


RESEARCH ARTICLE

What matters most: Exploring the everyday lives of people with dementia

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Abstract

Objectives: Research on what matters most to people with dementia is crucial for developing tailored interventions and support. This study explored how people with dementia experience their everyday lives, providing insight into what is important to them to live the best they can at home.

Methods: Inspired by a phenomenological approach, open interviews were conducted with 15 people with dementia, supplemented by home tours and walking interviews. Data collection included one to three sessions per participant. Data were analysed using descriptive content analysis and followed the phases of open, axial, and selective coding. A co-researcher group of seven people with dementia was consulted during the analysis to help interpret the emergent findings.

Findings: Six dimensions of what matters most in everyday life were identified: 1) Engaging in meaningful activities, which included routines, household chores, leisure, day activities, and volunteering or work; 2) Keeping a sense of connection, in relationships within the home, with family, friends, groups, and the neighbourhood; 3) Having a sense of belonging, which included attachments inside and outside the home, and to cherished objects; 4) Connecting to self, which included the ability to reflect on past experiences, live in the present moment and anticipate the future; 5) Adjusting to ongoing changes, which included alterations in sensory perceptions, perceptions of the physical environment, and navigating shifts in interpersonal dynamics; 6) Being open to help and support, from professionals, community and society.

Conclusions: For people with dementia, everyday life is a continuous balancing act between what matters most and what can be achieved daily. This is not only related to dementia but is also embedded in the wider perspective of life history, relational networks, and the physical environment. This study highlights the importance of identifying what matters most to people with dementia to provide person-centred support.

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KEYWORDS

citizenship, dementia, everyday, home tours, life story, neighbourhood, participatory research, psychosocial, social relationships, time

Key Points

- A shift from a care-based approach to the lens of everyday life changes the focus to facilitating and enhancing what matters most to people with dementia in their everyday lives.
- The engagement of a group of people living with dementia and their input into analysis enriches the study's findings, adding an additional level of understanding and authenticity. This is not only of methodological importance in dementia research, but also a way to put people with dementia centre stage in the research process.
- Living with dementia is a continuum which necessitates individuals to constantly adapt and negotiate with everyday changes. What this study adds is how people construct their past through their contemporary understanding. This life story can be a source of connection and continuity but can also be a source of painful life experiences.
- The six dimensions of everyday life identified by people with dementia provide a potential framework for designing psychosocial interventions.

1 | INTRODUCTION

Dementia significantly affects an individual's ability to perform everyday tasks, making it an urgent public health issue, particularly as the population ages.¹ While policy initiatives aim to enable people with dementia to remain at home,² community services are frequently reported as suboptimal and not person-centred.^{3–5} Numerous intervention studies appear to be disconnected from the everyday experiences of those living with the condition, for example, focussing only on managing behavioural and psychological symptoms of dementia.^{6,7}

The 'everyday' can be described as a combination of the familiar and mundane, whilst being habitual in nature.⁸ Everyday sociology examines these experiences in shaping individual's perceptions of themselves, others, and society.⁹ This approach originated from a transition studying 'the extraordinary' towards 'the commonplace', which was previously disregarded. Reflecting the language of the times, Schütz & Luckmann¹⁰ explained this positioning: "the world of everyday life is consequently man's fundamental and paramount reality" (p.3), and "a basic spatial, temporal, and social arrangement" (p. 103). Building on these foundations, Bech-Jørgensen¹¹ described everyday life as an interplay between everyday conditions and how individuals manage them. In addition, everyday life involves exploring and attributing meaning to ordinary activities.¹²

In dementia studies, a focus on everyday life can help understand how people with dementia navigate daily challenges and what matters most. This everyday perspective aligns with the citizenship framework, grounded in sociological and political principles,¹³ which emphasises the rights and participation of marginalised groups like those with dementia.^{14,15} Taking this concept one step further, Nedlund et al.¹⁵ assimilated the sociological concept of everyday life into the notion of everyday citizenship for people with dementia as follows:

Linking everyday citizenship practice to agency provides a space to see individual citizens in relation to those around them and in the context of different social representations, social categories, and identities (p.7).

To provide further direction in the field, Huizenga et al.'s recent scoping review¹⁶ systematically analysed relevant research conducted since 2011 on the everyday experiences of individuals with mild cognitive impairment (MCI) or dementia. This review provided a detailed examination of disruptions, losses, and adjustments in everyday life. Highlighted themes included the importance of maintaining relationships, participating in activities, and feeling included in the community. Notably, the review indicated a need to explore the dimensions of everyday life and how people with dementia understand this experience in the context of their homes and neighbourhoods. Working in partnership with people with dementia, this study aims to address this need by exploring what matters most in everyday life for people with dementia.

