum

This book is part of an initiative of the University of Leuven (KU Leuven) called Metaforum. Metaforum is an interdisciplinary think tank that brings together Leuven academics and international colleagues to reflect on societal themes. Its mission is to make the wealth of scientific and scholarly expertise on pressing societal issues available to policymakers and the general public. In 2018, a working group on dementia was launched, assembling KU Leuven scholars and international experts with an interest in dementia from different fields, including medicine, biology, psychogeriatrics, epidemiology, nursing, social law, economics, social psychology, human movement sciences, moral philosophy, architecture and literary studies. This initiative was sponsored by Opening the Future, a philanthropic campaign at KU Leuven targeting neurodegenerative diseases. The gathering led to a series of animated interdisciplinary discussions and lectures on various topics related to societal aspects of dementia. The fellows consented to share their ideas in the form of a book that reflects Metaforum's way of working – that is, offering different perspectives on themes raised by the experts rather than aspiring to an exhaustive account on the consequences of dementia for the community. In general, choices were based on a common interest of scholars from different disciplines who participated in the discussions, the feeling that the topic required an interdisciplinary approach, and consensus among the fellows that the topic was timely and of interest to a broad audience eager to learn about societal aspects of dementia. Accordingly, most of the chapters are the result of intensive crosstalk between a group of authors of different disciplines and include different points of view.

## Preface

**Audience**

The book targets a broad audience of professionals working in the field of dementia, academics, students and lay readers with an interest in dementia, as well as policy advisors and representatives from politics who want to learn more about the impact of dementia on society and its citizens and good ways to deal with it.

**Flow**

All chapters stand on their own and can be read separately depending on the interest of the reader. For the reader new to the field of dementia, or with a more general interest in the topic, we ordered the chapters so that the reader's view on dementia gradually broadens as the book progresses. Although most chapters focus on a specific topic or perspective, they also contribute to the understanding of other topics or perspectives on dementia.

A clustering principle that we loosely kept in mind after introducing the origins of the concept and public perception of dementia (Chapters 1 and 2) was moving from the micro level – that is, the person with dementia (Chapters 3–5) – to the meso level – that is, close environment (Chapters 6 and 7) – and the macro level, corresponding with society and public policy (Chapters 8–14).

**Brief Outline**

To familiarize the reader with the concept of dementia, we describe in Chapter 1 the history and current definition of dementia and give an overview of perspectives on dementia beyond the biomedical approach. We discuss several psychosocial models as well as anthropological, societal and political views on dementia. In Chapter 2, complementary to Chapter 1, we offer a sociocultural perspective on dementia and explore the history and meaning of the stigma of dementia as well as how dementia is portrayed in language, media and literature. In the three following chapters, we discuss how dementia affects the person living with it. In Chapter 3, we discuss from a philosophical perspective how the dignity of persons with dementia can be respected, even if dementia affects identity, autonomy and personhood, and we confront this philosophical analysis with juridical and clinical reflections. In Chapter 4, we argue that meaning in life matters

for persons with dementia and is an important determinant of well-being. In Chapter 5, we examine what quality of life, as the main outcome of care intervention, represents, how different measures reflect different conceptions of well-being and how these cover what people with dementia find important in life. In the next two chapters, we discuss how dementia affects relationships and informal carers as well as the support provided to deal with it. Chapter 6 focusses on partner relationships, from the perspectives of both the person with dementia and the partner. We examine how dementia affects relational roles, intimacy and sexuality. In Chapter 7, we describe the characteristics of informal care and evidence-based interventions to support caregivers. Next, in Chapter 8, we discuss psychosocial interventions that could mitigate the risk of developing dementia, followed by a description of the principles of an empowering environment for persons with dementia and several operationalizations in Chapter 9. The COVID-19 crisis uncovered some serious shortcomings in the way care is organized for people with dementia, which are addressed in Chapter 10. In Chapter 11, we discuss participation and inclusion of persons with dementia, both from a human rights and ethical perspective, and in Chapter 12, the specific issue of end-of-life decisions. In Chapter 13, we turn theory into practice by discussing the specific case of driving in dementia, illustrating the delicate balance between individual freedom, social inclusion and public safety. Finally, in Chapter 14, we discuss the economic consequences of inclusive policies and care initiatives that improve quality of life of people with dementia.

