



‘Something is dropped out of the journey of life’: perceived spaces of opportunity among people with dementia

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Abstract Dementia brings forth different kinds of challenges to manage everyday life. Comprehension of the multidimensional nature of the challenges, varying from spatiotemporal disorientation to fears or lack of services gives us tools with which living as a good life as possible with dementia can be supported. The *time-geography* offers a useful approach to delve into the experiences of people by focusing on what individuals try/want to do in their environment and how they try to manage with growing difficulties. The time-geographic approach acknowledges individually perceived spaces of opportunities as being assembled of several human and non-human elements. This relational approach enhances understanding how the multiple interconnections among elements of disparate dimensions of time–space transform the lives of people with dementia illustrating the possible constraints and incentives they encounter in their activities. In this article, we examine the possible challenges

people with dementia experience in their lives by using the time-geographical approach. In doing so, we demonstrate topics such as social relations and spatiotemporal shrinkage affecting the well-being of the participants. Moreover, we stress the need to conceptualize indirect constraints in the time-geographic approach.

Keywords Spatiotemporal approach · Time-geography · Dementia · Finland

Introduction

‘Imagine that you are in the midst of an ongoing life, suddenly carried away in your sleep and transported to an unfamiliar place several decades ahead. You wake up with no recollection of how you got there or how you got to be so old’. (Öruly, 2010, p. 29).

This article explores the lives and perceived spaces of opportunity in the time–space of people with dementia and the *elements* in those spaces based on a time-geographic approach. Individually perceived spaces of opportunity are relatively subjective; that is, we experience objects intuitively and in relation to our former experiences (Nygård & Borell, 1998). We evaluate and plan our activities based on our experiences before determining what to do and how to do it. However, various forms of dementia, especially

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progressive neurodegenerative dementia, are associated with declining visuospatial skills (Dubois et al., 2021; McKeith et al., 2017; Rascovsky et al., 2011), including reduced movements in space. Moreover, the ability to recognise that an object has depth, height, and width (Mahoney et al., 2000) and the ability to remember mistakes and avoid repeating them may be impaired in people with dementia (for new diagnostics, see Dubois et al., 2021; McKeith et al., 2017). Consequently, (sometimes unconscious) reflections based on intuition and former experiences may be hampered, and spatiotemporal perceptions may differ between people living with dementia and unaffected people of the same age and education level (Pai et al., 2021). Spatiotemporal disorientation opens a black hole of possible locations and destinations, with no fixed point to hold onto (Örülv, 2010). It evokes feelings of insecurity since a person's whole sense of wellbeing is deeply attached to their sense of space and time (Caspi, 2014).

Earlier research has suggested that the world outside the home shrinks linearly as dementia progresses (Duggan et al., 2008). The world becomes harder to manage and control, begins to consist of limited tasks and situations that the affected person can cope with, and finally contracts to the person themselves (Nygård & Borell, 1998). However, recent research has questioned this assumption of linearity and provided a more nuanced understanding of how dementia influences people's access to and use of places outside their homes (Margot-Cattin et al., 2022), acknowledging that better days with few dementia symptoms may follow difficult periods with severe symptoms. Although recent research acknowledges the existence of a 'shrinking world' for people with dementia (Rowles, 1978), it challenges the notion of linear progression. Instead, the shrinking of the outdoor world appears to be more nuanced and complex (Margot-Cattin et al., 2021). Research has shown that people with dementia tend to shift their participation from places associated with social, recreational, and commercial activities towards places focused on health and medical care (Gaber et al., 2019; Margot-Cattin et al., 2021, 2022). However, according to Huizenga et al.'s (2022) literature review, people with dementia usually stay at home because feeling safe and comfortable in a familiar environment becomes increasingly important to them. They express a desire to navigate their homes safely and comfortably among

familiar belongings. Seeing other people, albeit through a window or from a balcony, provides a sense of connection with the outdoor world (Huizenga et al., 2022).

According to the Finnish Elder Care Act (980/2012), older people have the right to institutional care only for medical or safety reasons (Article 14a). However, executive functions are often impaired among persons with dementia (Kennedy & Smythe, 2008), making it difficult for them to continue their activities and achieve set goals, such as cooking a meal or getting dressed. In fact, a growing number of ageing people in Finland remain in their homes regardless of their weakening physical or mental capacity, leading to situations that may amount to abandonment, since in some cases, older people have died in their homes due to a lack of care (Karjalainen & Mäki-Petäjä-Leinonen, 2020). Kröger et al. (2019) discovered that a quarter of those in the 75+ group who require support do not receive adequate help and experience care poverty (Kröger et al., 2019). In this paper, we applied a time-geographic approach to discover the perceived spaces of opportunity of individuals with diverse characteristics and how they experienced elements of their lives.

Living at home requires the ability to plan, at least to some extent, one's routine. One needs cognitive abilities to think abstractly and, for instance, recognise a need to move from one place in the house to another, plan the route, initiate appropriate movements or tasks, continue them until they are completed, recall the initial purpose, realise that the tasks have been completed, and stop the activity, simultaneously filtering out irrelevant information and distractions and correcting one's mistakes (Caspi, 2014; Kennedy & Smythe, 2008). However, people with dementia may become unable to perform tasks or movements even when they understand that they are necessary (a phenomenon called apraxia). For more information on its symptoms, see the National Library of Medicine, (2022). Hence, when assessing such individuals, we should consider not only mechanistic (movement) capacities and possibilities but also a range of individual-specific traits that may limit or enhance people's access to resources and opportunities (Dodge & Nelson, 2023). Actions that are difficult for observers to recognise as meaningful are often categorised as behavioural disturbances (Nygård & Borell, 1998); thus, it is important to comprehend what people with dementia consider meaningful and why.

