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# Constructing the lived experience of older adults with dementia: lessons learned from an explorative mixed method approach

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**Abstract**: Understanding the lived experience of older adults with dementia is crucial in providing better care and living environments. However, a suitable and practical methodological approach is lacking to map this lived experience. These methods need adaptations due to dementia-caused behavioral, cognitive, and linguistic challenges. This paper aims to demonstrate innovative approaches for gaining a deeper understanding of the lived experiences of older people with severe dementia in collective spaces in nursing homes. An empirical mix-method study approach was used, combining fly-on-the-wall observations (including facial expression scales), physiological measuring (i.e., HR, HRV, PR, SCL, skin Temperature), and informal interviews. Based upon these measurements (n=20 people with dementia in four nursing homes), it turned out that the combination of spatial, behavioral, and biometric data provides a detailed and nuanced image of the lived experience of people with dementia in nursing homes. Practical recommendations to conduct this type of research are provided; for example, developing a baseline per participant, mapping activities in detail and carefully over time to link the different types of data, and conducting informal interviews to collect background information, preferences, and possible incentives or explanations of behaviors.

**Keywords**: lived experience, dementia, observations, physiological measuring, interviews

## 1. Introduction

The concept of "lived experience" is integral to understanding and improving the quality of life for individuals, particularly those who may not be able to fully articulate their needs and experiences. This concept encompasses the daily activities, experiences, and emotional responses of individuals. However, a significant challenge arises in interpreting the behaviors of people with dementia, who often exhibit behaviors and emotions that are difficult to interpret, such as apathy, agitation, inactivity, and limited engagement (Aboseif & Woo, 2020; Cerejeira, et al., 2012; Edvardsson, et al., 2014; Nording, et al., 2017).

Understanding the lived experience of this target group is crucial not only for providing better care but can also be used to improve living environments. This understanding helps to tailor care practices and

environments to meet the unique needs of these individuals, fostering a higher quality of life and wellbeing (Beerens, et al., 2016; Heggestad, et al., 2015; van Zadelhoff, et al., 2011).

Current research methods for mapping people's lived experience are often qualitative in nature and encompass methods such as interviews or diary studies. However, in research focused on individuals with dementia, these language-centric approaches can be limiting due to linguistic challenges and cognitive impairments often prevalent in people with dementia (Driessen, 2019; Hirschauer, 2006; Pols, 2005). The lived experience focuses on how people feel when living their daily lives and executing their daily activities. However, little research focuses on this experience for people with dementia (Bower, et al., 2019). Research that does, often uses self-reports and interviews (Stanyon, et al., 2016). However, these methods are difficult to apply to people with dementia (Arons et al., 2013) due to the inherent cognitive decline, specifically in recalling past events and emotions (Jones et al., 2016). Furthermore, interviews with care professionals or family about the feelings of people with dementia can provide potential social desirability bias (e.g., showcasing positive effects of care activities) and retrospective bias (i.e., difficulties in recalling information when questions are asked retrospectively) and are therefore less suitable. (Shephard, 2003). Lastly, some research uses observational scales for people with dementia to measure mood and agitation (Edvardsson, et al., 2014). However, these methods are still interpretations of the experience of people with dementia by second parties.

Methods that gather information from the person as well as contextual factors (such as personal, social, organizational, and physical) can contribute to gaining insights into the lived experience of this particular target group. Examples of these methods are observations and physiological measuring. Despite some observational research, comprehensive studies on the daily activities of nursing home residents with dementia are scarce. In addition, previous studies often focus on observable physical activities rather than the emotional experiences accompanying them (den Ouden, et al., 2015; MacRae, et al., 1996). Mapping the affective responses of people with dementia requires innovative methods. Biometric sensor data, especially from wearable sensors, offers a promising approach. These methods provide detailed insights into affective states, unhampered by the challenges of declining speech and retrospective memory commonly found in people with dementia (Bourne, et al., 2019; Kreiberg, et al., 2010; Vos, et al., 2012). While studies have used physiological measures to assess the impact of interventions like music and art on mood and agitation in people with dementia, fewer studies have explored these measures in the context of daily life (Izzo, et al., 2021; Thomas, et al., 2018).

