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

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1 Introduction

1.1 Dementia, social health and mobility

Globally, the number of people with dementia is increasing. The prevalence of dementia varies by geography however, the overall global increase is commonly associated with a worldwide ageing population (Livingston et al., 2020; Prince et al., 2013). The World Health Organization (WHO) has designated dementia as a public health priority and developed a global action plan to improve the lives of people with dementia and their caregivers, while decreasing the impact of dementia on individuals, communities and countries (Dua et al., 2017). It has been estimated that over 75 million people worldwide will experience some form of dementia by 2030 (Prince et al., 2015). The actual number of people with dementia is unknown where many people, especially at the early stage, are not diagnosed (Prince et al., 2015; Van Den Dungen et al., 2012). Regardless if a person is living with a formal dementia-diagnosis or dementia-related symptoms, they can benefit from innovations in care such as memory clinics and technology (Clare et al., 2019; Hoel et al., 2021; Low et al., 2011). Although age is the most well known risk factor for dementia (Abbott, 2011), evidence suggests that dementia is not a consequence of ageing and there are modifiable risk factors, such as hearing impairment, physical inactivity and low social contact, that can prevent or delay the onset of dementia (Livingston et al., 2020). In several Western countries, increasing healthcare costs and the preference to stay at home as long as possible has led to the deinstitutionalization of long-term care for older adults including those with dementia (Han et al., 2016; Low et al., 2011; Van Der Roest et al., 2007). Based on this shift in policy and preference, more people with dementia interact with public spaces however these spaces are not recognized as a dementia setting (Blackman et al., 2003).

The way that dementia is understood by the general public and portrayed in media, mostly illustrating the end-stage symptoms, has resulted in dementia being the most feared disease in many countries next to cancer (Awang et al., 2018; Van Gorp and Verduyck, 2012). The stigma of dementia has led to a dehumanizing view of people with the disease with a focus on loss and decline (Behuniak, 2010). An emerging approach to dementia research however, has been shifting the focus from loss and decline, to capacity and strength (Vernooij-Dassen and Jeon, 2016). Positive health was introduced by Huber et al. (2011)

who noted the limitations of the World Health Organization (WHO) definition of health. The definition is said to be outdated with a focus on disease and disability. The concept of positive health presents a new view of health with a focus on the ability to adapt and self-manage when experiencing social, physical and emotional challenges. Positive health has a range of indicators which are categorized into six domains: bodily functions, mental functions and perception, spiritual/existential, quality of life, social and societal participation (social health) and daily functioning (Huber et al., 2016). Positive health is reflected in several health policy initiatives in the Netherlands (Den Broeder et al., 2018). The social health domain of positive health has been operationalized for dementia to guide the development of innovative care models and support based on an individual's capabilities (Dröes et al., 2017; Vernooij-Dassen and Jeon, 2016). Social health, in relation to dementia, has been explained through three dimensions which include having the ability to i) fulfill one's potential (e.g., through work or volunteer jobs that relate to an individual's resident's talents), ii) manage one's life with some degree of independence (e.g., taking a walk alone) and iii) participate in social activities (e.g., attending an art club or spending time with friends at home) (Dröes et al., 2017).

The concept of social health has been identified as a valuable framework to study the integration of biomedical and psychosocial dementia research (Vernooij-Dassen et al., 2021). Understanding the mobility of people with dementia can further inform the integration of this research by exploring how social health is associated with place. The mobility of individuals, such as understanding interactions with the built and social environment, can provide valuable insight into the factors that influence health and well-being over time and place (Kwan and Schwanen, 2016). Further, dividing our understanding of mobility into two levels i) patterns (i.e., quantitative research) and ii) experiences (i.e., qualitative research) provides valuable understanding into the complexities of movement between places (Meijering, 2021; Rosenberg, 2016). The health and mobility practices of older adults have been explored by using GPS (Fillekes et al., 2018; Hirsch et al., 2016; Oswald et al., 2010; Wettstein et al., 2015), walking interviews (Otoni et al., 2016) and mixed-method approaches (Franke et al., 2019, 2017; Kaspar et al., 2015; Meijering and Weitkamp, 2016). Such studies have provided insight into how the mobility of older adults can be supported or restricted by the social