Time-geography provides a useful theoretical–methodological approach for investigating the experiences of people with dementia and their interactions with intertwined *elements of time–space*, such as other people, places, laws, roads, or creatures (Friberg et al., 2009; Hägerstrand, 2009; Schwanen, 2007). The starting point for our analysis was individuals’ *projects* and *goals* relative to their perceptions of spaces of opportunity in time–space. Specifically, we aimed to answer three interlinked research questions. First, what kinds of spatiotemporal elements do people with dementia describe in their environments? Second, what constraints and incentives do people with dementia experience in their environments? Third, what happens to people’s perceptions of spatiotemporal breadth as dementia evolves? The structure of the article follows a time-geographic framework, including some of its main concepts. The first section introduces time-geography. The following sections present our research findings relative to the time-geographic conceptualisation of spatiotemporal dimensions, constraints, and incentives.

Time-geographic approach to research on people with dementia

Time-geography mainly focuses on human activities and movements in time–space based on the work of Swedish human geographer Torsten Hägerstrand and his colleagues from the 1960s onwards. Hägerstrand’s aim was to create an exact but general approach for use by natural and social scientists (Ellegård & Svedin, 2012). He understood an individual as an indivisible, material entity moving in time–space (Ellegård, 2019), which, according to Hägerstrand, is challenging to comprehend before it is materialised or ‘filled with quanta’ (Hägerstrand, 1991, p. 135). To investigate time–space and individuals’ spatiotemporal activities and experiences in ‘the now’, Hägerstrand, inspired by the work of philosopher Karl Popper, divided the elements of time–space (artificially) into three interlinked *dimensions*: physical/digital, socio-cultural, and mental (Hägerstrand, 1985). The physical dimension comprises all physical elements of our environments or digital platforms; the sociocultural dimension includes cultural products, norms, legislation, and art works; and the mental dimension refers

to knowledge, thoughts, perceptions, memory, and emotions (Hägerstrand, 1985; Kranz, 2006).

However, if we want to understand individuals’ experiences and movements, we ought to pay attention to the *meanings* people give to the elements of time–space, not only what *is there*. What people want or try to achieve in their lives influences the meanings they give to such elements. For instance, if one is trying to sleep, another person talking loudly may be disturbing. Conversely, if one is afraid to be alone or needs advice, the same loud-speaking person may be perceived as beneficial. Thus, people have different goals or aspirations and strong desires for achievement, towards which they direct effort and transform the meanings they give to the elements of their environments (Hägerstrand, 1982).

Hägerstrand provided tools for exploring the restrictions people must deal with to live their lives fully and make choices (Ellegård & Svedin, 2012). Therefore, time-geographic *goals* and *projects* are useful for studying important elements in individuals’ lives. The things people aim to do often say something about their current circumstances and vulnerabilities: is one aiming for a higher salary, a healthy child, or merely to get out of bed and have something to eat? Hence, even fulfilling a basic need can become a goal for someone. In their everyday lives, people aspire to reach goals of different scales and consequently bundle together other people and resources that they consider useful for achieving those goals (Hägerstrand, 1973, 1982).

According to the time-geographic approach, all actions are *constrained* and *incited* by individuals’ capacities, laws, knowledge, and mental loads, to mention but a few factors (Gadd, 2016; Friberg et al., 2009). Since people have different life goals and aspirations, different elements constrain and incite their activities. Time-geography assigns constraints and incentives to four interlinked groups: capability, coupling, authority, and mental constraints and incentives (Gadd, 2016; Hägerstrand, 1976). These include, for example, nutrition and rest (capability constraint), a healthy body (capability incentive), meeting people and obtaining resources (coupling constraint/incentive), obeying rules and traditions (authority constraint), and laws that guarantee rights (authority incentive), but also fear and a positive state of mind (mental constraint/incentive) (Gadd,

2016; Hägerstrand, 1973). Perhaps the most important group of constraints in the time-geographic approach is the mental one, which includes, for example, fears, depression, anxiety, sadness, and trauma. These elements influence how individuals experience time-space (Crawley & Hagen-Zanker, 2019; Davidson & Milligan, 2004) and affect whether they experience the environment as hostile or offering possibilities for governing their lives and achieving set goal(s).

To arrive at a desired destination or accomplish a wanted goal, people must carry out projects, decide what to do, and remember what is needed to reach the goal (Berg, 2006; Kaplan & Kaplan, 1983). Actions are planned based on our previous experiences and evaluations of possible consequences. Hence, although time-geography recognises individuals' existence in time-space, this observable path is not sufficient. The inner world is tightly interconnected with the visible material world (Ellegård, 2019). People retain memories of the past, respect or disrespect rules, and relate future expectations to the past and their current knowledge (Hägerstrand, 1982). However, this process may be hampered for people with dementia.

Methods

For this article, we collected data using traditional interviews and experimental art-based research methods. The first author interviewed 12 people with dementia in 2023. Ten of these interviews were conducted in a daycare centre for people with dementia run by a local branch of the Alzheimer's Society of Finland. All participants lived in their own homes. We approached the workers at the daycare centre and gave them a detailed description of the research. They, in turn, talked with their clients at the centre and asked whether they were willing to participate in the interviews. This method of 'recruiting' participants allowed potential participants to decline without pressure. Moreover, since the interviews were conducted in the daycare centre, we were able to evaluate the condition of the participants on interview days with the help of professionals who knew the participants. If the day or time was not suitable for an interview, the interview was postponed, and we (the researchers) simply spent time in the daycare centre. Two of the

interviews were conducted by phone. We announced the opportunity to participate in our research in different newspapers and reached two participants with dementia using this method. For people with dementia, thematic interviewing allows interviewers to conduct interviews in an ethically sustainable way that considers the interviewees' wellbeing. The themes we discussed in the interviews were everyday phenomena (routines, activities, services used, etc.), experienced constraints (things the participants found difficult and possible solutions to perceived challenges), experienced wellbeing (incentives, what brought joy, and what decreased wellbeing), and views regarding the COVID-19 pandemic.