So, dementia is a complex condition that makes conducting research more challenging. Despite good attempts in current literature, the above mentioned challenges require adaptation in methods and approaches for people with dementia. While mixed-method approaches are common in qualitative research, insights and tools in practically applying these approaches in a reliable manner are scarce. Therefore, this research aims to demonstrate innovative approaches for gaining a deeper understanding of the lived experiences of older people with severe dementia in collective spaces in nursing homes using an empirical mixed-method approach including fly-on-the-wall observations, physiological measuring, and informal interviews.

## 2. Methods

An empirical study employing a mixed-method approach was conducted to investigate the lived experience of people with dementia residing in four nursing homes in the Netherlands. This approach aligns well with established empathic design methods (Mohammadi, 2017). The study's framework centers on observing what people with dementia do while measuring how they emotionally respond within the wards of these nursing homes, thus providing a deeper understanding of their lived experience. Conducted methods were fly-on-the-wall observations, physiological measuring, and informal interviews (see Table 1). This combination allows for a nuanced interpretation of affective states, identifying both positive and negative stress responses, arousal, and emotional states during activities (de Boer, et al, 2016; Tiberio, et al., 2019; Vos, et al., 2012).

The main focus of the paper is on the methodology. We piloted our methodology with a small sample and findings about the lived experience of older adults with dementia during the pilot phase are reported in the article of Hammink, et al. (under review).

Table 1. Research design overview

| | **The study** |
|---|---|
| **Methods to construct the Lived Experience** (what people *do* and how they *emotionally respond*) | • Fly-on-the-wall observations, including observational scales<br>• Physiological monitoring via biometric sensor (i.e., KANA and Empatica)<br>  ○ Measurements more continuously<br>• Informal interviews with nursing staff and (if possible with) people with dementia |
| **Sample** | n=4 nursing homes:<br>• Nursing home 1, care organization A<br>• Nursing home 2, care organization B<br>• Nursing home 3, care organization B<br>• Nursing home 4, care organization C<br><br>n=20 older adults with severe dementia |

### 2.1 Sample

In total twenty participants with severe dementia (n=20) divided over four different nursing homes were involved. All participants lived in psychogeriatric wards of the nursing homes, had dementia (mostly Alzheimer's Disease, sometimes fronto-temporal dementia), and were capable of moving autonomously. Participants were recruited via nurses.

### 2.2 Fly-on-the-wall observation

The study employed the fly-on-the-wall observation method as recognizable outsiders (Zeisel, 1993) to observe daily patters and observable affective states in communal areas for two days per nursing home. This approach, informed by Zeisel's framework, involved observing who is doing what, with whom, in what relationship, context, and where (Zeisel, 1993; p124), complemented with three observational scales on mood and agitation (Appendix I). The observational scale for mood was based upon the Observed Emotion

Rating Scale (OERS) (Lawton, et al., 1996) and the Maastricht Electronic Daily Life Observation Tool (MEDLO) (7-point Likert-scale, 1 for very negative mood and 7 for very positive mood) (de Boer, et al., 2016), while agitation was also assessed using MEDLO (5-point Likert-scale, 0 not present and 4 very agitated) (Appendix II). These scales were filled in by researchers and corroborated by nursing home staff to interpret the expressions of people with dementia (Lawton, et al., 1996). This observation data was collected via forms and annotated floorplans.