and built environment. For instance, supportive features of the built environment (e.g., good condition of sidewalks and benches) and the social environment (e.g., relationships with friends and family) have been positively associated with walkability. However, less is known about how the social and built environment intersect to support older adults' mobility in public space (Hanson et al., 2012). For older adults with cognitive impairments, including dementia, mobility studies are often focused on decline (Lloyd and Stirling, 2015; Van Ooteghem et al., 2018), inequalities through a comparison with healthy older adults (Oswald et al., 2010; Shoval et al., 2011), represented by caregivers or stakeholders (Montero-Odasso et al., 2018; Phinney et al., 2016) or an exclusion of people with dementia (Hirsch et al., 2016). Such studies contribute to the narrative of loss and decline of people with dementia. A recent study in the UK, Scotland and Sweden has shifted the way the geographies of people with dementia are understood by emphasizing how neighborhoods support the agency and positive actions of people with dementia who live at home. This perspective is gained through a mix of qualitative methods such as walking interviews and semi-structured interviews. Further, this study included participants with a range of dementia-related symptoms, not a formal diagnosis, as an approach to capture a range of experiences of individuals who are not diagnosed or choose not to disclose the type of dementia (Clark et al., 2020; Keady et al., 2012; Li et al., 2021; Odzakovic et al., 2021, 2020; Ward et al., 2021, 2018). This thesis, using a mixed-method approach, builds upon this research by exploring how people with memory problems and dementia in the Netherlands make meaning from their environment through daily mobility patterns (e.g., through GPS data) and mobility experiences (e.g., walking interviews). The mobility practices within social and built environments bring insight into interactions that inevitably implicate social health.

1.2 Dementia in the Netherlands

The Netherlands is a small western European country known for a flat landscape, cycling and innovation. The country's healthcare system has characteristics of both conservative and social-democratic regimes and a social health insurance system (Böhm et al., 2013; Esping-Andersen,

2003). Of the 17 million people who live in the Netherlands, 19.5 percent are over the age of 65 (CBS, 2020). It is estimated that 6.9 percent of the total population in the Netherlands has dementia (World Health Organization, 2017). The type of housing where people with dementia live in the Netherlands often depends on the stage of the disease, caregiver availability and other health impairments. People with dementia are housed and cared for based on three options: ageing in place at home with care provided in the number of hours required for care, institutional care/nursing homes and small-scale group accommodation (van Hoof et al., 2009). According to the Dutch National Dementia Strategy, the majority of people with a dementia diagnosis in the Netherlands live at home and 24% live alone (Alzheimer Europe, 2021). People who live at home with dementia in the Netherlands are often provided care by a combination of informal care (e.g., family member) and formal care provided by professional home care support. In addition, several Dutch institutional care home facilities make services available to the broader community, not only the residents. Services such as meals, social activities and adult day services allow the facility to integrate into the community as a support hub for both the residents of the facility and those living at home in the broader community (Glass, 2014). The Netherlands are also known for designing small scale, home-like environments for innovative dementia care including the internationally renowned dementia-village model known as the *de Hogeweyk*. This village is home to 152 residents who live in small houses and have open-access to village amenities including a grocery store, hair salon, and pub (Glass, 2014).

1.3 Thesis objective

The objective of this thesis is to explore how mobility research can contribute to the development of the concept of social health for dementia. Specifically, this thesis focuses 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. Well-being, in the context of this thesis, is defined as “when individuals have the psychological, physical and social resources they need to meet a particular psychological, social and physical challenge” (Dodge et al.,

2012: p. 230). The purpose of this research is to contribute to emerging research that highlights the abilities and strengths of people with memory problems and dementia. The limitations and barriers experienced by people with dementia have been well documented therefore, I have taken the opportunity to explore a more empowered side of dementia.