In addition, we collected data using experimental art-based methods. Together with a person experienced in organising art workshops with people with dementia, we organised art workshops in three different large cities at local branches of the Alzheimer's Society of Finland. We used photography and writing in the art workshops. We asked the participants to photograph important objects in their lives before the first workshop, and then they presented the photos to others during the workshop. The photographs depicted significant objects the participants valued, which sometimes even represented their identities (Nygård & Borell, 1998), and the photographs enabled us to discover meaningful objects in the participants' surroundings. People with dementia may be easily distracted (Chiu et al., 2004), so we needed to take this into account when using art-based methods to obtain knowledge. The photographs functioned as anchors for participants' identities or to the past and helped them focus on and talk about things that were not directly in front of them (although some memories could also be *confabulations*, meaning false memories). The photographs sparked discussion among the participants, and many talked about their own experiences based on others' photographs.

We analysed the data (transcribed interviews, wrote detailed notes after each art workshop, and assigned texts to the photographs) on an ongoing basis from the beginning to the end of the study and followed an iterative analytical process (Caspi, 2014). Time-geography guided the content analysis and suggested concentrating on the goals of the participants first. We obtained an understanding of what was important to these individuals, what they did, and why. Using Ellegård's (2019) approach, we

explored the participants' daily activities, with whom they engaged, why, and what technologies they used. We used thematic content analysis to code the elements of the participants' lives according to *dimensions* (i.e. physical/virtual, sociocultural, and mental). For example, the coding related physical places to the physical spatiotemporal dimension, relatives to the social dimension, and fears and memories to the mental dimension. Furthermore, we used empirically oriented content analysis to detect elements that fell outside time-geographic conceptualisations. The empirical material thus guided the analysis, helping us discover how the participants' actions were transformed by their perceived spaces of opportunity and the emotions they experienced while performing those actions. As noted by Ellegård (2019), this type of analysis enabled us to detect the situations and activities that triggered positive and negative feelings. It also revealed the participants' experienced constraints and incentives when they tried to achieve their goals, helping us identify their perceptions of spatiotemporal breadth.

Ethics

Our research entailed several ethical issues, which the Ethical Board of [the name of the university] evaluated. In addition to issues such as the recruiting process, confidentiality, informed consent, the right to withdraw, and data protection, there were some context-specific ethical issues. People with dementia may find verbal expression challenging. This meant that we had to pay particular attention to pauses and delays between speaking turns to enable the interviewees to think in peace and form sentences at their own pace. One participant used body language to compensate for difficulties in verbal expression.

People with dementia may also have difficulty comprehending task instructions, so instructions may need to be simplified and repeated (Caspi, 2014). Sometimes, we noted that other participants in the art workshop became distracted when instructions were repeated for one participant. Consequently, the workshops were designed to give the participants additional time to complete the tasks.

Sustaining directed attention requires mental effort. However, people with dementia may have a reduced capacity to retain information and thus experience mental fatigue in tasks requiring attention

(Kaplan & Kaplan, 1983). This needed to be considered in both the interviews and art workshops. The interviews were conducted in a way that enabled the interviewees and/or accompanying professionals to evaluate the extent of the participants' mental fatigue and the appropriateness of continued interviewing. We used pseudonyms for all participant names in this article to protect the participants' privacy.

Perceived multidimensional spaces of opportunity for people with dementia

Space is a part of individuals' lives in which they jostle multiple elements (Hägerstrand, 2009; Massey, 2005). Hence, elements such as past social relationships, memories, physical and digital spaces, laws, and future certainties/uncertainties all exist in past–present–future time-spaces in an endless circle constituting spatiotemporal *dimensions* (Hägerstrand, 1982). However, people with dementia do not necessarily perceive 'times' in the same way as people without dementia (Örülöv, 2010). This is important from a time-geographic perspective because time may not be conceptualised as absolute or linear, beginning in the past and moving from the present to the future, but rather in terms of temporal dimensions (past, present, and future) that overlap and amalgamate in the multiple relationships and activities that construct a space (Tedeschi & Gadd, 2021, p. 3).

To delve into other people's perceived spaces of opportunity, we should investigate the elements they perceive within those spaces. However, for a person with dementia, declining autobiographical memory often means that events in the middle years of the person's life are forgotten, whereas earlier events are clearly recalled (Örülöv, 2010), and this depends heavily on the elements the person perceives in spaces of opportunity in time–space and what kinds of meanings they are given.

Elements of the physical time–space dimension

Our research participants mentioned several elements in the physical dimension of their spaces of opportunity (e.g. doctor's appointments, supermarkets, assisted living, their own homes, nature, and walking routes sometimes covered in snow). Some participants mentioned physical elements in their

environments that seemed to relate to their perceptions of spatiotemporal breadth. The participants who mainly stayed at home mentioned fewer elements outside the home or stated that they experienced nature only through their windows.

Discovering certain elements only through windows or photographs taken by others is often a result of a person's inability to leave their home without assistance. People with dementia are prone to experiencing disorientation and becoming lost in familiar and unfamiliar environments and socially (Chiu et al., 2004; Örluv, 2010). Elements in physical surroundings may no longer seem familiar. Consequently, many of the participants decided to stay at home or had been advised by their relatives to do so. Huizenga et al. (2022) obtained similar results showing that people with dementia expressed a preference for familiar spaces that were very close to their homes. They tended to follow the same routes or paths regularly, and changes in their familiar environments could be challenging (Huizenga et al., 2022). Spatial orientation refers to a person's ability to mentally imagine or represent a physical setting and situate themselves spatially within that representation (Passini, 1984). In the place/places one frequents most, such as the home, it is easier (especially in the early phase of dementia) for a person to situate themselves. As Mirja explained, *'My own home is the most important thing for me. There, I know where I am'*. The concept of home and the meaning given to it were interesting. Following Tuan (1991), a home is not necessarily a built place or a material manifestation but is created symbolically and materially. Home is a unit of space organised mentally and materially to satisfy a person's real or perceived needs (Tuan, 1991). In time-geography, such units are called *pockets of local order* (Ellegård & Vilhelmson, 2004; Lenntorp, 2004). Mirja said that she 'knew where she was' in her own home, among familiar surroundings. However, Home with an initial capital, as expressed by Milligan (2009), referring to a person's own private Home, may eventually be replaced by a home (such as an institutional care facility). This replacement may also occur when clinical artefacts of care are brought into a person's Home, making it unfamiliar (Milligan, 2009). Although care technologies have the potential to foster wellbeing and independent living, they are also intended to reduce the number of individuals entering residential care (Milligan, 2009).