2 | METHODS

2.1 | Study design

We used a qualitative research design inspired by an existential-phenomenological approach¹⁷ and Ward et al.'s socio-relational and embodied-material perspective.¹⁸ This perspective positions people with dementia as actively reconstructing their realities. To support the participation of people in the research process, we adopted a mix of flexible data collection methods.¹⁹ We used open interviews in the participant's homes, home tours, and walking interviews. If the participant was willing to do so, the interviews took place in two or

three sessions. This approach increased the credibility of the findings and allowed for mutuality and reciprocity in the research process.²⁰ We followed the COREQ guidelines²¹ to report the findings.

2.1.1 | Participatory collaboration by people with dementia

This study aimed to actively involve people with dementia in the research process^{22,23} using inclusive methods of data collection and analysis.^{24–26} As this approach is new to the Netherlands, we sought advice from the UK-based Dementia Enquirers.²⁷ This resulted in the formation of a Dutch group of people with dementia, called Brain Power. The group, consisting of seven members aged 54–70, was involved as co-researchers, specifically during data analysis. Brain Power held four meetings between November 2022 and April 2023.

2.1.2 | Home tours and walking interviews

We used home tours inspired by Pink.²⁸ Participants were asked to show their homes to elicit narratives. We used walking interviews to understand how people interact with their neighbourhoods.²⁵ Participants could guide the home and neighbourhood tours. Walking and coordinating physical motion facilitates discussions about social and material features of the household and the surrounding community.^{29,30}

2.2 | Participants

Participants were purposively sampled based on self-reported, or professionally reported, dementia or MCI diagnoses, living at home, and capable of providing informed consent. A diverse sample was sought in terms such as gender, marital state, and educational background. Recruitment was conducted through three meeting centres and two healthcare organisations.

Fifteen people with MCI or dementia agreed to participate (Table 1). There were eight women and seven men, aged 65–87 years, with diverse education levels. Most participants did not disclose the type or length of their condition, although they seemed in the mild or moderate stages of dementia. All except one participant took part in a home tour and the majority of the sample declined walking interviews either because of the weather and/or underlying physical health conditions. Two participants suggested alternatives: a cycling tour and a museum visit by car.

2.3 | Data collection

Data were collected from May to October 2022. Participants were informed about the study's goals before obtaining written or oral

TABLE 1 Participant characteristics.

Characteristics	n (N = 15)		
Gender			
Male		8	
Female		7	
Age range (in years)		65–87	
65–69		2	
70–74		3	
75–79		4	
80–84		4	
85–89		2	
Diagnosis			
MCI		3	
Alzheimer's disease		4	
Parkinson's Dementia		1	
Not mentioned		7	
Country of origin			
The Netherlands		14	
Morocco		1	
Educational level			
Primary education		3	
Secondary education		4	
Further education		2	
Bachelor		3	
Master or phd		3	
Marital status			
Married or living together		9	
Widowed		3	
Divorced		3	
Area			
Urban		0	
Suburban		13	
Rural		2	
Data collection methods	n = 1	n = 2	n = 3
Interviews	4	8	3
Home tours		14	
Walking interviews		2	
Alternative (cycling and car tour to museum)		2	

recorded consent and provided with the option to withdraw at any time. A process consent approach³¹ was used with regular reminders of the research aim at the start of any new encounter. Participants could pause or stop the data collection process when fatigued. Participants living with a partner could participate alone or with their

partner. The interviewer closely observed these dyadic interviews and focussed on the experiences of the person with dementia.

The interviews started with the question “What does your everyday life look like?” to act as a guide and allow participants to share their experiences naturally. Follow-up questions were used with topics based on a scoping review of everyday life,¹⁶ such as the experience of activities and relationships. Participants were also enabled to discuss topics they considered essential. The first author conducted all interviews. To enhance reflexivity, the co-authors provided feedback on interview recordings and transcripts during the data collection phase. Field notes were taken to capture nonverbal cues and contextual information. Audio recordings of interviews were transcribed verbatim. All names in the article are pseudonyms in line with the study protocol.

2.4 | Data analysis

Data analysis involved descriptive content analysis with open, axial, and selective coding methods.³² Initially, the first and second authors independently performed open coding of five interviews and checked for inter-coder agreement. A code tree was developed and refined accordingly. Thereafter, the first author revisited the data underlying all codes to determine if codes adequately covered the collected data. The codes were then grouped into dimensions to illustrate the dynamic, interactive, and continual nature of adjustment over time. Findings were discussed multiple times with all authors to ensure investigator triangulation.³³ Atlas.ti software was used for data management and analysis.

