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

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Using the concept of activity space to understand the social health of older adults living with memory problems and dementia at home

Abstract

Globally as the population ages, the prevalence of dementia will increase. Simultaneously, there is a trend toward people ageing at home. Therefore, more people will be ageing at home with dementia, as opposed to institutional environments. In this context, there has been a recent shift in research exploring ways that people can live well with the consequences of the disease. As a part of this emerging research, the social and spatial aspects of the lives of people living with memory problems are becoming increasingly of interest. The aim of this article is to use the concept of activity space to examine the social health of older adults with memory problems and dementia who live at home. Activity space data were collected from seven older adults experiencing memory problems and living at home in the Netherlands. Using a mixed-methods approach, insight into their activity spaces were gained through walking interviews, 14 days of global positioning system (GPS) movement data, travel diary entries and in-depth interviews. The GPS data, travel diary data and interview transcripts were analyzed using a grounded visualization approach. Our findings show that participants interact independently in routine activity spaces but depend on others to participate in occasional activity spaces. Interactions within both these spaces contribute to the social health of older adults with memory problems and dementia who live at home. Additionally, participants used coping strategies and decision-making to maintain autonomy in daily life. The findings can inform dementia-friendly initiatives and social health care planning.

Keywords: The Netherlands; Qualitative GIS; Mixed Methods; Memory Problems; Dementia, Social Health; Older Adults; Ageing-in-place

5.1 Introduction

As the population ages, the prevalence of dementia will increase. Simultaneously, there is a trend toward people ageing at home. Therefore, more people will be ageing at home with dementia, as opposed to institutional settings. To promote healthy ageing and independence of older adults who live at home in general, and those experiencing dementia in particular, ageing-in-place policies and dementia-friendly initiatives are being implemented. Globally, communities are becoming more dementia-friendly by adapting practices, such as person-centered care, dementia awareness education and environmental design, to enhance the quality of life people living with dementia (Hebert and Scales, 2019). The foundation of these practices is to support people living with dementia to remain autonomous and engaged in society and enhance public awareness of dementia (Cahill, 2020; Førsund et al., 2018). While ageing in place is considered to be the desire of most people with dementia (van der Roest et al., 2009), it is important to note that living at home can present challenges for people with dementia related to navigating environments outside of their home and social isolation (Gibson, et al., 2007; Mitchell and Burton, 2006; Odzakovic et al., 2020).

In 2015, it was estimated that approximately five percent of the elderly population had dementia worldwide (Dua et al., 2017). These prevalence rates are predicted to increase due to population growth and demographic ageing. However, rates are prone to underestimation where many people experience a range of behavioral and cognitive symptoms associated with dementia but may not receive a formal diagnosis until the late stage of the disease (Prince et al., 2013). Without a formal diagnosis, individuals with dementia-related symptoms can be excluded from disease estimations and services (Michalowsky et al., 2016). A recommended approach to include the experiences of people with a range of dementia-related symptoms is using broader terminology, such as "memory issues" and only use the actual term "dementia" if it is used by the individual (Hellström et al., 2007; Novek and Wilkinson, 2019). This inclusive approach results in research that represents a new understanding of a range of experiences related to memory problems. The aim of this article is to use the concept of activity space to examine the social health of older adults with memory problems and dementia who live at home. Findings from this research can inform social health

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care planning and contribute to the development of dementia-friendly practices which are based on the perspectives of older adults experiencing memory problems.

5.1.2 Theoretical Framework

Social Health

Traditionally, dementia research primarily focused on the cognitive consequences of the disease but there is an emerging interest to understand the social and spatial aspects of a person with dementia's life (Dröes et al., 2017; Keady et al., 2012; Vernooij-Dassen and Jeon, 2016; Ward et al., 2018). An evolving concept of health is the foundation for this article. In this paper, we refer to Huber et al.'s (2016; p. 1) definition of health as having "the ability to adapt and self-manage when facing social, physical and emotional challenges" as the starting point. Huber et al. (2011) identified three aspects of health: physical, mental and social health. Social health is 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). These dimensions have been further operationalized for dementia (Table 5.1) 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).

Although this approach provides insight into the capabilities of a person, there is limited research on how to promote (Dröes et al., 2017) or measure the social health (Mangiaracina et al., 2019) of people with dementia living in a community setting. Ward et al. (2018) were the first to explore the social health of people living with dementia who live at home on a neighborhood level. Their findings highlighted how neighborhoods create conditions, such as routine practices and being connected to neighbors, which allow individuals to manage their lives with a degree of independence that supports social health.

Activity Space for Health Research

A useful concept to explore spatial interactions in neighborhoods is the concept of activity space. Building upon the findings of Ward et al.

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Table 5.1: The operationalization of the social health framework for people with dementia based on Dröes et al. (2017)

Dimension of Social Health	Description
Capacity to fulfil one's potential and obligations	The ability of a person living with dementia to function in the society according to their competencies and talents ("potentials") in the best possible way and to meet social demands ("obligations") on a micro and macro level
Manage life despite the disease	The ability to manage life with some degree of independence, can be operationalized as the ability to preserve autonomy and to solve problems in daily life, as well as to adapt to and cope with the practical and emotional consequences of dementia
Participation in social activities	The act of being occupied or involved with meaningful activities and social interactions and having social ties and relationships that are meaningful to the person living with dementia themselves

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(2018), and suggestions for future research on the dynamic outdoor space experienced by community-dwelling people with dementia (Keady et al., 2012), exploring behavior over time and space can provide further insight into an individual's relationship with their socio-spatial environments. The everyday experiences of people with dementia living in a neighborhood setting have been explored using a range of qualitative and participatory methods (Odzakovic et al., 2020; Phinney et al., 2016; Ward et al., 2018). Our study further explores the daily mobility patterns using a mixed-method approach. For the purpose of this article, activity space is defined as space outside of the home that includes a subset of locations that are routinely and non-routinely visited, and the corresponding travel routes, which an individual has direct contact with over a period of time (Hirsch et al., 2014, Golledge and Stimson, 1997; Zenk et al., 2018). The concept of activity space has been recognized as an important health research tool to explore environmental determinants of health and inequalities (Kestens et al, 2018), diet and physical activity (Zenk et al., 2011), accessibility of healthcare opportunities (Sherman et al., 2005) and social inequalities (Shareck et al., 2014). There are three common approaches to explore activity space: spatial methods, qualitative methods or mixed-methods. A common method to capture

the spatial and temporal components of an individual's activity space is through the use of GPS data. When using GPS data in health research, a minimum of 14 days of monitoring is suggested to accurately measure attributes of individual's routine activity space (Zenk et al., 2018). Qualitative activity space data, such as travel diaries, interviews and walking interviews, are also used to understand travel behavior. GPS data and qualitative data can be analyzed independently or further triangulated using qualitative GIS methods to provide a unique insight into the meaning and experiences of activity spaces (Cope and Elwood, 2011; Mennis et al., 2013).