Nevertheless, different technologies can enable people to remain in their own homes, changing the value and meaning given to the specific material manifestation of the Home.

Sometimes, elements that have been meaningful to a person in the past continue to be so, as Raija stressed: *'It is important that I see trees and nature when I look out of the window. It is important because my summer house used to be in the middle of nature'*. Keijo also found natural elements important: *'Lapland is important. I would like to travel there, but it has become impossible. This is now just about giving up life'*. The means to physically access those natural elements had changed. Orientation to a place is linked not only to moving bodily to physical points in time-space, but also to being socially in a place and understanding what one does (or is supposed to do) in that place (Örluv, 2010). This understanding, however, eventually becomes hampered as dementia progresses. Regardless of whether a person recognises the physical changes in their own brain, the changes are real. These changes could be seen as physical elements limiting the participants' environments. Such physical changes eventually affect other aspects of the lives and environments of people with dementia, highlighting the interconnections among elements because changes in the brain might also be categorised as mental/cognitive elements.

Elements of the sociocultural dimension of space

According to time-geographic thinking, the sociocultural dimension includes elements such as other people, cultural products, norms, legislation, and works of art. Half of the participants mentioned art pieces as elements of their environments. Many said that they had lost their former ability to read fast or remember the plots of books but had started to enjoy music instead. Some had heard that listening to music could enhance their brain health. Mirja described her passion for theatre: *'After being diagnosed with dementia, I began to enjoy the theatre. As I live alone, seeing other people and performances is important. A moment is enough. They don't bring any long-term happiness, but I remember the moments anyway'*.

Other people were the most frequently mentioned element in the sociocultural dimension. As Tauno stated, *'The children are most important. Without them, I couldn't continue. They take good care of*

me'. Social interaction is considered an important resource to help people with dementia maintain continuity with their previous lives (Örülv, 2010), since it reminds individuals of their origins and functions as parents, spouses, or professionals. However, the intensity of social contact often decreases as dementia progresses (Nygård & Borell, 1998). Some participants tried to hide their dementia. The ways in which people with dementia are talked about, how people (relatives or society) treat them, and what kinds of services are available for them reflect their social status. The participants in this study frequently mentioned social norms as a whole and in their respective hometowns. What services each person is entitled to, and on what basis, became a topic of conversation for many of the participants. Dementia is a condition that is 'doubly stigmatised' (falsely) as age-related and characterised by a progressive decline in cognitive abilities (Evans, 2018). This stigma can lead to social isolation, low self-esteem, and reduced quality of life (Batsch & Mittelman, 2012).

Elements of the mental dimension of time–space

Mental spatiotemporal elements are known to be significant for understanding individuals' perceived realities; the interrelationship between physical and mental elements and how they form and are transformed by social environments has been recognised (Milligan, 2009). The mental dimension of time-geography refers to elements such as knowledge, thoughts, perceptions, memories, and emotions, which epitomise the interweaving of different dimensions. The elements the research participants mentioned most frequently were different kinds of fear (e.g. of losing loved ones, becoming a burden to others, being unable to live in their own homes, and/or becoming too difficult for the others to cope with), cognitive impairment, disorientation, and loneliness. These elements of the mental dimension are highly interlinked with the sociocultural dimension (losing one's nearest and dearest) and the physical dimension (becoming lost in familiar physical surroundings).

Earlier research has shown that disorientation refers not only to being lost in a geographic space (Örülv, 2010), but also to one's role, confusion regarding what is happening around oneself, and how one relates to those aspects, demonstrating the interconnectedness of artificially separated spatial

dimensions. Furthermore, some elements of the past in time–space become extremely real to people with dementia. As Marja-Liisa explained, '*I don't know how these things [memories] come. I didn't actively remember them before, but now they seem to invade my mind*'. This example demonstrates the importance of understanding the elements of a person's experiences, rather than *what is seemingly there*. Another study participant (Keijo) claimed to have dreams that felt extremely real to him: '*I have dreams, which seem so real. When I wake up, it is difficult to know what is true and what is only a dream. It takes longer and longer to figure that out*'. He explained that he remained disoriented for a long time after waking up, not knowing what was happening, what was true, and what was a dream. He said he remembered his mother passing away and would therefore know that seeing her again must be a dream, but he acknowledged that having dementia made him question whether his memories were correct.

Spatial disorientation as a mental element, as mentioned previously, may cause misunderstanding of the environment and lead to the development of fear, anxiety, suspicion, illusion, delusion, and hallucinations, which in turn cause agitation and safety risks, such as the risk of becoming lost (Mahoney et al., 2000). As Aili explained, regarding the negative emotions that dementia had brought into her life, '*Melancholy moved into me. Melancholy, sickness ... they come into me without any invitation*'. How positively our study participants felt about their dementia varied greatly. Some considered the disease to be part of them, whereas Raija had not even told her children about her diagnosis: '*I don't want to tell them. I don't want them to think that I am unable to do things and patronise me. That's why I was motivated to use those widgets [IT tools]. They will not notice anything if I can pay my bills and book appointments for myself and my husband*'. This example demonstrates the impact of stigma, which can be seen as an element of sociocultural space, in triggering certain ideas within a person. Raija believed that people would consider a person with dementia unable to do things and in need of care. However, individuals with dementia may have impaired awareness of their deficits, or try to conceal their worsening abilities (Berg, 2006; Starkstein et al., 1997). This was the case with Raija, who was trying to fight against her weakening abilities. Some people with dementia do not ask for

help despite knowing that their abilities are declining (Caspi, 2014).

