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The social health and well-being of people with memory problems and dementia

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English summary

Globally, the population is ageing. In several Western countries, the preference to stay at home and budget cuts have led to the deinstitutionalization of long-term care for older adults. As a result, more people with dementia are living at home and interacting with public space. Yet, people with dementia are often not considered active citizens in society. Further, the way that dementia is understood by the general public and portrayed in media, mainly illustrating the end-stage symptoms, has led to a dehumanizing, hopeless view of people with the disease. This negative discourse is being corrected by exploring more diverse empowering perspectives of people with a range of dementia-related symptoms, not only a formal diagnosis, and in settings beyond the institutional environment. Capturing a range of experiences with memory problems and dementia within the community is shifting the focus from decline to how people adapt and self-manage. In particular, a focus on the social health of people with dementia has guided research and development of innovative care models based on an individual's ability to fulfill their potential, manage life with some degree of independence and participate in social activities. Understanding the mobility of people with dementia, such as interactions with the social and built environment, can further inform dementia research by exploring how social health is associated with place.

This thesis explores how mobility research can contribute to the development of the concept of social health for dementia. Specifically, the focus is on the mobility of people with memory problems and dementia and how interactions with the social and built environment support social health and well-being. This thesis begins with an overview of dementia, social health and how understanding the mobility of people with memory problems and dementia can support social health and well-being. Additionally, the introduction describes the context of this thesis in both a description of the Dutch setting and how the study is embedded in the COORDINATEs project, a larger international, interdisciplinary research project. Chapter 2 provides a detailed description of the COORDINATEs project including the theoretical and methodological context of which the data for this thesis were collected. The overall aim of the project is to understand the mobility patterns and mobility experiences of older adults with memory problems and

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dementia living at home in the Netherlands, Canada and Sweden. This data can be used to improve autonomy and inform the development of shared decision-making tools to guide housing options for people with memory problems and dementia. This thesis is based on data collected during the first phase of the COORDINATEs project in the Netherlands. Chapter 3 is a scoping review that summarizes and identifies knowledge gaps related to what is known about how people with dementia perceive the social and built environment and how features of these environments contribute to their well-being. The overall findings of the review were that features of the social and built environment can support connection to society and social interactions, and interactions with built environments can contribute to well-being. Most of the literature is based on UK and Sweden studies and did not identify studies in the Netherlands. Therefore, the remaining chapters of this thesis contribute to this knowledge gap by providing a perspective based on the social and built environment in the Netherlands. Chapter 4 builds upon the scoping review by identifying specific “assets”, as opposed to the more generic “features”, as described in the previous chapter. Referring to the Asset-Based Community Development (ABCD) framework, an inventory of physical, social and organizational assets were identified as contributors to well-being. The findings provided insight into the mobility experiences that indicate that assets can support navigation in public space and support social inclusion and encounters. Chapter 5 builds upon these findings through the use of the concept of activity space to explore the mobility patterns and mobility experiences related to social health of older adults living with memory problems and dementia. The findings illustrated two spatial mobility patterns: routine activity space and occasional activity space. In relation to the concept of social health, participants interacted independently in routine activity spaces but depended on others to participate in occasional activity spaces. Additionally, coping strategies and decision-making were identified as means to maintain autonomy in daily life. Based on findings from the previous chapters and additional qualitative data analysis, chapter 6 highlights aspects of public space that can hinder and promote social encounters for people with memory problems and dementia. Based on these observations, policy recommendations are made to deliver public services and design public space to be “dementia-informed”. A dementia-informed planning process, inclusive of land-use, housing,

transportation and commercial planning, can support social health by planning and designing spaces based on the experiences of people with dementia and removing barriers to social inclusion and engagement. Further, planning decisions can be informed and tested by a committee of experts, including people with dementia and their caregivers. Putting policy and planning recommendations into practice would support the social health of people with dementia and create socially accessible public spaces for all. The concluding chapter of this thesis summarizes the main results and reflects on the research contribution, research design and methodological approach.

This thesis provides a new understanding of the strengths and abilities of a population that is often labelled with a discourse of loss and decline. Mobility research can help correct socially constructed fears around dementia by challenging the loss and decline, confirming a positive discourse that people can navigate, adapt and live well with memory problems and dementia. The findings of this thesis contribute to the development of the emerging concept of social health for dementia by identifying how a focus on mobility can provide insight into capacity and self-management. Moreover, this thesis includes several distinct contextual findings unique to the Netherlands which have not been explored in other dementia research. Both the asset-based approach and the concept of activity space provided an improved understanding of how social and built environment characteristics can help people navigate their environments and gain a sense of inclusion in society despite their condition. These findings have important implications for supporting the social health of people with dementia in public space and suggest a dementia-informed approach to public policy. With an ageing population who will continue to live at home, society will need to be dementia-informed as a starting point to ensure social health for all citizens.

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