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Evolving dementia care: An explorative study on the lived experience of older adults living with dementia in nursing homes using observational and biometric sensor data

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Abstract

Introduction: This study explores the lived experiences of older adults with dementia in Dutch nursing homes, focusing on daily activities and emotional responses. With a growing number of older adults with dementia, gaining a deeper understanding of their lived experience is imperative.

Methods: Using a mixed-method narrative approach involving observations, informal interviews, and physiological monitoring through wearable sensors, the study engaged eight participants in psychogeriatric wards across two Dutch nursing homes. Observations and interviews aimed to provide context to daily activities, while wearable sensors tracked emotional responses through heart rate (HR) and heart rate variability (HRV).

Results: Key activities included eating, drinking, communication, mobility, and inactivity. Positive experiences were consistently observed during eating and drinking and communication, respectively influenced by the nursing home's social and organizational structures and social and personal contexts. In contrast, mobility and inactivity exhibited diverse physiological responses, reflecting a range of stress, concentration, or relaxation.

Conclusion & Discussion: This study offers valuable insights into the lived experiences of older adults with dementia in nursing homes. It highlights the generally positive nature of eating and drinking, shaped by social and organizational factors. Communication's impact varies with individual context. The study also reveals a complex interplay of emotions during activities related to mobility and inactivity, as evidenced by diverse physiological responses. Regarding implications for dementia care, the study emphasizes the need to redefine 'inactivity' as 'under-stimulation,' assess appropriate (in)activity levels, and acknowledge the significance of the nursing home's physical and organizational context. This redefinition should distinguish between 'physical' and 'mental' inactivity, address concerns related to under-stimulation, and cater to individual preferences. Recognizing the residents' restricted environment and reliance on care professionals and volunteers underscores the urgency of tailored approaches. Addressing these implications can provide fresh perspectives for evolving dementia care, creating a more supportive environment that promotes well-being.

Keywords

lived experience, nursing homes, daily activities, observational study, physiological measurements, narratives

Introduction

The ageing population has led to an increasing population of nursing home residents with moderate to severe dementia in the Netherlands. To ensure that this increasing number of nursing home residents is supported and stimulated in their well-being and quality of life, actively involving them in research is considered good practice (Beerens et al., 2016; Nygaard et al., 2020). However, people with severe dementia often have complex symptoms that can drastically affect their behavior and emotional responses. Older adults with dementia in nursing homes often show behavior that is difficult to interpret (Aboseif & Woo, 2020) such as apathy (Cerejeira et al., 2012), exhibit inactive behavior during large parts of the day (Nordin et al., 2017), or limited engagement in daily activities within shared spaces (Edvardsson et al., 2014). Gaining insight into their daily experiences is crucial for improving dementia care, enhancing the well-being of individuals with dementia, dignity, and fostering a more empathetic, person-centered approach in nursing homes (Beerens et al., 2016; Heggestad et al., 2015; van Zadelhoff et al., 2011). To examine the daily lives of people with dementia in nursing homes the question is not only what daily life looks like (which activities, where, when, etc.), but also how this daily life is experienced.

The lived experience

The concept of 'lived experience', used in qualitative phenomenological research, is particularly suited to capture people's experiences, choices, and options (Given, 2008). The lived experience combines what people *do* and how they *emotionally respond* to their day-to-day lives. It focuses on the comprehensible meaning of experiences rather than aiming to construct a 'factual representation' of this daily life (Lindseth & Norberg, 2004).

What people *do* includes all observable behavior during activities. In environmental-behavior research, Zeisel (1993, p. 124) describes six elements to map what people do: *who* (personal context), is doing *what* with *whom* (social context), in what *relationship* (social context), in what *context* (organizational) and *where* (physical context). These elements are embedded into four contexts, relevant for the lives of older adults with dementia living in nursing homes: (1) personal context, encompassing the dementia process, past occupations, hobbies, activities, and (dis)abilities; (2) social context, including interactions with staff, visitors, and fellow residents; (3) organizational/care context within the nursing home, which involves mealtimes, care routines, visiting hours, and policies; and (4) physical context of the nursing home, including aspects like architecture, furniture, and embedded technology (Schuhmacher et al., 2022; Teitelman et al., 2010; Wood et al., 2017). Through these contextual lenses, the data collected takes into account the uniqueness of this nursing home environment. While previous research (e.g., de Boer et al., 2016; den Ouden et al., 2015; Nordin et al., 2017) uses timeslots during observational studies, continuous measurements and observations throughout the day are essential to better capture the lived experience of older adults with dementia.

A rather innovative method to measure how people *emotionally respond* to activities is the use of biometric sensor data, specifically measured by wearable sensors (Bourne et al., 2019; Kreiberg, 2010), which is complementary to observational data (Vos et al., 2012). Physiological monitoring offers a more detailed understanding of affect, which is especially valuable for people with dementia, as the method can circumvent issues such as declining speech, difficulties expressing themselves, and declining retrospective memory. However, this type of measurement is still scarce in scientific studies (Bower et al., 2019), particularly for people with dementia (Bourne et al., 2019). And while some studies have applied physiological measures to assess the impact of music and art interventions on mood and agitation in people with dementia (e.g., Izzo et al., 2021; Raglio et al., 2010; Thomas et al., 2018), they do not examine it in the light of the day-to-day lives of older adults with dementia. Additionally, most research is conducted in laboratory settings rather than within the living environment, in this case, the nursing home.

The current study

While gaining insight into the lived experience can be important for improving policy and practice for enhancing the well-being of older adults with dementia in nursing homes, this concept of 'lived experience' for this particular target group is still limited (e.g., Chang, 2013; Moore & Ryan, 2017; Murphy et al., 2022). This is particularly the case of lived experience research examining the day-to-day life of this target group, perhaps amplified through difficulties capturing the lived experience of this target group due to dementia-related symptoms using 'regular' research methods in this field (i.e. interviews). Therefore, the research question of this article is "What are the lived experiences of older adults with dementia in Dutch nursing homes, and how do different contexts (personal, social, organizational, physical) shape these experiences?". This question is examined by combining observational methods, informal interviews and physiological monitoring via wearable sensors. In

this way, we can examine the lived experience by focusing on how people *feel* in relation to what people *do*. Here, we focus on the shared indoor spaces of the living environment where seniors with dementia can enter independently and where they spend most of their (waking) hours. Within these shared spaces (such as the collective living room and corridor), previous research has shown that the most frequent activities are (1) eating and drinking, (2) mobility, (3) communication, and (4) inactivity (de Boer et al., 2016; McCormack et al., 2011; Nordin et al., 2017).

Method

Research design overview

An explorative empirical study with a mixed-method approach was conducted to map the lived experience of older adults with dementia in two Dutch nursing homes, which fits well with the existing methods of empathic design (Mohammadi, 2017). This study used narrative inquiry to examine the lived experience by looking at the role of context(s) and through 'retelling' the story of the person with dementia (Clandinin & Connelly, 2000; Creswell, 1998; Islam et al., 2022). Figure 1 shows the research design overview, focusing on what people with dementia *do* and how they *emotionally respond* in geriatric wards of two nursing homes to gain insight into their lived experience. A narrative approach results in rich, contextualized stories that provide insight into how individuals understand and interpret their own lives and experiences (Islam et al., 2022; Riessman, 2008). To map what people *do*, we used fly-on-the-wall observations and informal interviews with staff, volunteers, and participants. Combined, these data resulted in narratives, which provided understanding and explored human behavior within their contextual layers (i.e., physical, organizational, personal, social) (Connelly & Clandinin, 1990) (cf what people do). Based upon the narratives, we selected scenarios (i.e., specific situations of activities) to map how people with dementia *emotionally respond* in these scenarios. These scenarios exemplified activities that are close to normal or typical patterns of observed behavior. Besides observing the behaviors during these scenarios, this response was measured by combining observational scales of mood and agitation with physiological monitoring, since the combination can give insights into affective states, interpreting positive and negative arisen stress, arousal, and emotional state during activities in scenarios (de Boer et al., 2016; Tiberio et al., 2012; Vos et al., 2012) (cf how people emotionally respond).