Elements of the digital dimension of time–space

An increasing number of activities are being conducted online. However, for most of the study participants, the elements of this spatial dimension were absent due to them not having appropriate devices, being unable to use digital devices, and/or not being interested in learning. Only a few participants were able to use digital devices. Access to digital technologies and their usage has attracted considerable research attention (Shastri et al., 2022), and it is not surprising that online services and information remain mostly inaccessible to people with dementia.

For a person with dementia, it may be difficult to retrace one's digital steps (Passini et al., 1998). This is the case with online 'clicks' when trying to take actions online, as Meeri highlighted:

I try to take care of everything online, but my concentration is very poor. I forget what I have done or what previous page I clicked on. For sites requiring strong identification, it is difficult to take backward steps. One needs to verify the login again and again or be thrown out of the site when trying to return to the previous page.

Some of the participants accepted that elements of the digital space were inaccessible to them: *'Everything is on the internet. I don't go there. They expect everyone to adopt those gadgets'*, Toini explained. However, for people like Raija and Keijo, the internet provided things to do: *'I watch the news and read magazines online. That is a good way to make time go faster'*, Keijo explained. Moreover, for Raija, mastering the digital elements of her perceived space of opportunity, such as notepads, smartphones, and computers, was a way to conceal her dementia: *'I play. That is how I spent my time. Colouring games are the best. I decided to learn this, and I did. By grasping this, I can still manage not to reveal my dementia to my children'*.

The elements that *are seemingly there* for healthy people are not necessarily there for people with dementia, who may struggle to identify the exact meaning of an element. Even a seemingly simple and unambiguous situation, such as sitting down at a lunch table or taking medication, can be obscure and

elusive (Örülv, 2010). Thus, to understand the experiences of the individuals themselves, we must ask about the constraints and incentives they experience. What people find constraining and inciting often tells us something about their situations.

Subjective constraints and incentives

At the community level, the actions and access to certain resources of people with dementia are limited by, for instance, policies, controlled access to or the cost of infrastructure, social programmes, public health policies, crime mitigation, and funding (Dodge & Nelson, 2023). Although the entire community is exposed to and encounters the same structural elements of time–space, the experience can significantly differ for different population segments and individuals (Dodge & Nelson, 2023). Constraints are highly subjective because they are closely related to individuals' goals and projects. Original time-geography defined three types of constraints (capability, authority, and coupling) that affect people's activities (Ellegård, 2019). However, it may be useful to assign mental constraints to a separate category (Gadd, 2016). Individual activities can also be incited by time–space elements. Thus, researchers have suggested adding the concept of incentives to the time-geographic approach (Gadd, 2016). Almost all the participants in our research expressed the goal of being able to remain in their own homes. Some, however, hoped that they would end up in a 'good place' if living in their own homes was no longer possible. Individual factors that contributed to the constraints they encountered included the fact that impaired awareness of deficits or incapacities is a common feature of dementia (Starkstein et al., 1997). As Toini explained, *'I must be doing OK. I don't remember, so I don't remember the difficulties'*. The following sections are devoted to the constraints and incentives identified by the research participants.

Capability constraints and incentives

Capability constraints are those that limit individuals' activities due to physical or biological traits (e.g. age or disability) (Ellegård, 2019) or simply because humans need rest and nutrition at regular intervals

(Hägerstrand, 1982). Dementia eventually decreases the capabilities of the people who live with it.

Spatial disorientation, mentioned as an element of the mental spatial dimension, is often a sign of neurodegenerative disease (Liu et al., 1991), which was recognised by some of the participants in our research. Mirja explained the feeling of disorientation: *‘When I am cycling, some parts of the route just disappear. It frightens me. Then I look for directions on my mobile phone’*. Heikki agreed, *‘Yes, yes, I could not find any place anymore without a navigator’*. Disorientation is clearly a constraint but one that can be managed with a digital device functioning as an incentive for physical movement. In addition, previous research has shown that physical features of the environment, such as signs, landmarks, colour contrasts, sidewalks, and good lighting designed to support safe movement for people with dementia, aid orientation in physical spaces and thus function as capability incentives prompting physical movement (Caspi, 2014; Freeman et al., 2022; Torgrude, 2006). However, roads that are difficult to walk on may discourage people with dementia from using them (Huizenga et al., 2022). Ultimately, disorientation can lead to a situation in which the person with dementia is unable to live in their own home (Liu et al., 1991). However, living in one’s own home was a major goal of our research participants, which disorientation could constrain. Leila described the meaning of Home and the emotion that this capability constraint would eventually cause her: *‘Home is my lifeline. It is a part of me and who I am. If ... or when ... I lose my Home, I will lose a part of myself’*. Leila’s comment highlights the interconnectiveness of constraints. Capability constraints can trigger mental constraints, such as fears of loss, which, in turn, are associated with people’s overall wellbeing.

Difficulties in recognising the shapes and sizes of visual and tactile modalities and positions in time–space have been acknowledged as constraints experienced by people with dementia (Chiu et al., 2004). Raija explained her difficulty in recognising the position of her cup in relation to the table or porcelain saucer: *‘It irritates me so much. When I put my coffee cup on the porcelain saucer, it makes a terrible noise, and my husband lifts his eyes from the paper he’s reading’*. Raija found it difficult to estimate the time it would take for her hand to move the cup to the porcelain saucer, meaning that she usually put it down too early. According to her, these kinds of

things were the first signs that prompted her to pay more attention to herself and eventually see a doctor. Now, she had been told to hold the cup with her little finger at the base of the cup so that her finger would touch the saucer first, enabling her to put the cup down more quietly—an ability that she saw as an incentive for her to have her coffee as usual while her husband read the paper.