To ensure authenticity and strengthen credibility, we engaged with the Brain Power group during data analysis. Reflection and non-verbal methods were used to prompt discussion, such as bringing to the group an object that symbolises what matters most in their everyday lives. Subsequently, the emergent findings were presented to the participants who provided input on whether they aligned with their own experiences, or not and needed further attunement. Inspired by Synnes,³⁴ facilitators also created poems using contributions from group members and shared them with the group as a form of reciprocity.

2.5 | Ethical considerations

The study followed The Dementia Enquirers Gold Standards for Ethical Research.³⁵ The study protocol was approved by the Research Ethics Committee of HU University of Applied Sciences (reference number 2022-5).

2.6 | Findings

We will describe the findings about the dimensions of everyday life that matters most, followed by Brain Power's reflections on these findings.

2.6.1 | Dimensions of everyday life

Six dimensions of everyday life emerged in the data. Table 2 shows the dimensions of everyday life with subcategories.

1. Engaging in meaningful activities

Participants emphasised the importance of engaging in meaningful activities, finding them stimulating:

All those things really stimulate you... And continuing to participate in activities as well. You are, of course, socially engaged, and while I may be out every evening, I do not worry. You are tired, but you have had a fun evening with social interactions. (Maria)

However, some participants reported having quiet days and spending a lot of time at home, which some appreciated, whereas others expressed boredom.

1.1 Routines and household chores

Participants shared their daily routines, such as waking up and taking medication. Some held tightly to their daily routine, as regularity provided them a sense of daily fulfilment and prevented forgetting things. However, changes in the routine could lead to confusion.

Many shared their experiences with the household chores they regularly engaged:

To continue doing things at home, I do not spend the entire day sitting on the couch. (Ans)

TABLE 2 Dimensions of everyday life.

Dimensions	Subcategories
1. Engaging in meaningful activities	1.1 Routines and household chores 1.2 Leisure activities 1.3 Day activities for people with dementia 1.4 Volunteering and work
2. Keeping a sense of connection	2.1 Home relations 2.2 Family 2.3 Friends and groups 2.4 Neighbourhood
3. Having a sense of belonging	3.1 House 3.2 Meaningful objects 3.3 Outdoors 3.4 Transport
4. Connecting to self	4.1 Past time 4.2 Current time 4.2 Future time
5. Adjusting to ongoing changes	5.1 Sensory and interaction with environment 5.2 Interactions with people
6. Being open to help and support	6.1 Professional support 6.2 Informal support 6.3 Society

Participants still contributed to chores such as shopping. Several participants reported experiences with cooking, with some cooking independently, while others assisted their partners or used meal delivery services.

1.2 Leisure activities

Participants emphasised participating in leisure activities as long as they could. Some mentioned activities they could no longer perform, which they regretted, or activities that they struggled with and required assistance, but they persisted in their efforts. Getting up and about and moving was part of daily life for almost all participants, including walking and cycling. Some participated in sports group activities and enjoyed having fun with others. One respondent articulated the importance of feeling more confident about progress in sports. Participants also enjoyed cultural and creative activities, such as painting, attending museums, and listening to music:

For your brain. [...] It's good for that. You can really find an inner calmness with good music. (Ray)

Some participants mentioned clubs they liked to visit, such as dog sports and excursions. Being part of a group of people made them feel part of a bigger whole. Some engaged at home in puzzles, gardening, and staying informed with news, while others had special interests, like the Second World War and literature.

1.3 Day activities for people with dementia

Most participants joined day activities organised for people with dementia, such as a meeting centre. The significance was to stay busy, learn something new, or contribute, for example, assisting in making soup. Contributing gave them a sense of value and meaning. Activities mentioned included caring for animals, group discussions, and art activities. Participants highlighted the diversity of activities, the nice group atmosphere, the distraction of mundanity, and the excitement of pursuing a personal interest. Participants also encountered others who shared similar experiences. This peer support was valued, even if it did not have to be the main topic of conversation. Participants used specific language to describe their activities, which emphasised their humanity and being free of stigma, referring to their fellow participants as 'colleagues' and the meeting centre as their 'club'.

Some others were dissatisfied with the activities offered:

Sitting there all the time and just watching, it's not something that suits me. (Ron)

1.4 Volunteering and work

Participants did not work, but two mentioned volunteering. One educated others about what it was like to live with dementia. Another participant did volunteer work, but in the second interview, he shared that he resigned due to feeling patronised by the professionals. He and his partner were looking for a new place. They considered volunteering work at another place nearby with a mixed group, aimed for people of different ages and needs, and with leadership more focussed on giving autonomy to participants.