When using narrative inquiry, the researcher is often considered an active participant, co-constructing meaning with participants through the engagement in storytelling. As such, the researcher's positionality as well as biases, background and perspective can influence the narratives and understanding of the context. While this study took a different approach to 'collecting stories', by combining observations with informal interviews and biometric measurements, the researcher's own experiences, values and relationship with the residents shaped the data collection and analysis within this paper. Next to engaging in reflexivity, qualitative rigor of the study was maintained through using triangulation (different data sources, methods and different researchers involved in the data collection and analysis) as well as member checking by verifying outcomes with nurses, informal caregivers or family, and sometimes residents (depending on the types of questions asked as well as the ability of residents to express themselves). Lastly, by using the six elements from Zeisel as well as the four contextual layers, rich, contextualized descriptions aimed to ensure credibility of the findings.

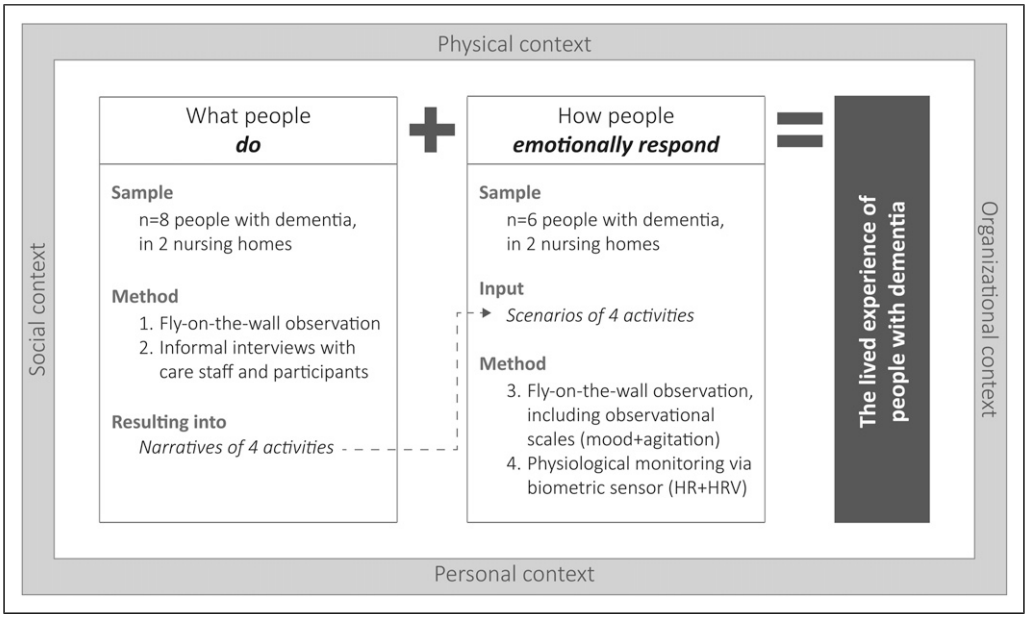


Figure 1. Research design overview on capturing the lived experience of older adults with dementia.

What people do

Sample. Residents of the two nursing homes could participate in this study if they lived in psychogeriatric wards, had dementia, were capable of moving autonomously, and did not use heart medication (because of possible influence on biometric sensors). The information for the inclusion criteria was obtained via unstructured interviews with care staff (Appendix I) and resulted in eight participants ($n = 8$, four participants in each nursing home). Consistent with the narrative approach in this article, we refer to fictional names rather than to participant 1, etc.

Method 1: Fly-on-the-wall observations. The fly-on-the-wall method was conducted to map the daily patterns of the participants in the corridor and communal living room. Activities over five whole days were mapped. The overall structure of the observation list was based on Zeisel (1993, p. 124): *who* is doing *what*, with *whom* in what *relationship* in what *context* and *where* (Appendix II). The observation list for *'what'* was based upon earlier observational research in nursing homes (e.g., de Boer et al., 2016; den Ouden et al., 2015; Nordin et al., 2017; van Buuren et al., 2019) and reflects the activities of the daily life of people with dementia in nursing homes (Appendix III). This method (as well as method 2) took into account the four contextual layers (i.e., personal, social, organizational, and physical).

Method 2: Informal interviews. Informal interviews with staff took place before, during, and after observation times and focused on gathering additional information about the four contexts in which the activities took place. Interviews with participants were conducted to identify possible motivations for and experiences about their behavior. These were held during observations, as affected retrospective memory does not allow for the recall of past events.

Narratives of four activities. To understand what people *do*, information from both methods was integrated and transferred into narratives. The detailed data collection involved context-specific elements, like verbal and non-verbal communication, routines, rituals, and personal information about older adults with dementia (Appendix II, III). The deductive thematic analysis (Creswell & Plano Clark, 2017) was based upon the observational framework as described above and on the types of activities as well as contextual layers identified common patterns, differences, and similarities in personal and contextual aspects. Using deductive thematic analysis allowed for systematic analysis of qualitative data as pre-established themes and concepts are used (i.e., observational framework and four contextual layers). Two researchers were involved in coding the observations and interviews, with cross-checking of observations in all case studies. Interviews with caregivers were used when additional information was needed (in particular pertaining to specific contexts). The constructed narratives serve as examples of recurring themes, offering a deeper understanding of the lives of individuals with dementia in the context of nursing homes.

How people emotionally respond

Sample. While eight participants were observed in 'What people *do*', biometric measurements could only be obtained from six of them in total ($n = 6$), as one of the participants refused to wear the sensor during measurement days, and the sensor of another participant did not register any data.

Scenarios of four activities. The constructed narratives provided insights into the daily life events of the participants, such as eating and drinking, communication, mobility, and inactivity. Specific situations of these daily activities per participant closest to their 'normal' pattern were selected as scenarios. This means that participants were never 'prompted' to do certain things. The chosen timeslots of the scenarios were during morning hours and lunchtime, since method 1 showed that more activities in the shared spaces took place during these timeslots. Only scenarios in the shared spaces were included in the measurements. Appendix VI shows the executed scenarios, numbering each scenario. While 60 scenarios in total were measured (10 per sensor-wearing participant), only 38 recorded instances were analyzed in this article, because they yielded both sufficient quality HR/HRV data and observational data. The scenarios were timed and annotated in an observational list (including what people *did* using the same activities from the observation list) to match the different outcome measures afterwards (Appendix VI). The scenarios varied between 2–10 min of measurements.

Method 3: Fly-on-the-wall observation, including observational scales for affect and agitation. Two observational scales for mood were used: the Observed Emotion Rating Scale (OERS) (i.e., pleasure, anger, anxiety/fear, sadness, interest, and contentment) (Lawton et al., 1996) and Maastricht Electronic Daily Life Observation Tool (MEDLO) (i.e., 7-point Likert scale) (de Boer et al., 2016). The latter one was also used for measuring people's levels of agitation (i.e., 5-point Likert scale) (Appendix V). Both tools were previously used in research on people with dementia (de Boer et al., 2016; Lawton et al., 1996). These observation scales were filled in after discussion/checking between two researchers. Thereafter, two observation measurements per participant were verified (double-checked) by the care professional on duty at that time. There were no conflicting interpretations between care professionals and researchers. The scores of the observational rating scales were incorporated in the data from the fly-on-the-wall observations, as such allowing for not only activities as well as observed emotion, mood, and agitation to be examined. The researchers

examined both data sets to identify recurring themes and patterns in the behaviors/emotional states of the participants as well as performed a contextual analysis to examine the context in which these behaviors took place.