Some found that the COVID-19 pandemic intensified communication challenges due to social isolation. *‘After coronavirus, we needed to learn how to hold conversations again’*, said Marjatta, describing her post-COVID-19 experience. This phenomenon occurred due to a decrease in social communication, especially in cases where individuals had not fully grasped digital communication technologies. Heikki felt that there was no coming back from such communication difficulties: *‘The words get locked within me. I cannot get them out anymore, and it irritates my wife’*. He often communicated with his hands—a technique that functioned as an incentive for communication, but which was not possible to use, for example, on the phone.

The ability to exercise and take walks was mentioned by all participants as an incentive for maintaining wellbeing, but many were no longer able to leave their homes for walks. Those who exercised knew about its positive impact on dementia, but also felt that it increased their overall wellbeing. Those participants who said they took regular walks also found that it decreased the symptoms of their dementia.

Some people with dementia can decouple themselves from constraints caused primarily by their disease and compensate for the lack of services for people with dementia by paying for care in their homes, which increases the possibility of them remaining in their homes. At the individual level, this is a functional solution, but at the society level, it can create inequalities in access to justice, since not all are able to purchase the necessary services. Furthermore, healthcare access is governed by regulations and policies (as well as health insurance) that assume spatial proximity between healthcare facilities and home, and technology may introduce new opportunities and barriers to healthcare (Dodge & Nelson, 2023). Access depends on an interplay among proximity and distance, economic considerations (e.g. the financial means of the individual and their family), and the availability and cost of alternative sources of support

(Milligan, 2009). Regulations, policies, and reliance on technologies can lead to authority constraints.

Authority constraints and incentives

Authority constraints, in time-geography, refer to laws, regulations, and traditions constraining individual actions. For our study participants, the regulations defining the services to which people are entitled were highly relevant. In Finland, the welfare services provided for older people are based on counties' different laws. In principle, services are provided based on general legislation, such as the Social Welfare Act (1301/2014), and people's needs, not their ages (Karjalainen & Mäki-Petäjä-Leinonen, 2020). High-quality care services must be accessible and affordable to all to meet the population's care needs (Kröger et al., 2019). As important as the service provision laws and regulations is the possibility of obtaining effective tests for diagnosing dementia. Without a diagnosis, no-one with dementia can access the services they are entitled to or receive compensation from the Social Insurance Institution of Finland for prescribed medication. A few participants had visited several doctors before obtaining proper tests and being diagnosed with dementia.

Which services are provided and to whom are tightly interlinked with social and political perceptions of rights and responsibilities (Milligan, 2009). In Finland, there have been two major transformations since the early 1990s, making services more strictly targeted and increasing the number of services outsourced to for-profit providers (Kröger et al., 2019). Furthermore, in terms of healthcare, the practice of relying on digital services, whether for booking appointments or meeting doctors online, can prevent some people with dementia from receiving healthcare due to their lack of access to digital technologies (Rodrigues et al., 2022). Most of our research participants had difficulty grasping digital technologies. For instance, many received help from their relatives in paying bills, booking appointments, or arranging electricity contracts. Some did not bother with doctors' appointments. *'If you don't try to book an appointment, you can't have any problems either'*, said Toini, laughing.

Nygård and Borell (1998) noted that their research participants' experiences of order and control over objects and tasks, and their sense of coherence within

everyday reality and their own persons, were threatened by dementia. We also observed this when discussing the meaning of home. At Home, the participants could do what they wanted without considering the order in which things should be done or whether the time was socially correct for a certain activity, such as going to the sauna. As Heikki explained, *'I like to go to my summer house. There, I can go to sauna three times a day, even in the middle of the night, and no one can say anything. I like that'*. This highlights Tuan's (1991) notion of home as an elastic concept with economic, psychological, and moral dimensions. Heikki's description epitomises the time-geographic concept of a pocket of local order that people establish to perform activities that must be shielded from 'destructive' outside world influences, such as other peoples' rules. Such pockets are endowed with time, the right resources, and the space to facilitate an individual's goal achievement (Hägerstrand, 1973; Lenntorp, 2004). In Heikki's example, we see a mental image of *'how things should be done'* as an authority constraint and his summer house as an incentive liberating him from that authority constraint. It was often mentioned that this kind of liberty would be lost if the participants could not live in their own homes.

Coupling constraints and incentives

Coupling constraints refer to the need to couple not only with the necessary people, but also with the required resources, such as equipment or knowledge, to complete projects (Hägerstrand, 1982). However, attempts may be hampered by several factors, such as the availability of resources, lack of time, or the ability to complete the coupling.

To receive care, one needs to travel to an appointment or have someone visit the home. The digitalisation of our lives, accelerated by the COVID-19 lockdowns, has amplified some forms of access but has also created barriers to access (Dodge & Nelson, 2023). Dodge & Nelson (2023) highlighted that healthcare can require travel time to an in-person appointment or can be decoupled from travel time through e-health services. However, constraints related to in-person appointments (or access to appropriate tests) can arise from a lack of resources at the structural level or a need for assistance in travelling or using e-healthcare. Technological advances have

improved access by removing the need for travel to obtain goods, services, and necessities, or even socialise (Dodge & Nelson, 2023). Nevertheless, resources are scarce, and nurses who drive between clients need to consider the time it takes to reach the next client, and thus cannot decouple from travel time. The time spent with the client in their home is the only time that can be reduced if necessary.

Conversely, coupling with others potentially offers opportunities for co-construction and negotiation (Öruly, 2010). Most of the participants found coupling with others and social connections vital (including those who lacked everyday connections). Coupling was perceived as an incentive for maintaining their wellbeing and their ability to continue living in their own homes. Tauno confirmed the enabling role of coupling with the children for his living at home: *'I have three children. They come every week, bring food, pay the bills, and even decorate the Christmas tree'*. The intensity of relatives' care for people with dementia became evident. Caring for others also has a spatiotemporal dimension. The choice to care for others is based on cultural factors, such as kinship ties, and social mores characteristically motivate the decision (Milligan, 2009). Mirja highlighted the point about co-construction and negotiation made by Öruly (2010): *'With a spouse, the dementia halves. Within normal conversations, one is reminded of regular things'*. When people with dementia discuss everyday issues and agendas with others living in the same household, they naturally obtain information that might otherwise be lost.