2. Keeping a sense of connection

Participants highlighted the importance of relationships in their daily lives, even after the loss of loved ones. Dementia affects these relationships, often through care received from others. The participants also showed reciprocal care for others through acts of kindness, for example, by calling people when they were sick. Some participants reported having fulfilling social networks, while others, particularly some men, missed social interaction since retirement or the COVID-19 pandemic. Some had a small network due to living alone, a lack of friends, or the passing of loved ones. Although loneliness was not directly mentioned, it was hinted at through actions like keeping the television on to avoid silence.

2.1 Home relations

Most participants with a partner emphasised that everyday life is a shared one, speaking about their togetherness through shared activities. Their lives together created a bond, with some couples being married for over 50 years. Many expressed gratitude for their partner's support. The ongoing experience of living with dementia required finding a new balance as partners took care of tasks the person could no longer handle. For some, this resulted in feelings of dependence or concerns regarding the delicate, reciprocal balance of giving and receiving:

She deserves much more from me, but, whenever needed, she is there. [...] I notice that it is gradually becoming less and less...that I am putting a lot on her. However, I want to do it myself. Otherwise you have to do everything and that is not necessary. I ask a lot of her. However, I know she likes doing it very much. But yes, I find it difficult. (Ron)

Some participants expressed worries about their partner's well-being, such as when leaving their partner alone while going to the care farm. Others experienced challenges in their relationship, like maintaining good communication. Four participants struggled with anger towards their partners and expressed regret and despair. One explained that his anger was like a curve, with two conflicting voices within him colliding, leading to impulsive behaviour.

Living alone also means managing dementia symptoms on their own. One participant emphasised the advantage of maintaining independence:

Others have the disadvantage of having a partner. What do these partners do? They take everything over. As a result, they no longer received stimulation to do things themselves. I have to! (Maria)

Some participants had relationships with their pets and put effort into caring for them. One participant described the companionship of her dogs and talked to them with sweet words like 'girl'.

2.2 Family

Many participants showed photos of their children and grandchildren, expressing joy in spending time together and gratitude for

the support they received. Some reported that their children were involved in maintaining their everyday lives, such as by helping with administrative tasks:

My daughter is a true sweetheart. I never abandoned her, and, in a way, she is giving that back to me. I don't have to feel guilty about that. (Ray)

Some participants expressed their role as grandparents in the upbringing of their younger (great)grandchildren. However, some reported difficulties in their relationships with their children or siblings and felt powerless to overcome these difficulties. For example, one participant was concerned about not seeing his son for months and feared that he felt left out compared with his daughter.

2.3 Friends and groups

Several participants shared experiences of having supportive friends with whom they enjoyed spending time, some of whom lived in the neighbourhood and others they had known for years:

I suggested that the group of friends come to visit me from time to time, to watch birds. We understand each other as well. (Leo)

Some mentioned feeling the absence of friends or friends who passed away. For example, a woman showed a mourning card for a close childhood friend with whom she became closer after losing their husband.

Most participants shared positive experiences with groups they joined in meeting centres, clubs, and churches. They appreciated the opportunities to interact with others who shared similar interests. In peer groups with other people with dementia, many felt valued for who they were and supported each other like a family:

It's all so fun and positive. We treat each other well. Occasionally someone may have a bad day. We talk about it: "What went wrong?" And that's why it's a very close group. (Ray)

2.4 Neighbourhood

Several participants described a form of social cohesion in their neighbourhood, where they knew and greeted each other:

In this courtyard, we all have nice people living here. There is always someone to ask if something is needed. [...] Enjoyable conversations, and sometimes they come over for a cup of coffee. (Julia)

Some got to know their neighbours through longer stays or by living in an apartment for older people. Several participants shared their dementia diagnosis with people in their neighbourhood. However, others found that their neighbourhood had grown larger and lost its sense of community. Some expressed less need for contact.

One person felt isolated and compared it to his former life in Morocco:

My country of birth. I know all the people there, and they also know me. We sit together while drinking tea or coffee. Everyone is in their own situation here. (Iram)

3. Having a sense of belonging

3.1 House

The participants lived in various types of houses, from rental apartments to detached houses. Most participants expressed happiness with their homes where they spend a large portion of their time. Reasons for satisfaction included one-floor accessibility and the size of the house. Many participants made it clear that they felt at home in their house. Some actively chose their current homes and were glad they did so in time.

During home tours, the rooms prompted the participants to show and describe activities they did or difficulties they encountered. For example, the confusion about which door led to the bathroom, or of no longer using rooms in the same way before. A few female participants showed off flowers in their living rooms. Some participants shared their safety measures to prevent falls or crime. Two participants shared feeling unsafe in their homes, such as climbing stairs:

She or I will then fall down the stairs. We must use the stairs to go up, and we still have an attic to go to. These stairs are disasters. It's irresponsible. (Albert)

One apartment had an incomplete floor and was cluttered, including demand letters and an outdated agenda from 2009. This participant reported that he could not afford the necessary improvements, resulting in the need to scavenge discarded materials from neighbouring flats.