Method 4: Physiological monitoring using wearable sensors measuring HR and HRV. The indicators HR and HRV were used in this study to measure stress and arousal (Tiberio et al., 2012). They were measured using a body-worn sensor on the chest (Kana Daily Life | Kana, n.d.), that gathered individual responses of participants in terms of arousal in stress or excitement. As long as the gathered data did not contain abnormal outliers (i.e., very sharp peaks or dips indicate the sensor shifted or was bumped, yielding incorrect data) and was continuous (no missing measurements during the recording) it was included in the study. Data quality and interpretation were checked with researchers working at the company of the sensors that were used.

HR and HRV values are highly individual. Therefore, the interpretation of these values should be considered within individual participants, and not between participants (Hollien, 1980). This means that whether HR and HRV values are high or low, is determined by the baseline of that individual participant: i.e., deviations from the personal mean, from activity to activity (see van Buuren et al., 2024). This personal mean is calculated from all recorded instances (including primarily longer baselines measurements) from that particular person.

Based on the literature, roughly four categories can be distinguished to interpret the data: low HR and low HRV would mean physiologically stress or focus, with emotions of sadness (non-crying); low HR and high HRV would mean physiologically relaxation; high HR and high HRV would mean physiologically excitement; and high HR and low HRV would mean physiologically focus, stress, or exertion, with emotions of anger, fear, and anxiety (Figure 2) (TaheriNejad & Pollreisz, 2017; Kreibig, 2010; Kana, n.d.). High HRV values may indicate amusement, low HR contentment, and high HR joy and surprise (Kreibig, 2010). Some research shows that these interpretations are similar for older adults with dementia compared to other target groups (Izzo et al., 2021; Osaka et al., 2017; Thomas et al., 2018). That being said, with a multitude of interpretations possible, particularly when experiencing low HRV and high HR, a combination of biometric data and other data is crucial for interpretation.

Before this combination of methods was executed in the two nursing homes, the Ethical Review Board of the Eindhoven University of Technology approved the set-up of the study (ERB2021BE68). Thereafter, informed consent was gained by the staff members of the care organizations of the informal carers of the nursing home participants. During the scenarios, specific consent about wearing the sensor was requested from the nursing home participant. This meant if the participant refused to wear the biometric sensor, no attempt was made to put it on.

Results & analysis

In the following paragraphs, the results and analysis are displayed of what people *did* and how people *emotionally responded* during specific activities: eating and drinking, communication, mobility, and inactivity are described.

Eating & drinking

What people do. Eating and drinking activities were observed often in the nursing homes. Breakfast was served in the collective living room, but was not at a set time with all residents. During lunch, all residents are gathered in (one of) the living room(s):

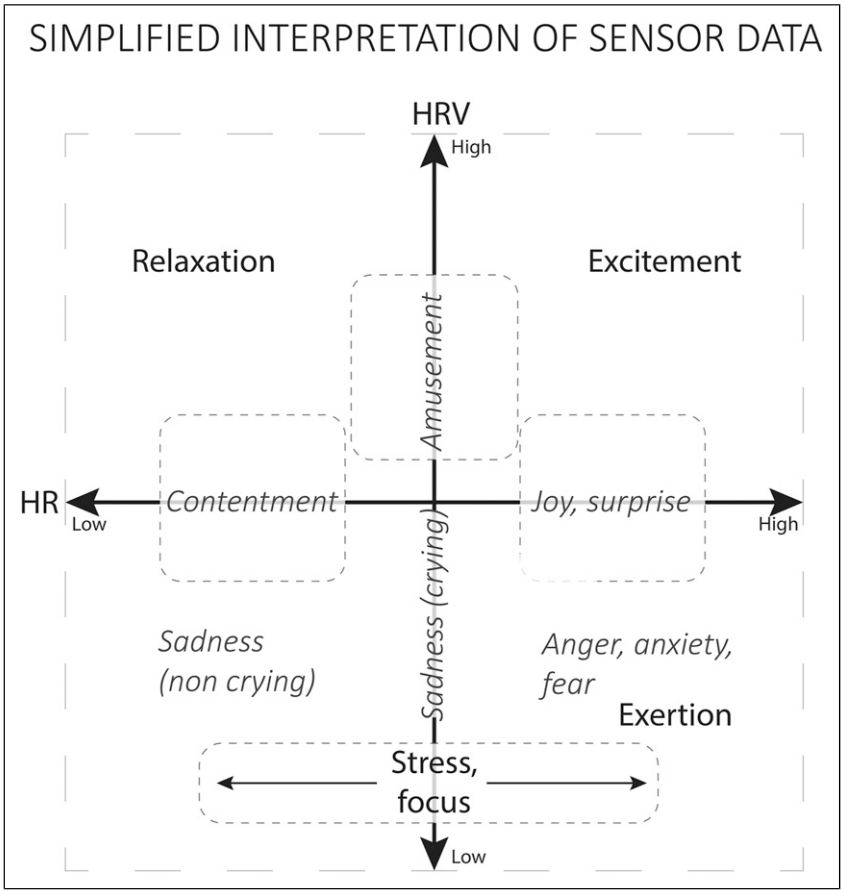


Figure 2. Simplified interpretation of HR and HRV values.

Ben is an older gentleman with Alzheimer's disease, who tends to walk a lot through the communal areas of the nursing home ward: the corridors, the three living rooms and personal rooms (if they are unlocked). He is not specifically looking for something or someone, but he likes to look around in the living rooms or in the care office. Here and there, he stops to look out the window or to have a chat. Around noon, it is time for lunch, a hot meal that is eaten together. Although the three living rooms of the ward are equipped with a kitchenette, these kitchens are not set up for preparing a full hot meal. The hot meal is prepared in the central kitchen of the nursing home. There is no choice in the menu for the residents. Around noon, a care professional from the ward picks up a trolley with the hot meal from this central kitchen. When she arrives on the ward, the smell of the food spreads through the corridor. Some residents naturally drift towards their own (or any) living room and sit down at the table. The care professional walks into each living room and serves the food on the plates. Before entering the living room where Ben normally lives, she walks through the corridor and meets Ben. She kindly but firmly invites him to come and eat: "It's lunchtime, you are coming right, Ben?". He looks at her and nods in assent: "I guess if there is food, I have to.." he mumbles to her and follows her into the living room.

Although the dining table in the living room was the most commonly used space for eating and drinking activities, some residents also made deviate from this, as the following narrative shows:

> Chloë, a quiet lady with advanced dementia, often walks back and forth along the straight corridor. She does not speak much anymore, but sometimes nods encouragingly at you. She has a regular spot at the dining table in the smaller of the two living rooms in the nursing home. While it is clear to the residents that lunch is eaten at the dining table, this is not as straightforward for other drinks and snacks throughout the day. Especially for residents who wander a lot, like Chloë, 'sitting at the table' is not a prerequisite for eating and drinking. In the morning, another resident, together with a care professional, baked a cake which is served in the afternoon. Around four o'clock, the coffee pot is placed on the table and slices of cake are handed out. Chloë picks up her plate with cake and walks with it to the corridor. There, she stands in the middle of the corridor to enjoy her snack on the way.