1.4 Data and methods

This thesis is based on data collected in the Netherlands during the first phase of the COORDINATEs project (teChnology tO suppORt DeclsioN making about Aging aT homE). COORDINATEs is a multi-pronged study comprising four work packages, each under the leadership of team members in a different country (Box 1.1). The aim of the overall research project is to understand the mobility patterns and mobility experiences of older adults with memory problems living at home and how this data can improve autonomy and inform shared decision-making (SDM) about housing options. Chapter 2 outlines the structure of the project including a description of the objectives, design and methodology used in each work package.

The objective of the first phase of the COORDINATEs project was to assess the mobility patterns and mobility experiences of people with memory problems and dementia using a mixed-method approach.

Box 1.1: COORDINATEs project overview

The COORDINATEs project (teChnology tO suppORt DeclsioN making about Aging aT homE) is:

- A three year mixed method study with a focus on older adults with memory problems
- An interdisciplinary, inter-professional, inter-sectorial study
- Led by an international project team with representatives in Canada, Sweden and the Netherlands
- Designed to collect data to provide a comparison between countries

Data were collected through i) a sociodemographic survey, ii) a walking interview, iii) GPS tracking, iv) travel diary entries, and v) an in-depth interview. Each method provided unique data and, in combination, the data provided a comprehensive overview of mobility. Participants for this thesis were recruited throughout the northern part of the Netherlands between November 2018 and July 2019 using several methods including community outreach, flyers and media.

There were three inclusion criteria for participation in this study: i) being over the age of 65 years, ii) living at home independently iii) and experiencing memory problems. Careful and sound ethical best practices for ethically involving people with dementia in research were considered throughout this study, specifically the recruitment and informed consent processes (McKeown et al., 2010). The term “memory problems” was used to recruit and refer to participants for this study where the terminology is considered a less contentious term for a dementia study where not all people with dementia, especially at the early-stage of the disease, have a formal diagnosis or may feel stigmatized by the word (Hellström et al., 2007; Novek and Wilkinson, 2017). This broader, inclusive approach to recruit participants with a variety of experiences related to memory problems. The term “dementia” is only used in circumstances where participants, or the caregiver, used the term. Also, using a flexible approach to data collection, participants were not excluded from the research if they could not participate in all data collection activities. In these circumstances, the research methods were adapted based on participant preference. The findings are presented in Chapters 4, 5 and 6.

1.5 Thesis structure

This thesis consists of seven chapters inclusive of an introduction, a research protocol, a scoping review, two articles based on empirical data, a policy analysis and a discussion. Chapter 2, *Technology to Improve Autonomy and Inform Housing Decisions for Older Adults with Memory Problems who Live at Home: Protocol for a Multi-Pronged Mixed Methods Study in Canada, Sweden and the Netherlands* (Sturge et al., 2021c), is the research protocol of the COORDINATEs project which describes the theoretical and methodological context of which the data for this

thesis were collected. Chapter 3, *Features of the social and built environment that promote the well-being of people with dementia who live at home: a scoping review* (Sturge et al., 2021d), is a scoping review which summarizes findings from the literature on how features of the social and built environment contribute to the well-being of people with dementia in a community context. The majority of the articles included in this review were from the UK and Sweden 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, *Exploring assets of people with memory problems and dementia in public space: a qualitative study* (Sturge et al., 2021a), builds upon the scoping review by identifying more specific “assets” opposed to the more generic “features” as described in Chapter 3. 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 provide insight into the mobility experiences which indicate that assets can be used to support navigation in public space and support social inclusion. Chapter 5, *Using the concept of activity space to understand the social health of older adults living with memory problems and dementia at home* (Sturge et al., 2021b), builds upon the previous chapter through the concept of activity space by exploring both mobility patterns and mobility experiences. Chapter 6, *Exploring dementia-informed policy and practice to promote the social health of people living with memory problems and dementia in Groningen and villages in the Netherlands* (Sturge, 2021), brings together the findings from the previous chapters into a planning and public policy context. Chapter 7 is the concluding chapter which discusses the results and the implications of these findings on policy and future research.

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