In a city in southern Finland, some people with dementia engage in daytime activities (normally) once a week, and transportation may be provided from home to the venue and back again. The activities were experienced as a coupling incentive for most participants. They felt that coupling with other people with dementia, and the activities provided, improved their overall wellbeing and capacity to remain independent. Tauno stated, *'I feel that my memory has improved since I have come here [the daycare centre]'*. Only Pekka, who attended these meetings, was slightly reluctant to engage in the activities: *'I come here [the daycare centre]. The activities are not quite for me, but I come anyway. My wife organised this for me, and I guess she needs some time on her own, too. I feel as if this is storage for me'*. Coupling was highly constrained during the COVID-19 pandemic, partly

because of regulations regarding the use of public spaces and coupling with others but also because of fear of the unknown.

When the number of constraints increases, the coupling constraints are intensified for people with dementia because they often need assistance with their daily routines. Specifically, when a person needs assistance with regular everyday tasks, such as getting out of bed and remembering to eat, the reliance on coupling with others increases. The life of a person with dementia becomes increasingly interwoven with the life of the person who assists them. Consequently, the constraints of other people become indirect coupling constraints for the person who needs assistance.

Mental constraints and incentives

Coupling with a loved one was seen as an incentive for improving wellbeing and the likelihood of living at home. The participants believed that the company of others activated their brains. Another person can help a person with dementia keep their life stories intact (Öruly, 2010; Woods, 2001). Our research participants acknowledged the importance of their relatives but expressed concern about the length of time they would be able to remember them. As Mirja explained, *'The love I feel towards my children helps me to go on, but I constantly fear I will forget them'*. Aili was worried, too: *'I am worrying about how my husband will take all this and for how long he will have the stamina to take care of me'*.

People with dementia may have difficulty understanding how they reached their current situations, triggering sensations of discontinuity and disconnection (Woods, 2001). The individuals we talked to acknowledged the changes occurring in themselves. Concerns about everyday life were related to the perceived order and control of elements in their perceived spaces of opportunity, ranging from tasks and objects, such as what to do and how to do it, to their personal identities. Heikki said, *'I wish I could keep my memories'*. This concern raised further discussion in one of our art workshops. Aili told us, *'Thoughts affect my state of mind. Sometimes my mind wanders into the past, and I become sad because of past events'*. Mirja had other concerns regarding the future and was worried about worries. *'When the worries grow, the illness [dementia] worsens. It is a vicious cycle'*, she said, describing how one constraint might

intensify the other. Aili's example reinforces the conceptualisation of mental constraints as a separate category. Affectual atmospheres and emotions do not directly affect a person's capabilities (mental constraints were originally conceptualised as capability constraints) or reduce their know-how; nevertheless, their own processes may constrain or incite intentions to carry out projects. Emotions, as mental elements, affect the way we respond to time–space, who we are, and how we are transformed by how we feel (Milligan, 2009) based on our mental condition.

Our study participants had different approaches to mental constraints, which could be seen as incentives for maintaining their wellbeing. Emphasising independence and the capability to do things, as in the case of Raija's technical skills or Heikki's sauna practices, may be a way of resisting dementia and prolonging the period of life unaffected by the disease. Some of the participants mentioned spirituality as an incentive to cope with their changing selves.

Shrinking the perceived space of opportunities

Dementia is a progressive disorder that gradually interferes with cognitive, social, and even occupational performance, causing disability and increasing dependence on coupling with other people, which affects the outreach of individuals in time–space (Dubois et al., 2021; McKeith et al., 2017; Nygård & Borell, 1998; Rascovsky et al., 2011). Confidence in knowing where one is and anticipating where one is going is fundamental to people, but it may be jeopardised as dementia progresses (Örülv, 2010). Being lost or fearing becoming lost can lead a person to avoid certain environments or to reduce their mobility altogether (Kaplan et al., 1998). As Toini explained, *'I don't dare to go out often any longer. The bus brings me here [the daycare centre] and takes me back. My daughter even put a paper on the door, saying, "Don't go out", but sometimes I do'*. Huizenga et al. (2022) found that crowded public places with high levels of noise triggered feelings of insecurity in people with dementia. However, being in public spaces without any people in sight also created feelings of insecurity (Huizenga et al., 2022). These unpleasant experiences triggered within certain spatiotemporal settings may make people with dementia stay indoors, even when they are physically capable of moving.

Reduced mobility may particularly affect people's autonomy, self-esteem, and wellbeing (see Chiu et al., 2004). As Raija stated, describing her reduced spatial outreach, *'Since my movements have deteriorated, I cannot join the others on trips anymore. It was a sorrow to me. Luckily, my husband still has a driver's licence'*. Jussi also noticed his perceived space of opportunity shrinking: *'Now the space has shrunk so much that I only see a pine tree and a birch from my kitchen table'*.

Not only does spatial outreach shrink as dementia progresses, but the experience of time also changes. Previous research has shown that as the time–space one can physically reach shrinks, there is an increased tendency to relive personal events from the past or to focus on the now through tactile objects in the environment (Requena-Komuro et al., 2020). After being silent for a long time, Keijo said, *'I sit a lot and recall past events ... There is not much else anymore. Those things just come to me'*. Indeed, the existential meaning of life can come from the daily tasks that people with dementia perform, as if they are the very core of their everyday being in the world (Nygård & Borell, 1998). Leila said that she cooked and baked for her daughter. *'I will continue as long as I can'*, she said, revealing the meaningfulness of the activities she was still able to engage in at home. A temporal constraint, referring to a constraint with a clear beginning and end, such as a COVID-19 lockdown (drastically reducing physical movements in space) or a policy change (e.g. affecting who is entitled to transportation services), may have implications after the actual constraint has been removed. Marjatta's and Heikki's experiences of reduced communication capabilities due to COVID-19 illustrate the shrinkage of the sociocultural spatial dimension and its continuance despite the constraint being dismantled.