> Lunch at the nursing home is a communal affair, but Doris, an older lady with Fronto-Temporal Dementia, prefers to sit alone. While other residents are guided to the central dining table, Doris evades this and chooses a separate spot. The staff believes this arrangement is best for everyone, including Doris, as she can be angry and disruptive in social settings. Her stubbornness and obstinacy, according to her family stemming from her dementia, often lead to negative reactions towards others. She often reacts negatively to the other inhabitants: what they say, what they do—there are moments when nobody can do anything right in her eyes. The communal dining setup seems to trigger her, and she keeps telling the same stories about her husband, who also lives in the nursing home. Doris insists that 'they' are keeping them apart despite their 45 years of marriage, exclaiming, "That is very long, you see! It's not fair!" The caregivers explain that her husband lives downstairs and that they had already been living separately before coming to the nursing home due to her changed demeanor. However, Doris has forgotten this and remains adamant about being mistreated by the care organization, or 'them' as she calls it. Allowing Doris to choose her own place for lunch gives her a sense of control and helps maintain a more peaceful environment for everyone.

How people emotionally respond. In total, ten scenarios (n = 10) were analyzed in the category 'eating and drinking', performed by all six participants. Participants were drinking coffee, having breakfast, or (group) lunch. The left diagram of Figure 3 shows the interpretation of sensor data. Each circle represents one scenario, and the numbers correspond to the list of performed scenarios per participant in Appendix VI. A green circle exhibits corresponding biometric data with observational data. The data in Figure 3 is adjusted to the baseline of the participant. The observational data on mood and agitation is displayed in the diagram on the right in Figure 3.

The interpreted sensor data showed varied affect, from excitement to stress or focus. Almost no agitation or relaxation was measured, and in general, participants had neutral and content emotional facial expressions. From the observational scale and sensor data, it seems that eating and drinking is an activity that is positively experienced, but does require the participants' focus. This can be seen in the sensor data (excitement and focus), although it is not as straightforward in the observation scales (not agitation, neutral expressions). The following narrative, in which the associated HRV/HR data indicate amusement (scenario #23), illustrates this:

> While drinking coffee or juice can be an individual activity, lunch in the nursing home is a group affair. Betty, a lively and sociable resident, enjoys engaging in conversations with other residents and staff members, often singing to herself or chatting freely. She appears to thrive in the lively atmosphere, savoring the social aspects of the meal even before food is placed on her plate. As lunch is being

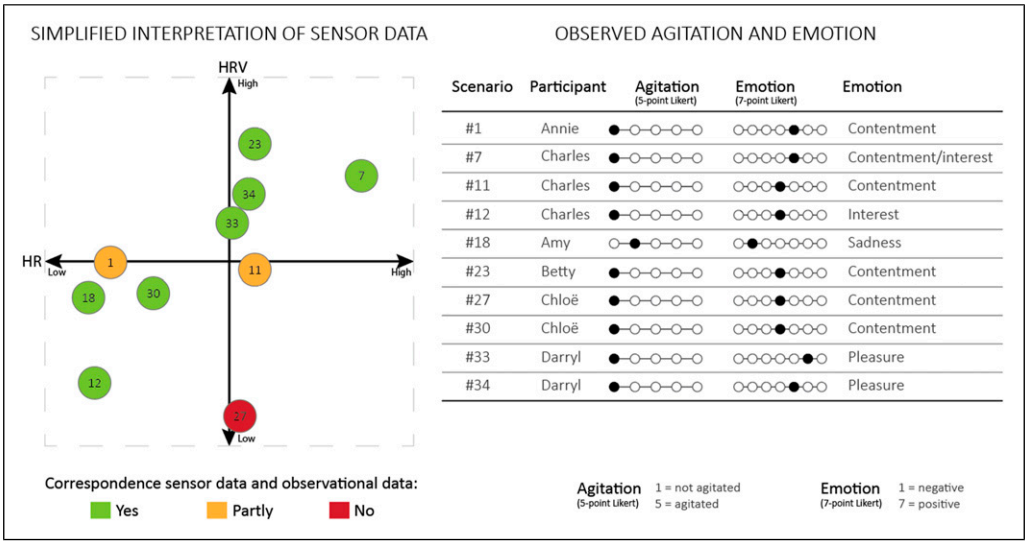


Figure 3. The scenarios of lived experience performed within 'eating and drinking' (n = 10); each circle represents one scenario with the corresponding number in the diagram on the right side.

prepared, the nursing staff tries to keep conversations flowing, encouraging interaction among the residents. The residents and the staff members are gathered at the table, using this time not only to serve food but also to socialize a little themselves—something they rarely have time for outside of direct care tasks. Once the plates are served, the mood changes slightly. Betty, like most residents, shifts her focus from conversation to her meal. Occasionally she struggles with a specific aspect of her plate, like the cutting of the meat or the mashing of her potatoes. She does not ask for help, but nursing personnel notice and help. Other residents eat quietly, focused on their plates. The wandering and distractions that might normally characterize parts of the day of the nursing home staff seem to pause, as the structured environment of the mealtime keeps everyone focused on eating. During lunch, the staff is less burdened by other care responsibilities or planned activities.

The combined narrative. The narratives show how eating and drinking take place in a structured *social setting* (social context) in which, particularly at lunch and dinner time, all residents eat together (sometimes with the help of volunteers or nurses). Furthermore, as mealtimes as well as drinking coffee/tea/lemonade is highly dependent on what is offered, rather than initiated by the residents themselves, one can see the particular importance of the *organizational context* in this activity. With a dominant organizational context, the *physical context* is more fixed: almost all eating and drinking activities take place in the living room, with all eating activities at the dining table. That being said, there are particular *personal circumstances* (dementia characteristics, personality) that occasionally cause deviations from these patterns, such as how people react in the social setting around the dining room table or physical limitation (e.g. bedridden in later stages of dementia or residents who are ill/indisposed). Overall, eating and drinking could be both an enjoyable activity as well as one that requires focus.

Communication

What people do. Of the observed activities, many involved different forms of communication were observed. The vast majority of these communication activities (also) concerning verbal communication. A majority of the communication was directed at or in response to somebody, and not initiated by the residents themselves. The following narrative illustrates this:

> Many residents seem to enjoy interaction with others and caregivers, just like Darryl. Though he rarely initiates conversations or activities, Darryl is responsive and receptive to personal invitations from nursing staff and volunteers. He does not often start activities on his own, as few things seem to spark him into action. One morning, a nurse working on the ward approaches Darryl while he is sitting quietly in his chair. "Darryl, would you like to bake a cake with me today?" she asks warmly. Darryl, who had been staring at nothing in particular, perks up at the invitation. He nods and mumbles something in agreement. The nurse already had brought the necessary utilities and ingredients to bake this cake and sat down in the chair next to Darryl. Although the nurse takes the lead in the baking process, she makes sure to include Darryl in every step. First, she asks him to put the preprepared mix in the bowl. Afterwards, she asks Darryl to mix this ingredients with a spatula. He diligently stirs, and looks at the volunteer when she is doing the rest of the work. With each request, Darryl complies happily, seemingly pleased to be involved but also content to let the volunteer manage the more complex parts of the process. After the mix was put on in the baking tin, they both rise from his chair and walk together toward the kitchen, which is part of the nursing home's living room area. After they place the cake in the oven, Darryl returns to his chair, sitting comfortably. Twice during the morning, the volunteer gently taps him on the shoulder, inviting him to check the oven with her to see how the cake is baking. Each time, Darryl slowly rises, walks to the oven with her, and peers inside as the cake rises and turns golden brown. He nods in approval, satisfied with their progress, before returning to his chair.