Most participants enjoyed having a garden or balcony, and some showed their favourite places. Others shared their appreciation for butterflies, plants, and birds for whom they had birdhouses and their views outside. A few were dissatisfied with their outdoor spaces because of loud traffic or missing former gardens.

3.2 Meaningful objects

Participants displayed cherished objects in their homes, some even held them while sharing stories. These objects seemed to serve as anchors for meaningful memories. Participants looked delighted and sometimes touched emotionally. One participant had a tear in her eyes while showing a piece of art depicting her father, whom she greeted with 'good morning' every day.

Photographs of loved ones were prominently displayed in various rooms. Many photographs were related to the participant's life histories like their wedding day, or favourite leisure activities. Meaningful objects included souvenirs from their past work or from other countries. Some participants showcased tiles engraved with proverbs or symbolic items:

(Showing a drawing with a flag of Morocco and one of the Netherlands) This is my country and here is the other country. Those two countries are in my heart. (Iram).

Several participants displayed artwork that held special meaning, some of which they crafted or painted themselves. The connection to art ran deeper for some:

(Showing his letterbox): Every little thing has a story behind it. Even with lessons, every cloud has a silver lining: You should not view everything negatively because even if it is bad, there is still some good aspect to it. I am attached to it. Then so many memories come back. (Ray)

3.3 Outdoors

Participants discussed their neighbourhood's characteristics, such as its location and atmosphere. The participants who joined an outside tour commented on what they saw, which seemed to reflect their sense of belonging to their community. Some mentioned changes in their town over the years, such as the loss of services due to municipal restructuring. Most participants commented on the weather, which could influence their decision to go outside. Some shared their appreciation for organised events in their towns. Many mentioned the convenience of having nearby shops. They also discussed suggestions for shop improvements, including better customer service when help is requested and clearer store layouts. Several participants loved nature nearby, especially birds:

I have a thing for little birds. I am fond of them. It makes me feel nice. (Ron)

3.4 Transport

Some participants still drove, but many no longer felt comfortable driving or were not permitted to drive anymore. They missed the freedom that comes with driving. One participant was shocked by a message informing her that she was no longer allowed to drive:

This is something you have never experienced. I have never had an accident or collision. Something so strange. [...] Suddenly, they take it away. (Julia).

Some participants used cycling as their primary mode of transportation. Most participants used taxi services for transport to day activities. Some were happy with this, picking them up at their house and the kind drivers. Others made negative comments, such as the longer route to pick others.

4. Connecting to self

Participants shared how they experienced their past time, current time, and future time. Each personal story shed light on how they came to be who they are today; what joys have shaped them and what pain has tested them. These narratives highlighted the significance of connecting with one's past, present, and future experiences.

4.1 Past time

All participants shared stories about their past, sometimes in great detail, and some even did so from the start of the interview. For many, memories of the past served as anchors that connected them to loved ones and to accomplishments of which they were proud. Some compared their current lives to earlier years, while others explained how certain pleasant activities reminded them of their youth or work-lives. For example, one participant linked his enjoyment of the care farm to his days on the family farm. Experiences of loss, mourning, and painful recollections were also shared, particularly by those who had experienced family issues or adverse childhood experiences of migration or Second World War:

My mother taught us how to read and write at the Japanese prison camp. In the midst of all the misery, my mother did so. When my brother turned ten, he had to go somewhere else in the camp. We were already separated from my father. [...] Every morning we had to stand in a neat line, and if you didn't stand properly, then you were hit. (Alice)

Some participants stressed how the past influenced their everyday experiences. For example, one participant shared that memories of the Second World War had become more vivid, whilst another participant shared that her fondness for oatmeal stemmed from the War when it was scarce.

4.2 Current time

Several participants emphasised the importance of living in the moment and seizing the day, aware that every day is a new day. Some noted that living with dementia prompted them to accept their reality, put things into perspective, and focus on the things they could still enjoy:

You have to enjoy the day, tomorrow things can be different. (Julia)

4.3 Future time

Participants seemed reluctant to disclose their perspectives on how they envisioned the future. However, several participants shared their thoughts about when they might not be able to live independently at home. Some wanted to live in their homes for as long as possible but were preparing for the possibility of moving to a care home whereas others shared their thoughts about death. Several participants stressed that they were not thinking about the future too much and tried to live in the present moment. All participants recognised that everyone would eventually face death. A few participants had already arranged for euthanasia, connecting this idea to a future moment when they might no longer be able to care for themselves.