### 2.3 Physiological measuring

The rather innovative method to measure affective states physiological monitoring using wearable sensors was used in this study. The indicators Heart Rate (HR), Heart Rate Variability (HRV), Skin Conductance Level (SCL), Pulse Rate (PR), and skin temperature provide a more detailed view of the emotional responses to activities (Kreiberg, 2012; Tiberio, et al., 2019). The sensors KANA Daily Life (body-worn sensor on the chest) (Kana, n.d.) and Empatica Embrace Plus (wristband sensor) (Empatica, n.d.) were used in this study to measure these indicators. Based on literature, certain combinations of HR and HRV values, as well as high versus low values of SCL and skin temperature can be interpreted as relaxation, excitement, joy, anger, anxiety, fear, exertion, stress, focus, sadness, and contentment (see Figure 1) (e.g., Kana, n.d.; Kreiberg, et al., 2010; TaheriNejad & Pollreisz, 2017; Vos, et al., 2012; Jang, et al., 2015). For example, high values of HRV combined with high HR indicate excitement, while low HRV values and high HR values could indicate e.g. anger, stress, focus, as well as exertion. SCL reveals arousal, for example high SCL values could indicate e.g. anger, anxiety, as well as happiness, and low SCL could indicate non-crying sadness. Lastly, high skin temperature could indicate e.g., pain as well asl exercise, and low skin temperature could indicate stress. The shifts in the indicators' values are highly individual, therefore, the interpretation of high or low values should be considered within individual participants, not between participants (Hollien, 1980).

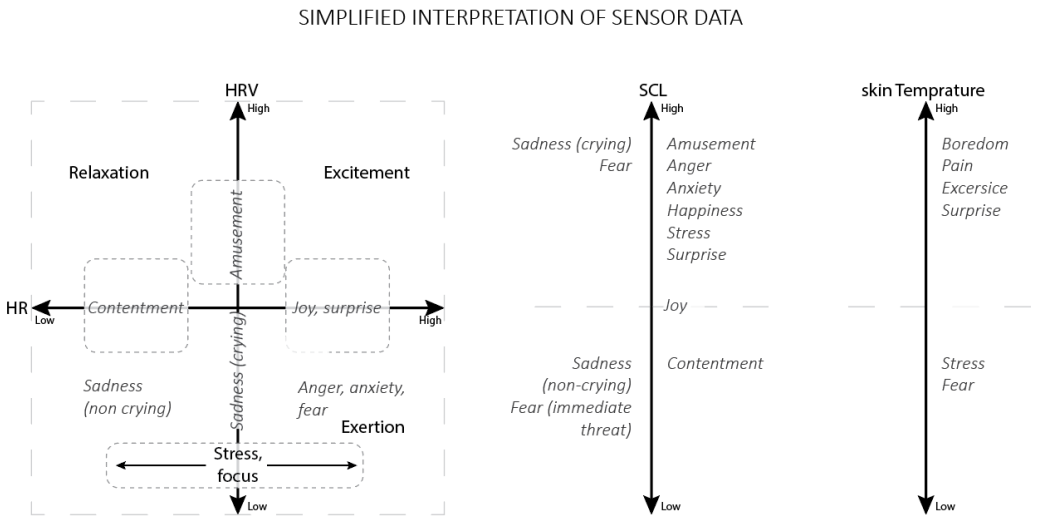



Figure 1. Simplified interpretation of biometric sensor data (indicators: HR, HRV, SCL, and skin Temperature)

2.4 Informal interviews

Additional informal interviews with care staff and participants before, during, and after the observations and measurements, provided background information about contextual factors and possible incentives or explanations for certain behaviors. This data was collected via fieldnotes.

2.5 Ethical approval

The Ethical Review Board of the Eindhoven University of Technology approved the setup of this study beforehand. Family members provided informed consent for the older adults with dementia in the nursing homes via staff members. Specific consent about wearing the sensor was obtained by people with dementia themselves, meaning that they could refuse to wear the sensor.

## 3. Results and analysis

During the main study, 1.993 unique observations have been registered over twenty participants with dementia in collective spaces of four nursing homes; with 28h and 48min sensor data with KANA and 100h and 20min sensor data with Empatica. This section provides preliminary results of the study; specifically focusing on examples of baseline development, long measurements, multiple indicators, and 'inactivity'-activities.