Mornings generally witnessed higher activity levels in the living room often involving coffee or tea consumption and social interactions at the dining table. However, sometimes participants communicate to no one in particular. For example Betty:

> While conversations would conventionally be between people, some of the residents engage in many types of undirected conversation. Like Betty, for her it does not matter much if there is an audience, she just seems to love to chat and sing. She sits at the dining table in between meals and is first mumbling something unintelligible while looking at her hands in front of her. After a while, she starts humming a song, sometimes singing a couple of words, then again some more humming. For Betty, these 'conversations' seem to be as enjoyable and relaxing as much as the directed conversation is.

How people emotionally respond. Six scenarios ($n = 6$), performed by three participants, concerned communication activities, receiving visitors (e.g., #13), and singing (i.e., #8). The combination of data (Figure 4) shows how all recorded communication activities of these three participants seemed to be experienced relaxing or exciting; with a positive overall mood and little signs of stress. An exceptional high HRV measurement was mapped within scenario #13, which indicates (extreme) pleasure and relaxation. The data in Figure 4 is adjusted to the baseline of the participant. The observational data on mood and agitation is displayed in the diagram on the right in Figure 4.

> Every day, at three o'clock sharp, Charles gets a visitor: his long-time partner Molly. Charles almost always spends his afternoons at the dining table, humming or talking to himself or the staff. It is a quiet

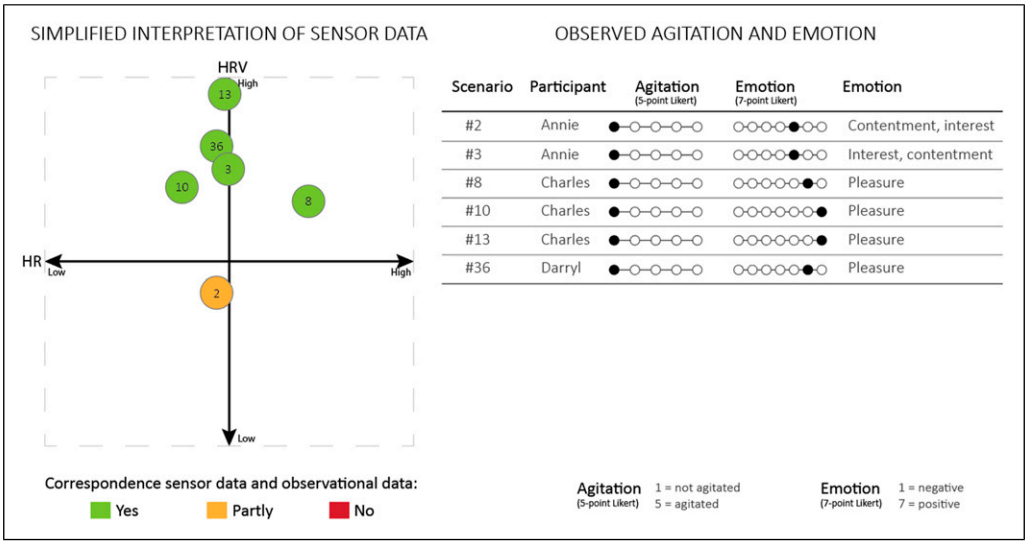


Figure 4. The scenarios of lived experience performed within 'communication' (n = 6); each circle represents one scenario with the corresponding number in the diagram on the right side.

afternoon this Tuesday, only Charles (and one of the observing researchers) is in the living room. Regardless, Charles is staring at his hands, his occasional mumbled conversation the only indication that he is not asleep. His back is to the door where Molly always enters. Before Charles can see her, she whistles a particular tune. It is something between them, a specific melody he seems to recognize that carries a personal meaning according to Molly herself. Charles hears the whistle, lifts his head and throws his hands up laughing: "Ha-ha! Yeah! Ooooh! … Molly!". Every day he reacts overjoyed and happily surprised to see Molly again: "Who is there? Is it Molly? Ha! Wonderful! Yes!".

The combined narrative. The narratives show the variation of communication in different *social settings* (between residents, with care professionals, with visitors, or undirected) in which the initiative of the conversation often lies with the care professional, showing the importance of the *organizational context*. Already with only three residents performing the scenarios, large differences in initiation, type/tone of conversation and topics can be seen, with each resident having their own personal and medical background, preference, social network, previous occupations and personality (*personal context*).

Overall, data showed participants seemed to enjoy their conversations, experiencing them as exciting or relaxing and following observational scale data. Important to note is that while the vast majority of the observed instances in the fly-on-the-wall observations corroborate these images, not all communication was – at first glance – positive and these measurements are only from three out of the six participants. Some negative exchanges (including shouting, angry remarks or negative comments towards other inhabitants) did take place. However, these did not occur during the biometric measurement days. As such, the question remains what kind of biometric data more seemingly 'negative' (agitation, anger) or 'confused' (what should I do? Where am I? what is expected of me?) communication activities would yield.

Mobility

What people do. The vast majority of the observations concerned movements throughout the shared space. In both nursing homes, some participants showed 'necessary' movement (e.g., using the bathroom) and 'frequent' random movement. The following narratives illustrate this:

> While many residents tend to wander around the ward, others only walk with a specific purpose. One of the latter is Doris, who takes the same few routes over the ward, rarely ever leaving her personal room or living room. She mostly walks from her room, to the living room to 'her' table -separate table which only has two chairs – or she goes straight for the nurses or volunteers with her requests (which are often more formulated as demands than requests). When exiting her room she often softly announces her goal: "I'm going to get more towels" or "I'm going to use the bathroom". In this case it is the first, she walks up to the nurse sitting in a chair at the central dining table and proclaims: "I would really need some clean towels. I have piles of dirty laundry. It is not nice. I want to do laundry". The nurse patiently explains that it is Thursday and today they are going to do the washing, she can give the wash to her and can walk with her for some clean towels. She grudgingly agrees and follows the nurse out of the living room to one of the service rooms. From there, with an arm full of clean towels, straight back to her room

> Many residents, specifically the people who wander a lot, often mention that they are looking for something but cannot find it. Such as Chloë, who is looking for her room in the ward. She walks through the hallway and looks puzzled at every door she passes. She has already been past all doors twice and turns around for a third round. Meanwhile, a member of the nursing staff walks past and sees Chloë looking around and says: "Chloë, do you see that picture on the wall?", a picture of Chloë on the wall indicates her private room so she can 'find' her room. Chloë moves closer to the picture. However, she seems not to recognize her own picture, and she continues her stroll in the corridor.

Notably, available walking spaces were actively utilized for mobility when accessible. In the afternoon, communal area activity declined as many residents either retreated to their rooms or wandered within the corridors or living rooms in the ward. Ben is a wanderer, especially in the afternoon. Sometimes, he has a walk with Annie:

> Ben and Annie often take walks together, were they chat (or more accurately: Annie chats and Ben listens) and walk circles in through the hallways. There is one exit to the rest of the nursing home, which are sliding doors with a poster print of a forest on it to 'conceal' this exit. However, Ben and Annie want to drink coffee, downstairs in the cafeteria and keep pressing the 'lift button' (the access key pad). They keep saying to each other: "this lift takes forever" (Annie) "I want to get that coffee now" (Ben) "yes, yes we need to press the button for it to come". One of the nurses walks past and overhears their plans and says: "ah Annie, Ben, sorry the lift is broken". To which they collectively decide that if they bring Annie's walker to her room they can take the stairs later. In looking for her room (which takes some time), they seem to have forgotten about drinking coffee downstairs and together they stroll to the living room. They sit down and are asked if they would like a cup of coffee or juice to which Annie happily says "yes, sure, if you have some I would like coffee!".