**Cross-links**

There are many connections between the different chapters, leading to complementary insights on various topics. Let us illustrate this point by focussing on one of the book's central themes – namely, *social inclusion* as a means to improve the quality of life of persons with dementia. In Chapter 1, we introduce the person-centred care model, which is about knowing the person through interpersonal relationships and actively involving persons with dementia in social life, searching for sources of fulfilment or meaning, and being aware of disempowering communication strategies in social interactions with

broad negative effects. The latter includes discriminatory attributions of the general public, called public stigma, that hamper integration of persons with dementia, which we discuss in Chapter 2. In Chapter 4, we argue that experiencing meaning in life, which is frequently related to having social connections, strongly contributes to well-being in dementia, and that people with dementia are still able to indicate what the sources of meaning are in their life, even in advanced stages. However, creating togetherness and finding shared meaning in relationships and activities is challenged by dementia and also dependent on the well-being of caregivers, as discussed in Chapters 6 and 7 respectively. In Chapter 9, we discuss how the organization of both the physical and social environment can maximize social inclusion and quality of life, and in Chapter 10, what detrimental effects disruption of this empowering environment can have, which became dramatically clear during the COVID-19 crisis. Although the effects of loneliness and lack of social engagement on well-being and cognitive outcome have been well known to the field for many years, the COVID-19 crisis clearly exposed the negative consequences of social isolation and demonstrated the necessity of good psychosocial care for people with dementia. The presence of such negative psychosocial factors may even increase the risk of developing dementia, as discussed in Chapter 8. Finally, Chapter 14 shows that there is a clear association between some of the factors that negatively impact social inclusion and socio-economic status, leading to inequality in health at old age. Thus,

throughout the book, different perspectives complement each other, creating a multifaceted view on social inclusion and on other themes that are important for living well with dementia.

Rational scientific language is not adequate to capture all the different dimensions of the experience of persons with dementia and of the persons interacting with them. That is why we have included in the book some selected poems that have the power to touch more directly our emotions.

Clearly, we took advantage of the many interactions between the experts during the meetings organized by Metaforum. We also believe that many authors were inspired by the interdisciplinary discussion during the writing process. Nevertheless, despite the high interrelatedness of the contributions, we found it challenging to bridge the gaps between theory and practice and to really integrate the viewpoints of the different disciplines. We strongly feel that this book is not an end point, but rather an attempt to find a common language between various disciplines which is an indispensable first step to address a complex problem such as dementia. We hope that this book will be a source of inspiration for an integrative policy that aims for a better life for people with dementia. We also hope that it becomes increasingly clear to the reader, as it became to us, that improving the lives of people with dementia is a collective responsibility.

*Mathieu Vandenbulcke, Erik Schokkaert and  
Rose-Marie Dröes*

**Then it was autumn.**

**Carol Frost**

Each morning she would rise and dress  
and walk out the back door where orange rounds  
hung from boughs – breasts, big acorns, eggs, jewelry bags?  
She waited, she told me, for the right word  
to come back to her. Maybe she stood on the patio a few minutes  
or hours. The closing click of the door behind her  
made her look back, and she stepped inside.  
I don't think I believed her then. The weeks passed,  
the months, then her forgetfulness blended with angers,  
as if red wild bees were knocked from large red blossoms  
by witches. When she began her wandering  
along cracking pavement, by blank billboards, toward lights  
that in the distance must have seemed mythic (or she slept,  
intent on making time go away, like a vagrant),  
then I felt hushing in her before, by dark severance,  
flesh no longer could feed the sweetest mind.  
Honeycomb, goddess, death, fate, and the human heart,  
they lived in her until too many of her words  
flew like birds of the muses away, so few at first  
that their disappearance didn't much matter.

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