There is limited research on activity space in later life. According to a recent systematic review (Smith et al., 2019), there are just nine studies that used the concept of activity space to explore the time-space interaction of older adults. The contributions of these studies to the knowledge of activity space in later life have been threefold. i) The size and structure of activity spaces in later life provides important insight into the mobility of older adults related to neighborhood walkability, driving patterns and physical support to go outside (Hirsch et al., 2014). ii) The everyday mobility practices and different modes of travel of older adults can be understood by using GPS (Hirsch et al., 2016) and mixed-method approaches (Franke et al, 2017; Meijering and Weitkamp, 2016). The work by Hirsch et al. (2016) compared older adult activity spaces boundaries, created with GPS, with administrative neighborhood boundaries. Findings indicated that compared to activity spaces, neighborhood boundaries do not reflect the geographic space or resources used by older adults. A mixed-method approach provides insight into socio-spatial and temporal complexities of older adult mobility (Franke et al., 2017) and furthermore, a deeper understanding into population specific data collection methods, time-geographies and micro-geographies (Meijering and Weitkamp, 2016). Franke et al. (2017) found that combining perceptions of place and time provided insight into the factors that influence movement in neighborhoods overtime and how older adults rely on public transportation to maintain mobility patterns. Meijering and Weitkamp (2016) observed social mobility patterns of older adults and noted that mobility patterns can be constrained when a participant's time-geography differs from time made available by their family and social contacts. iii) Using a qualitative GIS approach, the everyday activities of older people are understood on a neighborhood

level by exploring person-place interactions (Hand et al., 2018), linking social factors to perception and interactions (Milton et al., 2015) and understanding how neighborhood environments and transportation impact livability (Vine et al., 2012). Based on Smith et al.'s (2019) review, activity space studies on older adults have so far focused on older adults in good health or who experience the "normal" impairments that come with age. This means that insight into the activity spaces of older adults with a specific illness or disability is lacking. Therefore, one of the key contributions of this paper is to provide insight into the activity spaces of older adults who experience memory problems and dementia.

5.2 Methodology

When involving people with dementia or memory problems, careful and sound ethical practice is essential, which is why we begin our methodology section with an ethics discussion. Best practices for ethically involving people with dementia in research, specifically the recruitment and informed consent processes (McKeown et al., 2010), were thoroughly considered in the design of this study. For the recruitment phase, the research team met with dementia case planning teams and community organizations to ensure the recruitment material, terminology and research methods were appropriate to connect with participants. Based on these consultations and findings from earlier research, the term "memory issues" was used to recruit participants for this study. "Memory issues" 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, 2019). It was decided to use a broader, inclusive approach to recruit participants with a variety of experiences related to memory problems and mention "dementia" in circumstances where the participants, or the caregiver, used the term. A layered approach, based on an adaptation of the process consent model for people with dementia (Dewing, 2002), was used to obtain written informed consent from participants. During this process, participants were carefully explained detailed information on the research project, with what participation would entail, as well as safeguard measures in place to protect data, rights of participants and how to contact the

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research team in case of queries including withdrawing consent. After this information was carefully explained, the participants were asked if they wanted to participate. If they agreed, they signed a consent form and provided a copy for their records. Consent was also re-confirmed at the beginning of the second meeting with the participants.

Participants for this study were recruited throughout the northern part of the Netherlands using several methods including community outreach, flyers and media. There were three inclusion criteria: i) being over the age of 65 years, ii) living at home independently iii) and experiencing memory problems. Although our age limit for recruitment was 65 years and older, a case manager made a referral for a 59 year-old who had a dementia diagnosis. After speaking with the referral, it was decided to accept them as participant where their lived experience of dementia and life phase was similar to other participants.

All data were collected in Dutch with five methods: i) a socio-demographic and self-reported health survey, ii) a walking interview iii) GPS tracking, iv) travel diary entries, v) and an in-depth interview. A layered approach of data collection provides complementary data and is considered a best practice in dementia research (Clarke and Keady, 2001). Project information material was developed to include infographics and text to clearly describe the methods and the sequence of data collection to stakeholders and participants (Figure 5.1).

After obtaining written consent, and completing a short socio-demographics survey, participants were asked if they could walk a typical route they regularly take near their home. During the audio-recorded walking interview, participants were asked about typical experiences and social encounters they have when taking the route. This interview was also used as an opportunity to demonstrate how to use the GPS tracking device. Participants were provided with a GPS tracking device (QStarz BT-1000X) to track their movement for a period of 14 days. To complement the GPS data, travel diaries were provided to record activities outside the home. The participants were asked to record daily activity information such as date, day of the week, time of departure and arrival time, location, purpose of the activity, mode of transportation, with whom they traveled with and did the activity with, the use of a mobility aid and if the activity was planned. After two-weeks of data collection, an in-depth interview was set up based on the participant's availability. The purpose of this audio-recorded interview was to discuss

Provide basic information about yourself by filling out a short survey.
Filling out the survey takes around 15 minutes.

A walking interview: a one hour interview where you will walk with a researcher to a common or familiar destination in your living environment and discuss your experiences.
This interview will be audio recorded and lasts for about one hour.