How people emotionally respond. In the category mobility, twelve scenarios were executed ($n = 12$), performed by four participants. The scenarios varied from walking, sitting and standing, wayfinding tasks, sporting with TV, and wandering behavior. Combining the sensor data and observational scales, emotional responses vary. Measurements that can be seen as physical exertion, stress, and

focus only have slight differences (Figure 5). So, from HRV and HR data alone it is difficult to ascertain mood or agitation. The data in Figure 5 is adjusted to the baseline of the participant. The observational data on mood and agitation is displayed in the diagram on the right in Figure 5.

The combined narrative. The narratives depict varying forms of 'mobility behavior' among residents, for example wandering behavior, purposeful walking, and exercising. While it is unclear whether wandering behavior in general is perceived as positive or negative, some observed conversations do reveal confusion, attempts to access closed doors (for example Ben and Annie and the "broken elevator"), and other behaviors that could affect mood and emotion:

> Annie is a resident who generally finds her way through the nursing home on her own. The ward is designed with a circular corridor connecting three sections, each looking identical to the other, which sometimes makes it hard for residents to distinguish between them. Despite this, Annie usually walks with purpose, navigating directly to what she believes is her room. One day, Annie confidently heads towards what she assumes is her room, stopping at a familiar door. However, the door is locked. Confusion flashes across her face and she stands still in front of 'her' door. She glances around nervously, her voice rising as she calls out, "Why is my door locked?" She peers back down the hall, visibly unsettled.. A caregiver, noticing her distress, approaches calmly. The caregiver explains, "Annie, you're in the wrong hallway. Your room is just over here, on the other side." Upon hearing this, Annie immediately relaxes and her expression softens. She gives a small nod of understanding and, with the guidance of the caregiver, makes her way to the correct section of the ward. Soon enough, Annie reaches her actual room, and everything is fine again as she steps through her door.

The room Annie tried to enter is the 'right' one, but in the wrong section of the ward. An understandable mistake as these three sections are identical in many aspects. These situations underscore how the *physical environment* of the nursing home significantly shapes the experience of

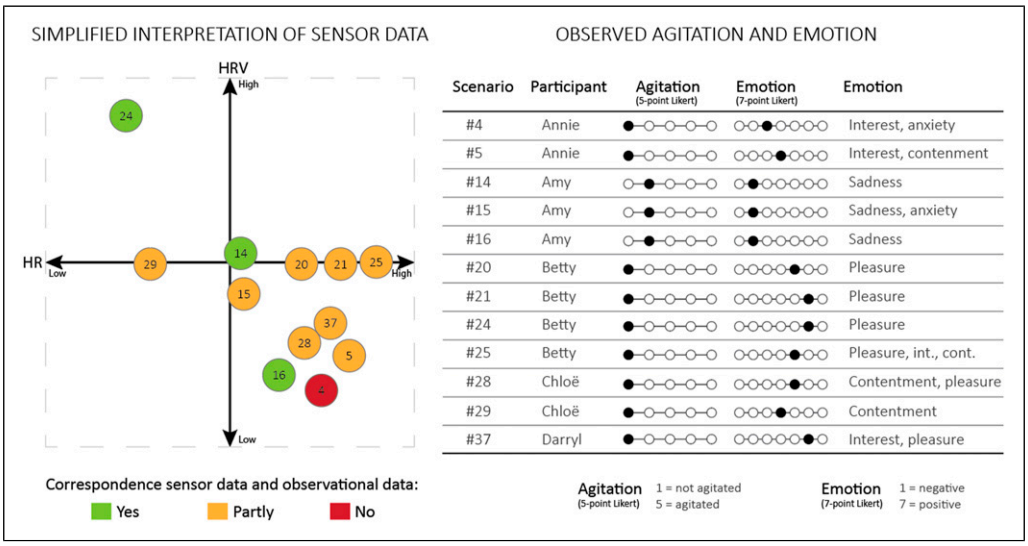


Figure 5. The scenarios of lived experience performed within 'mobility' (n = 12); each circle represents one scenario with the corresponding number in the diagram on the right side.

walking, including factors like 'concealed doors', restricted access, and the absence of personal keys. Moreover, physical wayfinding cues, such as photos or personal items near individual rooms (which are not always noticed), further contribute to the lived experience. These wayfinding clues can be found in the physical environment, but often staff also (has to) assist(s) the residents by giving them physical guidance or verbal prompts. Together with organizational protocols and habits, such as allowing people outside the ward, giving them personal keys (or not) and time available for physical activity with residents, this shows the importance of the *organizational context.*

It turns out that for mobility, the interpretation of the biometric data is difficult as physical exertion creates similar physiological responses as stress/focus. For example, one can see these differences when Betty and Darryl performed the scenario 'sporting with tv' (#24 and #37).

> Darryl is sitting in his favorite lazy chair in front of the television. The nurse turns on a TV show about exercise, which is designed to make people participate at home. The nurse tries to get Darryl to join as well by enthusiastically inviting him and showing what he needs to do. After some attempts, Darryl is actively exercising with the host of the TV show, while being encouraged by the nurse, who is still in the room. In the meantime, Betty walks into the living room and joins the activity already going on. She needs less prompting and joins in actively participating in the sporting activity.

While the observational scales show no agitation, quite a high mood, and signs of pleasure, different HR and HRV measurements were taken. While Betty (#24) showed low HR and high HRV indicating relaxation, Darryl (#37) showed high HR and low HRV indicating stress, focus, or exertion (Table 1). The question arises where these differences come from: is it because Betty is a frequent mover and Darryl is not (*personal context)*, and Betty has a better physical condition? Or does Betty enjoy the activity (more)?

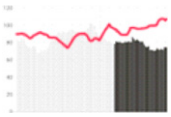
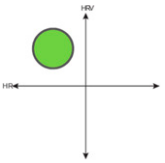
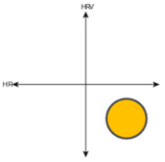
That being said, particularly for physically exerting activities, it is important to combine observational data, personal information (e.g., physical condition), as well as physiological data. Not only is it relevant to determine e.g., the enjoyment of activities or if stress is experienced during wayfinding, but it can also indicate the physical strain particular activities put on a resident with dementia. While people may enjoy certain activities very much, they may still be very strenuous and overexertion, and physiological data may give additional insights into this particular aspect.

Inactivity

What people do. Although 'inactivity' (e.g., watching TV, sitting) was often seen for long periods of time, it is underrepresented in the observations due to two reasons: (1) inactivity as "doing nothing" was not written down continuously, due to the focus on performed activities (that is to say: the observations note instances, not durations of activity), and (2) observations took place in communal areas, while sleeping and lounging often (also) takes place in personal rooms. The following two narratives illustrate moments of 'doing nothing':

> After coffee, Annie takes her walker and walks towards the two chairs near the first-floor window. There are not many other people in the living room, all seats are open still. She navigates the space and proceeds to sit down at the far end of the room, with a view outside to the street below. She proceeds to look outside, seemingly watching the activity on the road and the sidewalk with mild interest.

Table 1. Comparison mobility.

No	Part.	Activity	Observed behavior	Affect		Sensor data (HRV & HR)	Interpretation HRV & HR
				Observational scales			
24	Betty	Mobility	Sporting with tv, moving hands	Agitation Emotion* Emotion**	No agitation Positive (6 out of 7) Pleasure		
37	Darryl	Mobility	Sporting with tv	Agitation Emotion* Emotion**	No agitation Positive (6 out of 7) Interest, pleasure		

A group of residents is sitting at the dining table, with some conversation going on between residents and nursing staff. The conversation is mainly chitchat about their daily lives, plans for activities for the residents, but also some jokes and laughter between nursing staff and some of the residents. Betty has been quiet during this time, looking a bit at her hands, then around the room, not reacting to the conversation around her. At some point during this all, Betty rests her head on her arms and proceeds to sleep on the table, apparently utterly unbothered by the noise and chatter around her.