5. Adjusting to ongoing changes

Participants experienced changes related to their dementia diagnosis, which impacted different aspects of their everyday lives. They felt that they had to adjust and adapt to these changes continuously because of the progressive nature of dementia. Some

tried to accept their new reality, although it was sometimes difficult. They used humour and commented on relativising their situation:

You just have to accept it. Then, it will be much less present in your thoughts. [...] And think about nice things. (Julia)

Others expressed feelings of sadness, frustration, and helplessness, such as:

I wouldn't wish this upon my worst enemy. (Ans)

The changes participants described could be divided into changes in sensory and interactions with the environment and changes in interactions with people.

5.1 Sensory and interaction with environment

Participants discussed how dementia affected their sensory experiences, showing that it went beyond memory loss. They reported difficulties in perceiving and processing environmental information and in impacting bodily sensations and motor skills:

I feel like a zombie. As if on a sort of cloud. You feel strange. You walk and don't feel your feet. (Maria)

Others referred to their head, such as metaphorically "it waves a bit", and reported feeling tired or easily overwhelmed by sensory input. They adapted by taking rest breaks. Some struggled with concentrating on complex tasks, such as finances, due to difficulties with attention and visual processing. Participants also noted variations, with good days and bad days. Emotional states were affected, with some feeling irritable due to information-processing issues.

Temporal orientation was a challenge as one participant put it "time fades away". Different aids were mentioned, including special clocks, alarms, and routines. Orientation in the environment was another challenge for some participants, and confusion about the location could be frightening:

That was so scary. I thought, 'What's going on here?' I had no idea! I completely lost my past. Or no, I had lost my present for a moment and was living in the past. (Ray)

Participants attempted to develop strategies to manage this, such as trusting the body more than the brain or orienting to familiar landmarks in their environment.

5.2 Interactions with people

Participants shared how memory problems affected their communication with others, including forgetting what was said, leading to repetitive questioning:

Then I ask again, and he says, "You already asked that just now." I say, "I'm sorry, I've completely lost track. (Ans)

Participants also experienced difficulty finding the correct words. Some tried to avoid the issue by talking around the topic or asking others to rephrase. Others shared how they forgot names, with one participant stating "Waving is no longer possible". Experiencing frustration caused some to develop heightened sensitivity towards criticism, ultimately leading to anger.

Some participants shared about self-acceptance, as they acknowledged their disability and worked to overcome feelings of shame:

I do not have to defend myself. You cannot do anything about it. You don't have to be ashamed. You just have to be honest about it. There is no one who will react strangely to it. (Julia)

Talking about their experiences with dementia and receiving support from others were considered essential.

6. Being open to help and support

Participants shared their experience of receiving adequate support or facing a lack of assistance in their daily lives. Living with dementia required openness to receiving help and support tailored to their specific needs. This can be divided into professional and informal support, and the wider society.

6.1 Professional support

Participants had mixed experiences with professional support. Some valued capable and friendly social workers at meeting centres. A meeting centre should offer a variety of activities. Some found it valuable to discuss strategies for dealing with dementia rather than simply receiving "day care". Others appreciated the support of case managers, dementia coaches, or psychologists. They appreciated their personal attention and proactive attitude towards finding practical solutions to challenges:

She (the case manager) looks at my fridge and walks through the house. (Maria)

Some participants were dissatisfied with the limited support after receiving a dementia diagnosis. They felt unprepared and uninformed. They emphasised the importance of guidance and support from professionals who understand how to address the challenges of dementia. Their case manager was too passive or focussed only on practical aspects, neglecting the emotional challenges they faced, such as those related to partner relationships.

Many participants found it challenging to navigate the complex community service system and understand rules and regulations. Some shared frustration with complicated letters and a lack of clear information, highlighting the need for better communication and support. One participant expressed regret, losing autonomy due to an administrator. Despite these challenges, some participants expressed that case managers or social workers helped them navigate the system and access relevant services, such as homecare. However, participants also expressed the need for more individualised care, such as one participant who had issues with transportation and felt worried about solving the problem:

The worst part is that you have to pay for it yourself again, and... you don't get any reimbursement for the plus bus. Now we have figured out what kind of reimbursement it is, and they say "No, you do not qualify". (Shows a letter: "We have indicated that we cannot provide transportation. You have agreed to this, and it will remain so. Would you please confirm by email that you understand and agree with this?") (Albert)

6.2 Informal support

Participants highlighted the importance of having a support system for demanding tasks. For those with partners, their role was essential, while those living alone faced more visible difficulties without a partner to compensate for them. Family and neighbourly support was often relied upon, with examples including one participant's neighbour having access to the case manager's telephone number and another participant entrusting a spare key to their case manager. Some participants shared their diagnosis in group settings where accommodations, such as a chair, were provided to participate comfortably.