Life becomes narrower as people's ability to comprehend abstractly and connect the present situation with previous experiences and future expectations declines (Eggers et al., 2005). Furthermore, some people with dementia face challenges in imagining the world outside their concrete present moment, resulting from deteriorating cognitive function, which may lead to a fragmented experience of the world and the self (Eggers et al., 2005; Nygård & Borell, 1998). Some participants no longer thought about the time or where they could go within a certain time. As Jussi explained, *'Time has lost its meaning. I don't plan anything anymore. The time has shrunk to the narrow now'*.

Concluding remarks

In this article, we have explored the lives of people with dementia using a time-geography approach. Investigating the life experiences of people with dementia is facilitated by time-geographic concepts that not only make individuals' physical movements/immobility visible, but also the motivations behind them. First, we explored the elements in the study participants' perceived spaces of opportunity that they considered worth talking about. They mentioned their own homes, relatives, other loved ones, nature, doctors' appointments, and emotions ranging from happiness to fear and anxiety as meaningful elements. Since we wanted to understand and illustrate individual experiences in this article, we paid attention to the *meanings* the participants gave to the elements in their perceived spaces of opportunity, not only to what *was there*. The research participants wanted to continue living in their own homes and maintaining their wellbeing. Consequently, we wanted to discover the constraints and incentives they experienced in their perceived spaces of opportunity. Home, for example, had the meaning of a physical and mental entity in which the person felt safe and could perform their daily activities in the way they wanted, thus decreasing constraints related, for example, to assisted-living facilities. However, dementia progression imposed different constraints on the study participants, such as spatiotemporal disorientation and communication challenges. These constraints, in turn, triggered emotions, such as anxiety and fear. What became evident was the role of relatives or other loved ones in the lives of people with dementia. Even when the participants' movements were limited, relatives managed to create incentives for them. Relatives provided security by organising extended services, paying bills, bringing food, or assuming the role of intermediary between the person with dementia and online services. Furthermore, relatives made efforts to communicate with their loved ones despite their dementia and changed personalities. Finally, the study participants mentioned that the love they felt for their relatives was a great incentive. As Mirja stated, '*The love I feel for my children helps me to go on*'. Third, time-geography gave us concrete tools to discover what happens to the perceived spatiotemporal breadth of people with dementia, their ability to reach physically distant locations, or to trace knowledge from the

past as the disease evolves. We have shown that spatiotemporal breadth narrows across all dimensions. As dementia progresses, physical movement decreases. Some of the participants wanted to bundle and get together with people less often than before, because they did not want to reveal their dementia or because communication had become challenging. Consequently, their social contacts decreased, narrowing the breadth of their social worlds. Moreover, due to the progressive neurodegenerative nature of dementia, the mind may begin to focus on the present (or the past, in some cases). This was evident in the lives of the participants, as if their thoughts were spiralling in smaller and smaller circles.

We live in a very individualistic world that is encompassed by the time-geographic approach. We focused primarily on individuals' own constraints and less often on the indirect constraints that emerge in individuals' lives due to other people's constraints. This became extremely obvious when we considered the lives of people with dementia who needed assistance with at least some daily activities. However, Hägerstrand's notion of the 'fabric of existence' provides tools and concepts for future such analyses.

To increase equality, Kröger et al. (2019) stated that we need spatially functioning policies that provide publicly subsidised care services or cash-for-care benefits. However, society does not have the resources to offer adequate services for people with dementia, either to enable them to live in their own homes or to offer assisted living to everyone in need. Relatives are resources. Consequently, we need to consider the constraints and incentives of the relatives of people with dementia to fully comprehend their situations. The participants in this research were relatively active, and they had relatives who took care of multiple aspects of their lives. However, there are many individuals who lack social contact and whose perceived spaces of opportunity are already extremely narrow. Heavy reliance on relatives is a severe challenge to accessing justice in the lives of people with dementia, which will be the topic of another paper.

Authors contributions Gadd has collected and analysed the data and written the first manuscript.

Mauranen has collected and analysed the data and conducted the literature survey for the study, contributed to the writing of the manuscript.

Issakainen has reviewed and revised the manuscript.

Ervasti has reviewed and revised the manuscript.

Mäki-Petäjä-Leinonen has reviewed and revised the manuscript.

Solje has contributed to the medical and neurological analysis of the data and reviewed and revised the manuscript.

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Declarations

The whole research has been carried out in compliance with good ethical research practice. The Ethical Board of the University of Eastern Finland evaluated the ethical parameters of our research. In addition to issues such as the recruiting process, confidentiality, informed consent, the right to withdraw, and data protection, there were other ethical aspects too. A person with dementia might have challenges in their verbal expression. This needed to be acknowledged by additional attention paid on pauses and extended times between speaking turns. This enabled the person to think in peace and form the sentence in their own pace. Moreover, one participant used his body language to compensate for difficulties in verbal expression.

There can be difficulties in comprehending task instructions and sometimes simplified and repeated instructions might be needed (see Caspi, 2014). Sometimes we noted that other participants in the art workshop got distracted when instructions were repeated to another participant. Consequently, the tasks in the workshops needed to be designed so that additional time could be used in going through the tasks.

Directed attention requires mental effort to sustain its functioning and has only limited capacity to hold a certain amount of information and is thus, subject to mental fatigue (Kaplan & Kaplan, 1983). This needed to be taken into consideration in both, interviews, and art workshops. The interviews were conducted so that the interviewee or professional workers evaluated the amount of mental fatigue and the suitability to conduct the interview. All participant names used in this article are pseudonyms to protect privacy.

Conflict of interest The authors do not have any conflicts of interest to report.

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