How people emotionally respond. In the category inactivity, ten scenarios ($n = 10$), performed by all six participants, were analyzed; varying between 'just' sitting, sleeping, and fiddling. The observational scales of mood and agitation often only show neutral expressions, whereas physiological data shows more variations between scenarios (Figure 6). For example, scenario #9 shows high HRV values, indicating relaxation.

Charles is still sitting at the dining table, by himself. One of the nurses walks past and sees him sitting, without saying anything to him, she walks to the stereo and puts on some local (old) music (i.e., Dutch sea shanties), and walks away to help another resident. When the music turns on, Charles slightly lifts his head and seems to relax in his chair. The music is on for quite some time, most of the time he looks up, a bit towards the ceiling, sometimes with his eyes closed and sometimes very slightly moving.

The question arises if Charles is indeed listening to the music and relaxes while listening to this music, or not. Another example is scenario #17, with low HR and low HRV indicating stress, focus, or sadness.

Amy is sitting at the dining table with her lunch in front of her, slightly away from the table itself. She has eaten something, but there is still quite a bit left on her plate. At some point she shoved her chair back a little bit, revealing the bottom of her sweater. She seems to be doing nothing in particular except fidgeting with the hem of this sweater. Picking at the button, turning the fabric around, plucking at the colored part of the hem, turning it around again and picking at a loose thread.

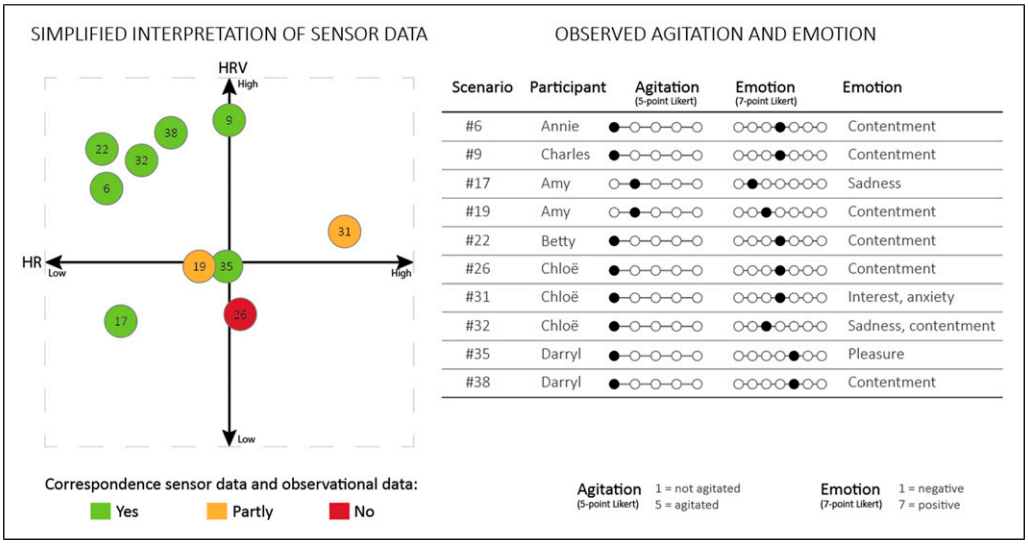


Figure 6. The scenarios of lived experience performed within 'inactivity' (n = 10); each circle represents one scenario with the corresponding number in the diagram on the right side

The question arises if she is focusing on fidgeting with her sweater or experiences stress/anxiety about something.

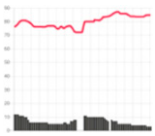
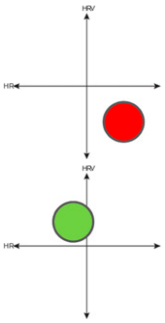
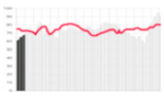
The data in Figure 6 is adjusted to the baseline of the participant. The observational data on mood and agitation is displayed in the diagram on the right in Figure 6.

Regarding 'inactivity', observed mood and agitation often appear relatively similar among participants. However, biometric data revealed distinct physiological reactions, highlighting the variability within this category. An example is provided in Table 2; Chloë is 'sitting' at the dining table with others around (#26) and Darryl is 'sitting' in a lazy chair alone (#35). Conversely, even seemingly identical activities can yield varying physiological measurements: yet one exhibits physiological signs of stress or anxiety (#26) while the other displays signs of relaxation (#35). Therefore, biometric data may be of particular additional value to uncover affective responses during more physically inactive situations.

The combined narrative. First of all, the narratives are illustrative of the variations of 'doing (physically) nothing' that may exist. While inactivity sounds like 'nothing is happening', the narratives show that different instances of inactivity are not the same. Namely, a couple of narratives hint at the possibility of a resident being physically inactive, but perhaps mentally engaged (e.g., Annie looking outside, Charles listening to music). In general, the narratives show how context can also be influential – not by something happening, but by the absence or lower levels of something (e.g., noise, activity, people). That is to say, most observed 'inactive' behavior also took place in the absence of social interaction (e.g., with visitors, conversations with others or coffee moments) and organizational activities (e.g., lunch, dinner, activities with volunteers or staff).

Furthermore, the physical space plays a role in facilitating certain activities (or the absence of them), such as the lighting, sounds (no music, no TV) or other 'visible' options for activities (think of a game on a table, a TV that is on, a newspaper on the dining table). The importance of the *organizational context* (also considering the accepted 'norm' that doing nothing is at certain times

Table 2. Comparison inactivity.

No	Part.	Activity	Observed behavior	Affect: Observational scales		Sensor data (HRV & HR)	Interpretation HRV & HR
26	Chloë	Inactivity	Sitting at dining table	Agitation	No agitation		
				Emotion*	Neutral (4 out of 7)		
				Emotion**	Contentment		
35	Darryl	Inactivity	Stting in chair	Agitation	No agitation		
				Emotion*	Quite positive (5 out of 7)		
				Emotion**	Pleasure		

desired/encouraged, e.g., after lunch/dinner), as well as *physical context* (what is on offer), seems of particular interest to this category of activities.

Discussion & conclusion

While insights into day-to-day life experiences of older adults with dementia in nursing homes are important for enhancing their well-being, this information for this particular target group is still limited. Therefore, this study aimed at understanding the lived experience of older adults with dementia in nursing homes through informal interviews, physiological data, and observational data. Our study emphasized that examining the lived experiences through various contextual layers provides a nuanced understanding of participants' experiences. The lived experience in this article captured what people *do* and how people *emotionally respond* during four daily activities: eating and drinking, communication, mobility, and inactivity.

This explorative study showed that eating and drinking activities were mostly experienced positively, in which organizational structures and social contexts were important influential factors. Conversations and social interactions were – based upon this study – enjoyable, although depending on social and personal context. Activities regarding mobility as well as inactivity varied greatly in physiological responses (ranging from positive to negative experiences). Specifically for inactivity, there is less correspondence between facial expressions (often neutral) and the biometric measurements.

By using the contextual lenses for analysis, the unique circumstances of living in a nursing home for mapping the lived experience can be better understood. Specifically, the daily lives of older adults with dementia in nursing homes become (literally and metaphorically) 'smaller'. Most of the days, activities take place in the confines of the nursing home and most interaction is with carers, other residents, and (if applicable) some regular visitors. Their lives focus mainly on the communal living room, hallways and their bedrooms. Even though (Dutch) regulation dictates an 'open door' policy, in which people with dementia should be free to move around the building as well as outdoor environments, many places struggle to balance this freedom of movement with safety and liability concerns. While the nursing homes often have cozy canteens,

activity spaces or outdoor environments such as gardens, actual access to these spaces is often restricted (locks, 'hidden' doors behind big stickers, access codes) or regulated (only with visitors, or sometimes only by some residents). In this way the *physical environment* and *(the organizational)* (in)accessibility of these spaces show the struggle between safety of residents with providing stimulation and freedom of movement. Furthermore, the location of private rooms, orientation and shape of the corridors and living rooms, and the physical organization of the ward itself may influence daily experiences. For example, continuous-loop corridors may prevent wanderers from leaving the ward, but can also be disorienting to them and other residents there. The layout of the living room is often centered around a central dining table, which literally becomes the center of attention, while there are often also other seating options available to the residents as well.