Between the two visits, the researchers will ask you to:

Wear a Global Positioning System (GPS) tracker for fourteen consecutive days to measure your movement outside your home. The tracker will be provided by the research team and they will provide you with an orientation on how to use it. The GPS tracker is safe to use anddoes not interfere with other – medical – equipment.

Keep a daily activities diary for two weeks. Filling out the diary takes about five to ten minutes per day.

A debrief interview: a one hour interview where the reseachers will ask you questions about your activities and the places you normally go. This interview will be audio recorded and will last for about one hour.

Figure 5.1: Data collection information material for participants and stakeholders (English translation)

the activities that the participants engaged in during the data collection period and to gain perspective on the meaning and the experiences of the activities. The travel diary was used to prompt discussion and allow participants to feel more confident to recall the events that they recorded. These interviews typically lasted between 45–60 minutes and the participants were provided a small appreciation gift for their contribution.

Once the data collection was complete, the audio-recorded interviews were transcribed verbatim, with the locations and names pseudonymized, and exported into ATLAS.ti 8.4. Data from the transcribed interviews were coded using a grounded visualization approach. Similar to the method described by Franke et al. (2017), an open coding approach identified codes based on most common issues, later compared across

interviews, and then combined into a theme. GPS data were edited in Microsoft Excel and imported into V-Analytics to create a spatial database of activity locations and trips between locations. Similar to the method used by Meijering and Weitkamp (2016), V-Analytics software was used for the time-space movement analysis – an analytical feature that is limited in other GIS packages. Activity locations and trips for each participant were identified by connecting GPS points. When GPS points were connected within an 80 meter bounding box for periods longer than five minutes, an activity was created and the points that fell outside the boundary were linked as trips between events. Once all the activity locations and trips were identified, the corresponding .csv files were exported from V-Analytics and imported into ArcMap 10.5.1. Within ArcMap, activity locations and routes were contextualized by linking maps to pseudonymized travel diaries. The emerging themes from the in-depth interviews were then connected to trends seen in the maps, which provided insight to participant's spatial behavior. Identifying information in the maps (i.e., street network files) were removed in the final stages of the analysis.

5.3 Findings

Data were collected between November 2018 and July 2019 from seven older adults who live in urban and rural settings in the Netherlands. Participants ranged in age from 59 and 93 years old and five were women. The Dutch old-age pension (AOW) was the main source of income for six participants and four participants were not educated beyond a primary school level. The length of time living in the neighborhoods varied from four to over 50 years and most participants mentioned having frequent social contact with their neighbors. During the data collection period, all participants had contact with family and spent time with friends.

  Two of the participants were referred to the project by a dementia case-manager while others self-referred and contacted the research team based on information presented at a community meeting (n=3), a flyer (n=1) and the project website (n=1). Two of the participants openly spoke about having dementia while others described memory problems that they encountered. All participants collected travel diary data for 14 days however; GPS data were collected for a minimum of

Table 5.2: Characteristics of research participants

Name	Gender	Age Range	Marital Status	Geographical Setting
Marie	Female	80 – 89 years	Widowed	Rural
Harold	Male	60 – 69 years	Single/divorced	Urban
Netty	Female	70 – 79 years	Widowed	Urban
Bea	Female	70 – 79 years	Married	Urban
Helena	Female	70 – 79 years	Single/divorced	Rural
Vera	Female	90 – 99 years	Single/divorced	Urban
Warren	Male	50 – 59 years	Married	Urban

nine to 14 days. For some participants, their travel diary data did not correspond with the GPS data and vice versa.

All the study participants were able to walk independently to locations nearby their home. Five of the participants used a walker or a mobility scooter and three used a bicycle. Even though activities occurred during different times of the day, doing activities in the afternoon was most common while doing activities in the evening was least common. Participants did activities independently but also with friends and family. All participants spent at least one day at home during the 14 days. The reasons for staying at home included needing a day of rest, not feeling well or waiting for an appointment (e.g., doctor visit or scooter technician).

Activity Spaces

There are two activity space patterns identified in this study: routine activity space and occasional activity space. Two clusters related to distance were observed in the spatial data; within 7.5 kilometers of the home and beyond. The distance threshold of 7.5 kilometers is considered a short distance trip in the Netherlands where people are more likely to use active transport, such as walking or cycling, than motorized transport (Scheepers et al., 2013). The data from the travel diaries provided further insight into the characteristics of these of spaces (Table 5.3). For example, activities within the small activity space

Table 5.3: Comparison of Routine and Occasional Activity Spaces

Features of Routine Activity Space	Features of Occasional Activity Space
Within a 7.5 km distance of the home	Beyond a 7.5 km distance from the home
Independent and dependent activities	Activities dependent on other people's time
Mode of Transportation: walking, bus, bicycle, car (passenger)	Mode of Transportation: car (passenger), bus, train
Activities and trips were routine – visited easily and often more than once during the data collection period	Activities and trips locations were an occasion - visited only once during the data collection period

were often "routine" while activities in the larger space happened less frequently and were "occasional".

1) Routine Activity Space

Routine activity spaces are characterized by travel patterns close to home with multiple activity locations and multi-purpose trips. Most activities were located nearby a participant's home and they traveled to these activities, often independently, by walking (with or without a mobility aid), mobility scooter, bicycle, bus or car. Routine activities include visiting friends, neighbors or relatives, shopping, grocery shopping or attending a health appointment. Several of the activities were scheduled (e.g., bingo, church or physio) or a part of a routine (e.g., coffee with neighbors on Sundays or taking a daily walk around the same time, along the same route). Three participants report going to nursing home facilities. One participant went to a nursing home several times a week for dementia daycare activities, while others visited the facilities for social activities or to visit a friend. Vera was one of the participants who regularly visits a friend in a nursing home. For Vera, most of her activities are near her home. Although she has access to a taxi service for older adults, she prefers to use the city bus where it makes her feel independent. Vera describes the typical route she takes (Figure 5.2) as well as the details of her visit.