3.1 Baseline development

The interpretation of emotional responses is based on the peaks and drops in (physiological) values. Since this interpretation is highly individual (Hollien, 1980), developing a baseline per participant is essential. A baseline concerns a starting point – a kind of average emotional status of a person on that particular day – from which you can interpret whether a certain physiological value is high or low. This baseline can be developed by observing activities and visible expressions over a long period in combination with long physiological measurements and conversations with healthcare professionals and the participants themselves. Figure 2 shows an example of such a baseline, including the location of the participant, multiple physiological values (i.e., PR, skin T, SCL), emotional observational scales (i.e., MEDLO emotion and agitation), time of the day, and type of activities (e.g., walking, sitting, communication, eating & drinking, medication). The female participant often walked independently around the building (e.g., note #1). She loved participating in activities and conversations (e.g., #1, 3). During the measurement day, she suffered from a headache and repeatedly asked for paracetamol (#2). Nevertheless, she showed various emotional responses: satisfaction, pleasure, fear, interest, and sadness. This is visible in, for example, the different values in the MEDLO emotion observational sales. A value of four indicates a neutral emotional state, and a value of two (#2) implies signs of negative mood, such as sadness, displeasure, and anger, which was acknowledged by contextual observations since she was suffering from a headache and asking for paracetamol. Furthermore, the PR value increases (#2), which might refer to physical activity or stress.

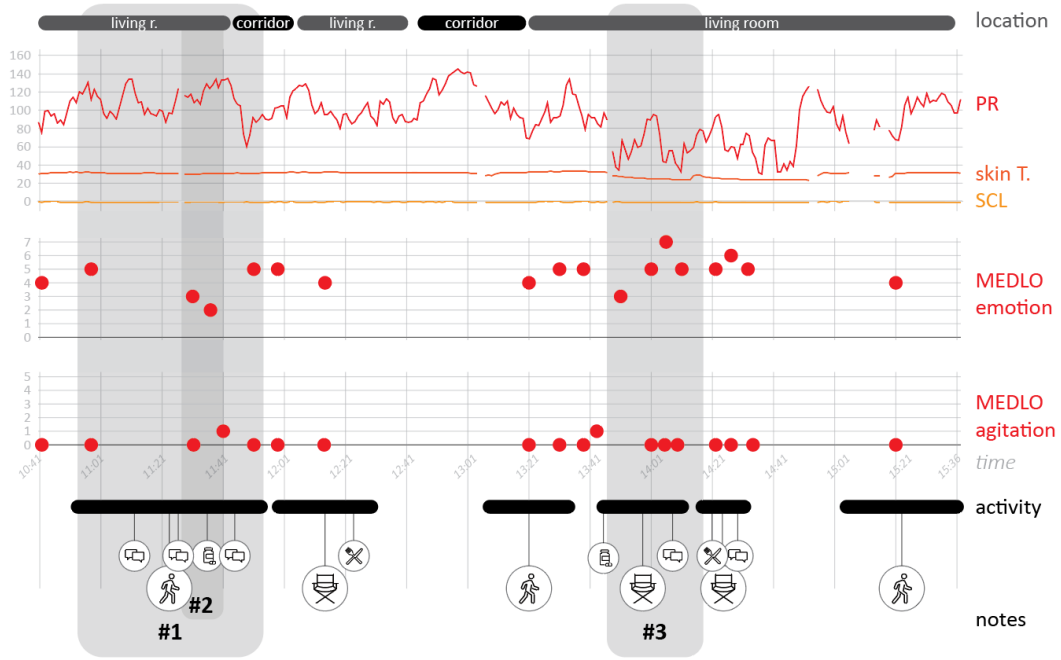



Figure 2. Example of a baseline, with location, physiological measures PR, skin Temperature, and SCL, observational scales of MEDLO, and activity. The notes refer to the text (Nursing home 4, participant A, day 1)

### 3.2 Measurement duration

While short measurements (2-10 minutes) provide insights into the stress response during a particular activity, longer measurements (30-60 minutes) could reveal better insights into recovery of activities and interpretations of affective responses. An example of a longer measurement is displayed in Figure 3. In this one-hour measurement, the HR and HRV values fluctuated (appointed by the arrows), just as the activities the participant performed (e.g., sitting, sleeping, chatting, walking). Based upon this longer measurement, we can interpretate the steepness of the peaks and drops of the HR and HRV values in a better manner, since we have a baseline including mean values as well.