6.3 Society

Some participants highlighted the significance of raising awareness and increasing understanding of dementia in society. They expressed the need for more education and information about the disease to reduce stigma. Sharing personal stories and experiences can help achieve this. Some stressed the importance of speaking respectfully and appropriately to those with dementia:

For people like me, the most important thing is to take them into account and reassure them. And don't end the conversation if they don't have an answer. (Joost)

Additionally, one participant highlighted the need for more inclusive communities for young people with dementia to fully participate in society.

2.6.2 | Reflection on the findings with co-researcher group Brain Power

The co-researcher group Brain Power provided their opinions on two issues that emerged during data analysis. The first was the finding that many interviewees discussed their past experiences, which was not found in the scoping review.¹⁶ The group shared possible reasons for this based on personal experiences. Firstly, the past can serve as an anchor for who you are and who you are closely connected to, since the future is uncertain. Secondly, the past is more easily accessible in memory than short-term experiences, making it easier to communicate about something you still know. However, some members cautioned against overemphasising the past by professionals as it could give the impression of incapability. Others emphasised the importance of living in the present, rather than dwelling in the past or future.

The second issue addressed the finding that what matters most was often implicit in the answers during the interviews. We used a non-verbal approach by asking the group to bring a cherished object that symbolised what matters most in their everyday lives. The objects included a telephone that supported daily structure, a family photo that provided emotional support, a picture of a piano that represented love for music, and a book about community building in the army. One member shared that her social network was most meaningful to her. All shared stories confirmed the interview findings.

During the meetings, the group highlighted their experiences of not being understood, being excluded, and feeling patronised. Some members experienced misconceptions about dementia on a daily basis. They categorised these into two variants. The first was the offensive belief that dementia meant being in its end stage. The second was the feeling of needing to justify their disability as others did not perceive or acknowledge their struggles: "You do not look like you have dementia". The group's message was clear: treat us without prejudice or preconceptions and recognise that dementia encompasses more than just memory problems.

In conclusion, the group was consulted on the six dimensions and subcategories of everyday life (see Table 2) and the visualisation (see Figure 1) which shows the interconnectedness of the dimensions. The group members recognised all dimensions and illustrated them with personal examples and details. They missed no aspect. One member expressed with tears in her eyes, "These dimensions are 'spot on'. This is what we experience. What you have written down is exactly what we have shared here".

3 | DISCUSSION

Six dimensions of everyday life are identified as important to people with dementia and are interrelated. Living with dementia is a continuum that requires people to constantly adapt and negotiate

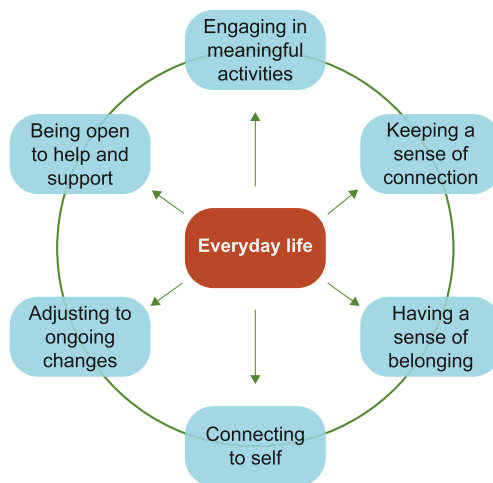


FIGURE 1 What matters most in everyday life for people with dementia.

everyday challenges. The interdependence of the dimension of adjusting to continuing changes with other dimensions is evident, influenced by having a sense of engagement in activities, feeling connected, having a sense of belonging to place and objects, connecting to oneself, and being open to help and support. These dimensions reflect similar findings in other studies on the everyday and what constitutes the lived neighbourhood³⁶ and that for the person with dementia, this is a continuous balancing act that shifts and moves over time and place.

The findings of this study are also congruent with Huizenga et al.'s¹⁶ scoping review, although the reported study findings provide a more nuanced understanding about what matters most in the everyday lives of people with dementia. The lens of everyday life reveals that people with dementia encounter various disruptions and challenges in the mundanity of their everyday lives, which can lead, for example, to a sense of disengagement in activities and disconnection in relationships. The study also shows how individuals with dementia actively shape and interpret their daily realities while confronting the disruptive effects of its lived experience, with the person often pushing against its boundaries and deleterious impacts.^{18,40} These intertwined and complex experiences of people with dementia need to be acknowledged and seen to challenge the 'living well' narrative that currently permeates the dementia studies and care fields.^{37–39}