> .... I have a friend with mental health problems who has lived in [nursing home name] for many years [...]. I go there, because nobody
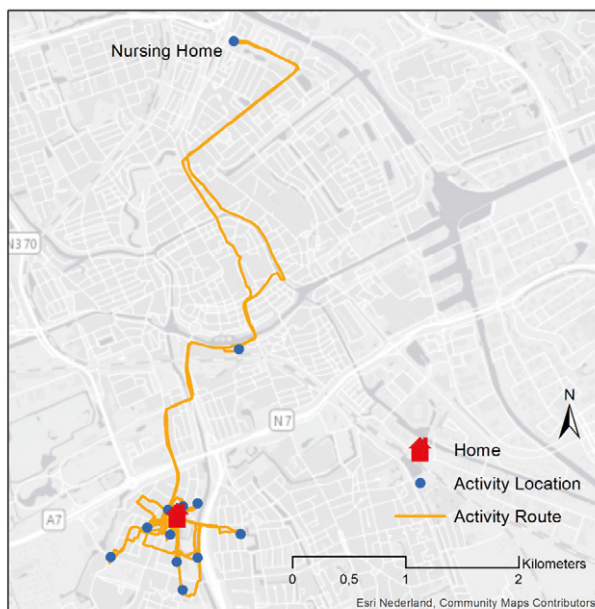
Figure 5.2: Vera's activity space

visits her […] I take bus number 77 and then to Daisy street, nearby nursing home. I will arrive at around 10:15 and then there will be different groups of course, experiencing impairments and mental health problems. They will come to me with open arms. Sometimes one of the helps [staff] asks "madam, would you like to stay and eat with us?" No, I say that is not how it should be [purpose of the visit] but sometimes I do stay to eat and they like it.

– Vera

Vera confidently described how she navigates the 6.5 km route to see her friend and the warm welcome she receives, with an option to stay for a meal. This quote demonstrates how participants travel independently within their small activity space to engage in activities that are meaningful for them.

2) Occasional Activity Space

The larger activity spaces were characterized by travelling more than 7.5 kilometers to a special event or appointment that occurred on an occasional basis. Four of the seven participants went to an appointment
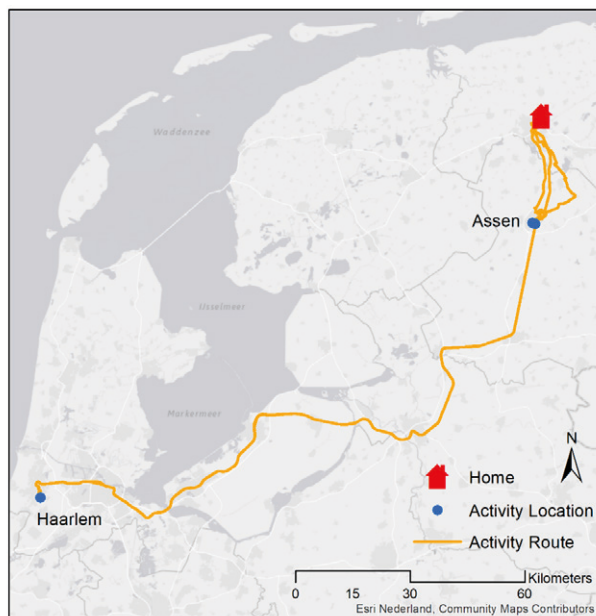
Figure 5.3: Harold's activity space

or an "occasional" activity located in a larger activity space. These activity locations were only visited once during the 14 days of data collection; activities were planned and mainly related to visiting family. Most participants travelled to these locations by car, as a passenger. An exception is Harold, who used public transportation to meet with family members on two occasions (Figure 5.3). For the first trip, Harold met his brother-in-law for a day out in Assen to which they both travelled. Harold travelled 102 km (return), of which 30 minutes by bus, and returned home by train while his brother-in-law travelled two hours by train. Together they visited a museum, ate, drank and walked around town. Harold explained that he likes spending time with his brother in law and they tend to get together, as they did, about once a year. For the second trip, Harold travelled two hours by train to the western part of the Netherlands (500 km return) to Haarlem to see his family. When asked about this family visit, he expressed both a sense of independence, and burden, related to taking the trip:

> [Travelling to see my family] is quite tough, and actually, it becomes harder every time. [The journey] becomes too long but they do not

come to me. Yes, actually I should say something about that because it is a one-way direction. And on one hand I do not like it, but on the other hand, I like to continue traveling for as long as I can.

– Harold

Comparing the two trips, the first trip was more enjoyable for Harold. It appears that the one-way relationship with his family was more of an issue for Harold than the distance. This experience highlights a theme of reciprocity in relationships, which was also mentioned by two other participants. For Helena, although she engages in several activities outside her home, she described the importance of having people also come to her home.

They (my friends) will come to me and I want them to visit in return. I do not want to go out all the time....they also have to visit me. That is very important

– Helena

Although both Harold and Helena are willing and able to visit others, they both emphasized how important and meaningful it is for them to people come see them in return.

Coping Strategies to Navigate Space
Four participants in this study talked about experiences of getting lost. Netty was one of these participants and she talked about how she would sometimes get lost while cycling. Netty moved to a senior's flat four years ago, as suggest by her son, after she had a stroke. She uses a bike to visit friends, shop and attend community dinners. Although Netty lived in her neighborhood for a number of years, she described the surroundings as unfamiliar and how she often practices routes with friends to ensure she can go to new places alone. Netty also described a situation when she got lost while biking:

I went to the library and I did not know the way home. I started cycling. I thought this is not going right, I have to ask [someone] [...] madam, listen, I have to go to [home location]. [They will say:] Oh, madam you are totally out of way. I say: yes, I figured that out. They then cycle with me. I say thank you very much, now I know the way.

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Well, but I felt like crying [because] I had already cycled for one hour. […] I became nervous, and I thought darn, why do I not remember it. That has to do with age, because I will become 78. I should not give up, and I will not, but I think it is annoying.

– Netty

Netty recalled how she biked to a location but then had difficulty remembering how to get back home. After cycling for an hour, she decided to ask a stranger for help. Other participants described similar situations where they were aware that they were lost and identified effective coping strategies to get home. Another coping strategy that was mentioned was the use of landmarks to get "back on track". Despite distressful experiences, such as Netty's, participants typically did not let these affect their activities and movement.