In that sense, the *physical environment* as well as the *organization rhythm* are dominant factors in the lived experience of people with dementia. While the constricted physical space may provide peace of mind for relatives and carers, allowing for more control over residents, it can be both a source of stimulation as well as frustration and confusion for residents.

When talking about control and agency: the role of the organizational and care rhythm is dominant for many of the common activities in nursing homes (e.g., eating, drinking, communication, hobbies, care activities), as opposed to an initiative from residents for example. This organizational context is determined by cognitive healthy people such as policy makers and carers, whose norms state that too much apathy and inactivity are detrimental to one's well-being. Also, research shows the importance of stimulation for older adults with dementia and there is a shift towards more stimulation-based activities in nursing homes. That being said, these instances of seeming 'apathy' or inactivity were not negatively experienced by the participants in this study. While undoubtedly a lack of physical and mental stimulation may have negative effects, our research begs the question of whether the activities we label as 'inactive' and 'stimulation' hold the same connotation for people with dementia. For example, can watching TV be considered a form of 'inactivity' if a resident is mentally engaged with the content on the screen? Furthermore, the *organizational* and care rhythm often also dictates the form in which interaction and activities are offered. Such as lunch and dinner being communal activities at the central dining table and collective activities offered in the central activity space on the one hand as well as individual activities when somebody working in the activities/well-being center picks up a resident or engages in a one-on-one activity on the other hand. While the type of activities is often tailored to the individual (*personal context*), the setting of this activity is predetermined (by the *organization* of care and daily rhythm). While not necessarily unfitting (some people may enjoy collective lunch time or individual activities), the effect of the group size and organizational rhythm on the individual's experience is unclear. Having a set rhythm and clear protocols is logical from a carer's perspective, as organizing everything per individual with separate rhythms, preferences, care requirements, meal(times), and activities is unworkable. Especially taking into account the shortage of nursing home personnel, which is only set to become larger with time.

Furthermore, this research showed that physiological data can complement observational data and vice versa to map the lived experience. It showed how physiological data can give clarification and nuance on the experiences of stress and emotions of people with dementia when observation data was 'neutral'. This means that we should be careful in relying only on non-verbal expressions and behavior of people with dementia in interpreting their affective state.

Some methodological remarks should be made. First, this explorative study had a rather small sample size of six older adults with dementia. Second, we have made use of rather short physiological measurements indicating immediate responses, while longer measurements could provide

more insight into the 'recovery' from effort as well as positive or negative emotions. Third, the used sensors measured HR and HRV levels. In future research, other sensors might be used as well to measure additional physiological measures like skin temperature, skin conductance levels, and respiration values.

The combination of what people *do* and how they *emotionally respond* yields three main implications for practice and research for older adults with dementia in nursing homes. First of all, a redefinition of 'inactivity' is necessary as indicator of 'under-stimulation', since our study showed a variety of emotional responses in activities in the category 'inactivity' (such as sleeping, sitting, listening to music). This redefinition should at least be mindful of the difference between 'physical inactivity' and 'mental inactivity'. Particularly the later poses challenges in gathering and interpreting of data for this target group.

Secondly, appropriate levels of '(in)activity' (and with that, the fear of 'under-stimulation') should be critically examined. While under-stimulation could certainly pose risks, defining what constitutes 'under-stimulation' and what (contextual) factors contribute to or combat this is crucial. What may be considered 'under-stimulating environments' for other target groups (e.g., watching TV) could still be (mentally) stimulating for older adults with dementia in nursing homes or some activities deemed appropriate for other groups may be too intensive.

Lastly, the physical and organizational context within the nursing home play a dominant role. As such, specific attention should be given to the physically and metaphorically shrinking world of the older adult with dementia in the nursing home. The ward is often the only place nursing home residents can freely access, this place being their living environment or home. They often (have to) depend on initiating eating, drinking, social, and hobby activities by care professionals and volunteers.

These insights into the lived experience can give new avenues for evolving dementia care, by taking into account a shrinking a social and physical sphere, redefinition of inactivity, and looking into appropriate levels of stimulation.

Declaration of conflicting interests

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Ethical statement

Ethical approval

Before this combination of methods was executed in the two nursing homes, the Ethical Review Board of the Eindhoven University of Technology approved the set-up of the study. Thereafter, informed consent was gained by the staff members of the care organizations of the informal carers of the nursing home participants. During the scenarios, specific consent about wearing the sensor was requested from the nursing home participant. This meant if the participant refused to wear the biometric sensor, it was not put on.

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Supplemental Material

Supplemental material for this article is available online.

Notes

1. **Where**. Where an activity took place is mapped and annotated on the floorplan of the ward. However, not only aspects visible on floorplans are relevant, also environmental conditions may influence the behavior during the activity (Zeisel, 1993, p. 163). During the observations, not only markings of the floorplan of where an activity took place, also notes regarding the weather conditions, indoor climate, and noise were made. Furthermore, conditions that can be seen as 'barriers' (Zeisel, 1993, p. 132) were indicated as well. These barriers include walls, screens, objects (such as an open or closed door), and symbols. These environmental conditions are particularly relevant for people with dementia due to their increased sensitivity towards them.
2. **Who**. In order to be able to interpret the activities of people with dementia in real-life settings, it is important to obtain a complete image of personal abilities, preferences, and histories per observed person (i.e., personal context). Dementia can impact cognitive, social, and physical functioning. Examples of physical functioning are whether people were able to walk (unassisted), had visual or auditive impairments, or had impaired motor abilities (Reisberg et al., 1985). Before the observations started, information about personal background and social functioning was obtained via unstructured interviews with staff.
3. **What**. For the list of potential observed activities, findings from different studies were combined (den Ouden et al., 2015; Nordin et al., 2017; van Buuren et al., 2019). Of this extensive list of activities, only activities that were taking place (or could take place) in communal areas were included. Activities taking place in private bedrooms and bathrooms (e.g., showering, dressing) where therefore excluded from the list. The list was consequently discussed with staff of the nursing home, in order to check if items were missing.
4. **With whom**. For the observation list, not only what people were doing was relevant, also with whom. If there was interaction with other residents in the ward, this can be indicated using the abbreviations as described in 'who'. Furthermore, staff that is working on the day of the observations are also inventoried and given a distinctive code for observations (S1, S2, …) Lastly, other people, such as visitors/family were noted and indicated if relevant/occurring during the observations. Descriptions of people were noted and checked with nursing staff or resident afterwards.
5. **Relationship**. In this element, the connections between 'who' and 'with whom' were described per activity. Descriptions go beyond 'doing together' or 'independently' (Zeisel, 1993), by describing the exact interaction between the resident with dementia and staff/visitor/other. Specific attention was paid to physical actions and (non)verbal interaction when doing an activity; these actions or interactions were noted down.
6. **Remarks**. The context in which certain activities took place, was highly relevant for observers; it may mean a difference between 'normal' behavior during the activity and behavior that was considered 'disruptive' or 'annoying' (Zeisel, 1993). Therefore, additional notes on personal, social, organizational, spatial, digital, and temporal context was noted down in the remark-column.

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