For example, the drop in HR values in #1 is not that steep compared to the baseline; combined with the decrease in HRV value, this would indicate contentment rather than focus. Another example of the benefit of this baseline is the stabilization of the HRV value in #4, rather than a decrease in HRV value. Combined with the steep decrease in HR values, this would indicate relaxation, rather than being stressed, focused, or anxious. This relaxation is also acknowledged by the contextual observations: the participant could sit and relax again, after physical effort of the walk.

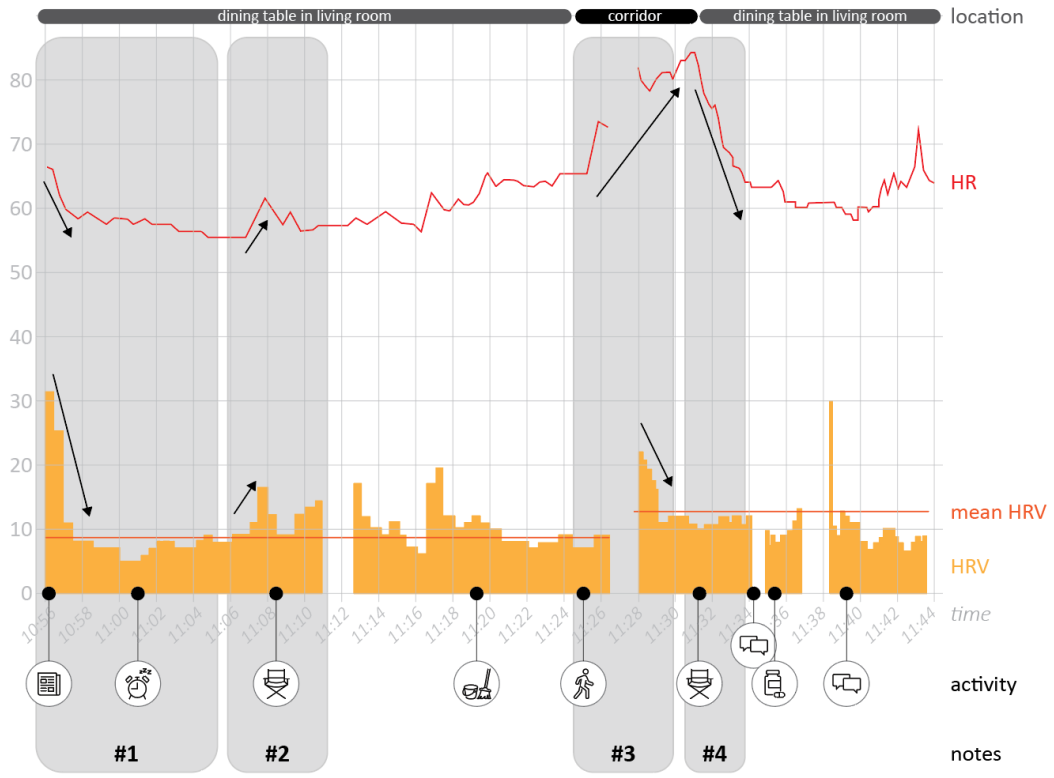



Figure 3. Example of a longer measurement, with location, increase/decrease arrows HR and HRV values, HRV mean, and activity. The notes refer to the text. (Nursing home 2, participant E, day 1)

### 3.3 Multiple physiological indicators

The combination of multiple indicators could reveal more insights into emotions; for example, during mobility scenarios in which HR and HRV values are not decisive. In this example, a participant was walking and searching for a given location, wearing both sensors (Figure 4). Based on the KANA sensor, the combination of HR and HRV values (#1) could indicate stress, focus, anxiety, fear, or exertion. The Empatica sensor provided additional information about skin temperature, PR, and SCL. An increase in skin temperature might exclude stress, anxiety, and fear. A drop in PR might also exclude stress. And the absence of peaks in SCL excludes stress as well. This exclusion leads to the possibility of exertion or focus; which she exhibited both. After #1, HR and HRV values increase, probably indicating excitement; which corresponds with the facial expressions and chatting activities.