Three participants talked about difficulties navigating traffic situations. Bea described how she has adapted her biking routes to avoid overwhelming situations caused by traffic:

I will go via Lilac Street where there is a traffic light. Then I do not have much to do with traffic. […] We took the outside route to the department store by bike, but then there are 3 or 4 roundabouts. Then all the cars come so and so. That is impossible [for me to navigate]. I cannot do that anymore. [But] when we biked back from the department store via Tulip Street, […] there was a traffic light and the you go left via the Dahlia Street and then you are at [adjoining street]. That is something different

– Bea

By avoiding routes with roundabouts, a common built environment feature in the Netherlands that are shared by cars, buses and bicycles, Bea confidently continues her route by bike. Identifying a route with traffic lights is an effective coping strategy that Bea uses to deal with overwhelming traffic situations.

Decision-making to Manage Activities

There were other busy activities, beyond traffic, that were managed by the participants. For Warren and his wife, for instance, they decided that a dementia diagnosis would not hold them back from the activities that

they like to do. They told us how Warren wanted to go to the community fair as he used to do. Although this is known to be a loud and busy event, they decided to go, just so that he could experience it. However, they decided to leave five minutes after arriving. That short time was enough for Warren to "get out of the house" and experience the fair. They also described a situation when their family made accommodations for him to attend a big family party:

Interviewer: *And how is that for you with 78 people?*

Warren: *That is too busy for me. Then I will go somewhere where it is less busy…They have a very big garden. There were people there, there were some there (pointing). Everywhere there were people of course.*

Warren's wife: *Warren notices quickly that somewhere at the back they [the family] had created a [comfortable] place for him where he could sit. Two chairs. Not more. So that someone could sit with him for a talk. They made the place purposely for him.*

During this situation, Warren clearly described how the activity is too busy for him but he makes a choice to find a way, or place, to still experience the activity but in a less busy way. Although some participants continue to go to "busy activities", others talked about deciding to no longer participate in activities that they experience to be too busy. Bea, for instance, described how she no longer participates in activities that she finds too overwhelming, such as going to church or a museum:

Bea: *…. I don't go to church anymore, there are too many stimuli for me….Since four or five years, I have vascular dementia, and from that time, those things (stimuli) started.*

Interviewer: *…. So that is not possible anymore to go there (church)?*

Bea: *No, that is too much [….] What I often did in the past with my parents, to the museum, a whole day. I'm not able to do that anymore. The last time that we were in a museum…I sat down on a bench. The impressions are too much for me and it takes too long. It makes me too tired.*

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Bea's story illustrates how activities that she used to enjoy, have become a burden and no longer enjoyable. As a result, she decided to discontinue these activities. Overall, in discussing busy traffic situations and activities participants openly talked about feelings of becoming overwhelmed, but also described ways they adapted to those situations to allow them to engage in a meaningful activity, or to decide that an activity has become so distressful that it is discontinued.

5.4 Discussion

The aim of this article was to use the concept of activity space to examine the social health of older adults with memory problems and dementia who live at home. Our findings show that participants interact independently in routine activity spaces but depend on others to participate in occasional activity spaces. Interactions within both these spaces contribute to the social health of older adults with memory problems and dementia who live at home. Additionally, participants described using coping strategies and decision-making to effectively manage overwhelming situations and activities. These findings support the concept of health proposed by Huber et al. (2011) and the social health framework related to dementia (Dröes et al., 2017; Vernooij-Dassen and Jeon, 2016). Further, this study sheds light on the capacity and contributions of people with memory problems and dementia which challenges the deficit and disability narrative associated with dementia (de Vugt and Dröes, 2017; Rahman and Swaffer, 2018). Highlighting the positive experiences that people have when navigating space, despite the consequences of memory problems, can inform dementia public awareness campaigns and person-centered care (Wolverson et al., 2016). Moreover, understanding where people go, and the reasons for engaging in particular activities, provides an important perspective that can contribute to making communities more dementia-friendly (Han et al., 2016).

All participants in this study were able to engage independently in routine activities nearby their homes. However, for activities beyond 7.5 kilometers from their home, participants were more dependent on other people to engage in "occasional" activities. Routine activity spaces relate to more positive social health experiences whereas participating in

activities within occasional spaces can both contribute to, and constrain, social health where participants depend on other people's time. These observations suggest an inverse relation between the size of an activity space and social health. Previous health research has differentiated routine activity spaces from activity spaces in general (Sherman et al., 2005; Zenk et al., 2018) and our study contributes to these findings by defining the activity space outside the routine space as occasional. Further, our findings build on the work of Hirsch et al. (2014), who identified small and large activity spaces based on GPS data from older adults in Vancouver, Canada. Similar to our study, they found smaller activity spaces to be associated with walkability while larger activity spaces were associated with car usage. Our mixed-method approach expands on their findings by providing insight into the specific experiences and destinations of a specific older adult population. In addition, neighborhoods in the United Kingdom (UK) and Sweden have been found to play an essential and supportive role in the day-to-day lives of people affected by dementia (Clark et al., 2020; Odzakovic et al., 2020, 2021; Ward et al., 2018). Our research builds on these findings as we explored everyday practices beyond the scope of a neighborhood. In spite of a different way of looking at space, we noted similarities between routine spaces and neighborhoods. For example, individuals use coping strategies to stay socially connected in neighborhoods (Odzakovic et al., 2021) and routines contributed to well-being (Clark et al., 2020). Another common theme that emerged from our analysis was the importance of reciprocity in relationships especially having family and friends taking time to visit the participants in their routine spaces. This theme follows on Ward et al. (2018) and Clark et al. (2020), who highlight the importance of reciprocity in the relationships for people with dementia. Reciprocal relationships have a positive influence on the health of older adults and support their ability to cope with life challenges (Fyrand, 2010). Therefore, we conclude that coping strategies, routines and reciprocity would be useful indicators to measure social health.