New insights that supplement the scoping review¹⁶ include the significance of place and objects for a sense of belonging and connection to self across past, current, and future time. The experience of future uncertainty, living in the present, and anchoring oneself in the past to maintain self is in line with research on lived time.^{41–45} As seen in this study, an individual's life story can be a source of connection and continuity, as well as a source of painful life experiences. The lens of everyday life in relation to someone's biography is important because exposure to childhood adversity has a profound impact in later life.^{46,47} Moreover, it increases susceptibility to physiological and emotional regulation challenges when facing daily stressors.⁴⁸ Jones et al.³⁷ also highlight that the presentation of complexity in dementia is influenced by re-experiencing past life traumas. As the prevalence of adverse childhood experiences in older adults is over 56%,⁴⁹ more attention is needed to understand how past traumas and life experiences may impact individuals with dementia in their everyday lives.

The six dimensions of what matters in everyday life can also be influenced by other personal characteristics and circumstances, as we see in this study for example, socio-economic circumstances. The intersection between dementia and socio-economic circumstances can exacerbate daily challenges, as people may have limited access to resources such as appropriate housing. This can be aggravated by experiencing stress associated with economic instability, and challenges in comprehending policies and regulations. Taking into account socio-economic circumstances is crucial, as they are associated with greater cognitive decline.⁵⁰ At the same time, having a strong social network appears to be supportive when having dementia.

3.1 | Methodological considerations

The sample reflects a diversity of participants from different backgrounds. As Christensen and Jensen⁵¹ state, inquiry of everyday life has the potential to explore intersectionality. During the phase of conducting interviews, reflective practises were employed with co-authors to mitigate potential biases. The interviews were conversational and the use of mobile methods was done in attunement to each person.⁵² This guided spontaneity, together with the mix of data collection methods resulted in rich data. Going for a home tour or outside democratised the researcher relationship. The spaces elicited narratives and memories and participants could show things instead of just talking. So these methods are helpful in inclusive research.⁵³ The walking interviews in the neighbourhood enriched the data-collection when they were undertaken. However, several participants were not willing to go due to the weather or mobility issues. Better preparation and more information about what the walking interview entailed could have improved uptake. The partner's presence during interviews was suitable for a relationship approach but could also influence participant responses. Notably, partners tended to correct answers as if it was important to tell their reality. By focussing more on the participant, for example, by inviting the participant for a home tour or walking interview often shifted the attention.

The study employed a rigorous data analysis process. The data were analysed collaboratively with the second author and subsequently reviewed by the entire research team and co-researcher group Brain Power. Participatory collaboration with the group Brain Power during analysis enriched the study's findings, adding an additional level of understanding and authenticity. This collaboration with Brain Power, as well as the first author's engagement in the broader community of people with lived experience, helped to raise the profile and potential for participatory research work with people with dementia in the Netherlands. For example, going forward, Brain Power will co-produce a magazine (also known as a 'zine') with the study's findings and their stories and tips for peers. This is a way of dissemination with people with dementia that is attracting interest in the field and as a source of meaning-making and impact (see for example Everyday and Dementia Zine Series⁵⁴). A possible next step is that this group contribute to setting the agenda for future follow up research on interventions based on the six dimensions of what matters most and actively take part in these projects as co-researchers.

3.2 | Implications for research and practice

This study proposes a shift from a care-based approach to the lens of everyday life. This changes the focus to facilitating and enhancing what matters most to people with dementia in their everyday lives, rather than solely treating dementia symptoms. The six dimensions provide a framework for psychosocial interventions that aligns with this. Social work, as a discipline that values the everyday life world as a central area of concern,⁵⁵ can play a vital role in advancing this shift

through a strength-based, human rights-based and relational justice approach.^{56–58} Future research can design and evaluate dementia social work interventions based on the six dimensions, including narrative interventions^{18,45,59} and community development fostering an inclusive neighbourhood.¹⁸ Additionally, support should be trauma-informed^{60–62} and should pay attention to difficult socio-economic circumstances. Furthermore, future research and practise can also explore non-verbal creative methods, such as art and music therapy, and embodied approaches like (trauma-sensitive) mindfulness^{63,64} and somatic experiencing.^{65,66}

4 | CONCLUSION

Six dimensions of everyday life are identified by people with dementia: engaging in meaningful activities, keeping a sense of connection, having a sense of belonging, connecting to self, adjusting to ongoing changes, and being open to help and support. These six dimensions provide a potential framework for designing interventions that align with their needs and preferences. Similarly, there are messages in the study findings that relate to the need to continue to de-stigmatise the experience of living with dementia through neighbourhood-based programmes. Everyday life is a continuous balancing act between what matters most and what can be achieved daily within the biographical life story, relational network, and the physical environment.

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CONFLICT OF INTEREST STATEMENT

The authors declare none.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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