Getting lost is a common behavior associated with dementia and memory problems. People with dementia can experience problems with recognizing environments or remembering where they were going (Gibson et al., 2007). Some of the participants openly discussed their experiences of getting lost and relying on coping strategies to orientate themselves. Despite these distressful experiences, some of which were

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noted to be happening more frequently, participants did not say that they would stop doing activities independently, which demonstrates an ability to self-manage circumstances related to memory problems. Contrary to the "shrinking world" model (Duggan et al., 2008), participants described changes in their outdoor lives as a result of memory problems but did not emphasize missing out on activities due to a loss of independence and control. Instead, they demonstrated a capacity to make decisions and choices, which is essential for a sense of agency. This finding supports the capabilities-led approach to dementia (Vernooij-Dassen and Jeon, 2016; Ward et al., 2018; Odzakovic et al., 2020) which emphasizes what people with dementia are able to do, rather than focusing on debiltating experiences.

All participants in this study could easily bike or walk to most activities within their routine activity space. It is important to note that the distance used to define routine space activity (i.e., 7.5 kilometers) is specific to the context of the Netherlands and it is likely that the flat Dutch landscape, bicycling culture and municipal planning has influence on our findings. The mobility of the sample reflects the findings of Kemperman and Timmerman (2009) who found that 23 percent of trips made by older adults in the Netherlands were by bike and over 25 percent were walking trips. These mobility patterns can be related to several age-friendly practices in the Netherlands, such as well-maintained sidewalks or designated bike paths, that support the mobility of older adults (van Hoven and Meijering, 2019). Despite these practices, participants described difficulties navigating traffic situations such as roundabouts. Similarly, roundabouts, a common Dutch traffic-calming measure for bikes and for cars, have been found to be difficult for older adults to navigate where the way they are used are not always consistent (van Hoven and Meijering, 2019; Van Velsen et al., 2019). This is relevant to consider where on an urban planning level one built environmental feature is in place to ease traffic congestion however, this design may influence the mobility of older adults. This finding is in line with results from van den Berg et al. (2011) and Buffel et al. (2014) who suggest that several policy fields, such as transportation policy, should integrate ageing-friendly principles and consider the safety of older adults who travel by bike.

This study contributes to the field of activity space in later life by exploring the day-to-day experiences of older adults with memory

problems and dementia. A notable strength of this study is that each method yields unique data and a qualitative GIS approach results in an enhanced understanding of activity space patterns. Our research also suggests that the temporal aspect of mobility in later life is impacted by memory loss as a chronic and progressive condition. The 14-day window of data collection allowed us to conclude that it is possible to engage in a variety of activities when living with memory problems and dementia. When zooming in to the temporal scale of a day, we found that participants seemed to be restricted to undertaking their activities in the afternoon. Further research may explore other aspects of time within these activity spaces such as the length of time spent traveling to, and engaging in, activities.

  There are limitations of this study. Some days were not recorded in the travel diary or with the GPS tracker which made it difficult to link all data. Similar inconsistencies have been reported in other studies (Meijering and Weitkamp, 2016; Zenk et al., 2018). It is possible that these discrepancies in our study were, at least in part, related to the consequences of living with memory problems, such as forgetting to turn on the GPS or being too tired to do a travel diary entry. Future research could explore these discrepancies in more detail by conducting a primary analysis on the GPS data and the travel diaries prior to the debrief interview. During the debrief interview, participants could then be asked to provide context for the discrepancies and missing data. It is also important to highlight the influence of selective daily mobility bias (Chaix et al., 2012) on the findings of this research. The selective daily mobility bias means that the type of destinations and spatial behaviors can be dependent on the proximity to resources, transportation options or personality characteristics (e.g., introverted or extroverted) which could influence how they would engage in their activity space and therefore influence their social health. Further research is recommended to explore how infrastructure, healthcare policies and urban design in different countries affects the mobility, activity space patterns and social health of older adults with memory problems. Additionally, our sample is ethnically homogeneous therefore, the activity space and social health of people with memory problems from different ethnicities and cultures should be further explored.

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5.5 Conclusion

The findings of this study demonstrate that the concept of activity space provides valuable insight into the routine and occasional activity spaces of older adults with memory problems and dementia who live at home. In this paper, we explored the capabilities of older adults who experience a dementia-related symptom, not necessarily a diagnosis, which provides a more inclusive and less stigmatized impression of dementia that we hope others will further explore. These Dutch findings contribute to the emerging research on social health and spatial aspects of the lives of older adults with memory problems and dementia. Our research demonstrates that individuals with memory problems and dementia engage in activities beyond a physically defined neighborhood setting. These findings have important implications for communities who are adapting dementia-friendly practices. The scope of these practices should reflect engaging in activities beyond the neighborhood level and be implemented on a provincial or national level. Further, this study identifies coping strategies, routines and reciprocity as social health indicators which would enrich person-centered care plans. To effectively enable people to age-in-place with memory problems, policies and care practices should be based on lived experiences.

This study presses the boundaries of dementia research by recognizing that people with memory problems and dementia can navigate routine spaces independently and engage in occasional spaces with support. These findings challenge the impression that older adults with memory problems are in a frail state of mind and cannot maintain autonomy. Future research on the capabilities of older adults with memory problems, will result in more effective decision aids, ageing-in-place policy and effective dementia-friendly initiatives.

References

Buffel, T., McGarry, P., Phillipson, C., De Donder, L., Dury, S., De Witte, N., ... & Verté, D. (2014). Developing Age-Friendly Cities: Case Studies From Brussels and Manchester and Implications for Policy and Practice. *Journal of aging & social policy*, *26*(1–2), 52–72.

Cahill, S. (2020). WHO's global action plan on the public health response to dementia: some challenges and opportunities. *Aging and Mental Health*, *24*(2), 197–199.

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Chaix, B., Kestens, Y., Perchoux, C., Karusisi, N., Merlo, J., & Labadi, K. (2012). An interactive mapping tool to assess individual mobility patterns in neighborhood studies. *American journal of preventive medicine*, *43*(4), 440–450.

Clark, A., Campbell, S., Keady, J., Kullberg, A., Manji, K., Rummery, K., & Ward, R. (2020). Neighbourhoods as relational places for people living with dementia. *Social Science & Medicine*, *252*, 112927.

Clarke, C.L & Keady J (2001) Getting down to brass tacks: a discussion of data collection with people with dementia. In The Perspectives of People with Dementia (H Wilkinson ed.). Jessica Kingsley, London, p. 25–46

Cope, M., & Elwood, S. (Eds.). (2009). *Qualitative GIS: A mixed methods approach*. SAGE.

de Vugt, M., & Dröes, R. M. (2017). Social health in dementia. Towards a positive dementia discourse. *Aging & Mental Health*, *21*(1), 1–3.

Dewing, J. (2002). From ritual to relationship: a person-centred approach to consent in qualitative research with older people who have a dementia. *Dementia*, *1*(2), 157–171.

Dröes, R. M., Chattat, R., Diaz, A., Gove, D., Graff, M., Murphy, K., ... & INTERDEM sOcial Health Taskforce. (2017). Social health and dementia: a European consensus on the operationalization of the concept and directions for research and practice. *Aging & Mental Health*, *21*(1), 4–17.

Dua, T., Seeher, K. M., Sivananthan, S., Chowdhary, N., Pot, A. M., & Saxena, S. (2017). [FTS5–03–01]: WORLD HEALTH ORGANIZATION's GLOBAL ACTION PLAN ON THE PUBLIC HEALTH RESPONSE TO DEMENTIA 2017–2025. *Alzheimer's & Dementia*, *13*(7S_Part_30), P1450-P1451.

Duggan, S., Blackman, T., Martyr, A., & Van Schaik, P. (2008). The impact of early dementia on outdoor life: A shrinking world'? *Dementia*, *7*(2), 191–204.

Førsund, L. H., Grov, E. K., Helvik, A. S., Juvet, L. K., Skovdahl, K., & Eriksen, S. (2018). The experience of lived space in persons with dementia: a systematic meta-synthesis. *BMC geriatrics*, *18*(1), 1–27.

Franke, T., Winters, M., McKay, H., Chaudhury, H., Sims-Gould, J., 2017. A grounded visualization approach to explore sociospatial and temporal complexities of older adults' mobility. Social Science & Medicine 193, 59–69.

Fyrand, L. (2010). Reciprocity: A predictor of mental health and continuity in elderly people's relationships? A review. *Current Gerontology and Geriatrics Research*, *2010*.

Gibson, G., Chalfont, G. E., Clarke, P. D., Torrington, J. M., & Sixsmith, A. J. (2007). Housing and connection to nature for people with dementia: Findings from the INDEPENDENT project. *Journal of Housing for the Elderly*, *21*(1–2), 55–72.

Golledge, R. G., & Stimson, R. J. (1997). Spatial behaviour: a geographic perspective. Spatial behaviour: a geographic perspective.

Han, A., Radel, J., McDowd, J. M., & Sabata, D. (2016). Perspectives of people with dementia about meaningful activities: a synthesis. *American Journal of Alzheimer's Disease & Other Dementias®*, *31*(2), 115–123.

Hand, C. L., Rudman, D. L., Huot, S., Gilliland, J. A., & Pack, R. L. (2018). Toward understanding person–place transactions in neighborhoods: a qualitative-participatory geospatial approach. *The Gerontologist*, *58*(1), 89–100.

Hebert, C. A., & Scales, K. (2019). Dementia friendly initiatives: a state of the science review. *Dementia*, *18*(5), 1858–1895.

Hellström, I., Nolan, M., Nordenfelt, L., & Lundh, U. (2007). Ethical and methodological issues in interviewing persons with dementia. *Nursing Ethics*, *14*(5), 608–619.

Hirsch, J. A., Winters, M., Ashe, M. C., Clarke, P. J., & McKay, H. A. (2016). Destinations that older adults experience within their GPS activity spaces: relation to objectively measured physical activity. *Environment and behavior*, *48*(1), 55–77.

5

Hirsch, J. A., Winters, M., Clarke, P., & McKay, H. (2014). Generating GPS activity spaces that shed light upon the mobility habits of older adults: a descriptive analysis. *International journal of health geographics*, *13*(1), 1–14.

Huber, M., André Knottnerus, J., Green, L., Van Der Horst, H., Jadad, A.R., Kromhout, D., Leonard, B., Lorig, K., Loureiro, M.I., Van Der Meer, J.W.M., Schnabel, P., Smith, R., Van Weel, C., Smid, H., (2011). How should we define health? BMJ (Online) 343, 1–3.

Huber, M., van Vliet, M., Giezenberg, M., Winkens, B., Heerkens, Y., Dagnelie, P. C., & Knottnerus, J. A. (2016). Towards a "patient-centred" operationalisation of the new dynamic concept of health: a mixed methods study. *BMJ open*, *6*(1), e010091.

Keady, J., Campbell, S., Barnes, H., Ward, R., Li, X., Swarbrick, C., Burrow, S., Elvish, R., 2012. Neighbourhoods and dementia in the health and social care context: A realist review of the literature and implications for UK policy development. Reviews in Clinical Gerontology 22, 150–163.

Kemperman, A., & Timmermans, H. (2009). Influences of built environment on walking and cycling by latent segments of aging population. *Transportation Research Record*, *2134*(1), 1–9.

Kestens, Y., Thierry, B., Shareck, M., Steinmetz-Wood, M., & Chaix, B. (2018). Integrating activity spaces in health research: Comparing the VERITAS activity space questionnaire with 7-day GPS tracking and prompted recall. *Spatial and spatio-temporal epidemiology*, *25*, 1–9.

Mangiaracina, F., Meiland, F., Kerkhof, Y., Orrell, M., Graff, M., & Dröes, R. M. (2019). Self-management and social participation in community-dwelling people with mild dementia: a review of measuring instruments. *International psychogeriatrics*, *31*(9), 1267–1285.

McKeown, J., Clarke, A., Ingleton, C., & Repper, J. (2010). Actively involving people with dementia in qualitative research. *Journal of clinical nursing*, *19*(13-14), 1935–1943.

Meijering, L., & Weitkamp, G. (2016). Numbers and narratives: Developing a mixed-methods approach to understand mobility in later life. *Social Science & Medicine*, *168*, 200–206.

Mennis, J., Mason, M. J., & Cao, Y. (2013). Qualitative GIS and the visualization of narrative activity space data. *International Journal of Geographical Information Science*, *27*(2), 267–291.

Michalowsky, B., Eichler, T., Thyrian, J. R., Hertel, J., Wucherer, D., Hoffmann, W., & Flessa, S. (2016). Healthcare resource utilization and cost in dementia: are there differences between patients screened positive for dementia with and those without a formal diagnosis of dementia in primary care in Germany? *International psychogeriatrics*, *28*(3), 359–369.

Milton, S., Pliakas, T., Hawkesworth, S., Nanchahal, K., Grundy, C., Amuzu, A., ... & Lock, K. (2015). A qualitative geographical information systems approach to explore how older people over 70 years interact with and define their neighbourhood environment. *Health & place*, *36*, 127–133.

Mitchell, L., & Burton, E. (2006). Neighbourhoods for life: Designing dementia-friendly outdoor environments. *Quality in Ageing and Older Adults*, *7*(1), 26.

Novek, S., & Wilkinson, H. (2019). Safe and inclusive research practices for qualitative research involving people with dementia: A review of key issues and strategies. *Dementia*, *18*(3), 1042–1059.

Odzakovic, E., Hellström, I., Ward, R., & Kullberg, A. (2020). "Overjoyed that I can go outside": Using walking interviews to learn about the lived experience and meaning of neighbourhood for people living with dementia. *Dementia*, *19*(7), 2199–2219.

Odzakovic, E., Kullberg, A., Hellström, I., Clark, A., Campbell, S., Manji, K., ... & Ward, R. (2021). "It's our pleasure, we count cars here": an exploration of the "neighbourhood-based connections" for people living alone with dementia. *Ageing & Society*, *41*(3), 645–670.

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Phinney, A., Kelson, E., Baumbusch, J., O'connor, D., & Purves, B. (2016). Walking in the neighbourhood: Performing social citizenship in dementia. *Dementia*, *15*(3), 381–394.

Prince, M., Bryce, R., Albanese, E., Wimo, A., Ribeiro, W., & Ferri, C. P. (2013). The global prevalence of dementia: a systematic review and metaanalysis. *Alzheimer's & dementia*, *9*(1), 63–75.

Rahman, S., & Swaffer, K. (2018). Assets-based approaches and dementia-friendly communities. *Dementia*, *17*(2), 131–137.

Scheepers, E., Wendel-Vos, W., van Kempen, E., Panis, L. I., Maas, J., Stipdonk, H., ... & Schuit, J. (2013). Personal and environmental characteristics associated with choice of active transport modes versus car use for different trip purposes of trips up to 7.5 kilometers in The Netherlands. *PloS one*, *8*(9), e73105.

Shareck, M., Frohlich, K. L., & Kestens, Y. (2014). Considering daily mobility for a more comprehensive understanding of contextual effects on social inequalities in health: A conceptual proposal. *Health & place*, *29*, 154–160.

Sherman, J. E., Spencer, J., Preisser, J. S., Gesler, W. M., & Arcury, T. A. (2005). A suite of methods for representing activity space in a healthcare accessibility study. *International journal of health geographics*, *4*(1), 1–21.

Smith, L., Foley, L., & Panter, J. (2019). Activity spaces in studies of the environment and physical activity: A review and synthesis of implications for causality. *Health & place*, *58*, 102113.

Van den Berg, P., Arentze, T., & Timmermans, H. (2011). Estimating social travel demand of senior citizens in the Netherlands. *Journal of Transport Geography*, *19*(2), 323–331.

Van der Roest, H. G., Meiland, F. J., Comijs, H. C., Derksen, E., Jansen, A. P., Van Hout, H. P., ... & Dröes, R. M. (2009). What do community-dwelling people with dementia need? A survey of those who are known to care and welfare services. *International psychogeriatrics*, *21*(5), 949–965.

van Hoven, B., & Meijering, L. (2019). Mundane mobilities in later life-Exploring experiences of everyday trip-making by older adults in a Dutch urban neighbourhood. *Research in Transportation Business & Management*, *30*, 100375.

Van Velsen, L., Van Weering, M. D., Luub, F., Kemperman, A., Ruis, M., Urlings, J., ... Neven, A. (2019). Travelling with my soulmate: Participatory design of an mHealth travel companion for older adults. In *ICT4AWE 2019 – Proceedings of the 5th International Conference on Information and Communication Technologies for Ageing Well and e-Health*.

Vernooij-Dassen, M., & Jeon, Y. H. (2016). Social health and dementia: the power of human capabilities. *International psychogeriatrics*, *28*(5), 701–703.

Vine, D., Buys, L., & Aird, R. (2012). The use of amenities in high density neighbourhoods by older urban Australian residents. *Landscape and Urban Planning*, *107*(2), 159–171.

Ward, R., Clark, A., Campbell, S., Graham, B., Kullberg, A., Manji, K., Rummery, K., Keady, J. (2018). The lived neighborhood: Understanding how people with dementia engage with their local environment. International Psychogeriatrics 30, 867–880.

Wolverson, E. L., Clarke, C., & Moniz-Cook, E. D. (2016). Living positively with dementia: a systematic review and synthesis of the qualitative literature. *Aging & mental health*, *20*(7), 676–699.

Zenk, S. N., Matthews, S. A., Kraft, A. N., & Jones, K. K. (2018). How many days of global positioning system (GPS) monitoring do you need to measure activity space environments in health research? *Health & place*, *51*, 52–60.

Zenk, S. N., Schulz, A. J., Matthews, S. A., Odoms-Young, A., Wilbur, J., Wegrzyn, L., ... & Stokes, C. (2011). Activity space environment and dietary and physical activity behaviors: a pilot study. *Health & place*, *17*(5), 1150–1161.

5