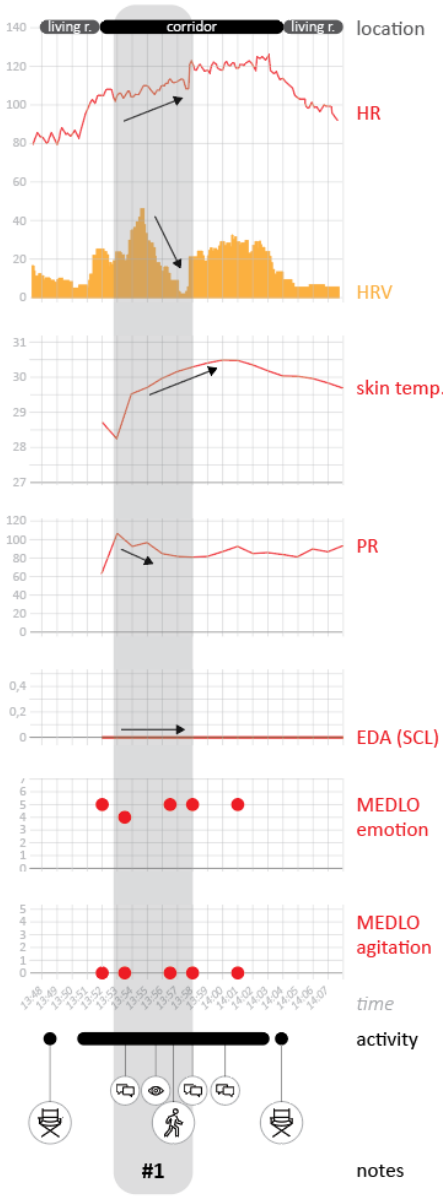
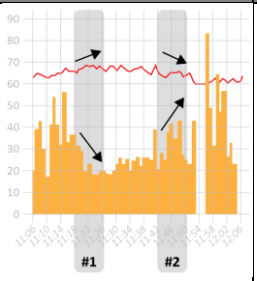
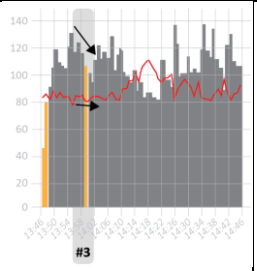



Figure 4. Example of the use of multiple physiological and observational indicators, with location, increase/decrease arrows, and the activity. The notes refer to the text (Nursing home 3, participant C, day 1)

3.4 Specify 'inactivity'-activities

Careful registration of the observed performed activities is crucial in interpreting the lived experience. Especially in the category of 'inactivity', what was exactly done and said by participants should be noted in detail. Various types of this 'inactivity' turned out to exist (e.g., sitting, standing, looking outside, watching TV, sleeping), and with different physiological measures. Table 2 displays examples of two different participants. The first participant is sleeping in her chair, while the second participant is sitting in the chair and might be focusing on the conversation surrounding him. Different emotional responses were interpreted.

Table 2. Two examples of different 'inactivities', displaying physiological and observational measures, including interpretation, the notes refer to the text in the table (*MEDLO, **OERS)

| Observed behavior | Emotional response | | | Interpretation |
|---|---|---|---|---|
| | Sensor data (HR & HRV) | Notes | Observational scales | |
| Around 11:00h, the participant arrived in the living room and sat down on a chair. She closed her eyes often, **like she was sleeping**. |   | #1 | Agitation: None<br>Emotion*: Neutral (4 out of 7)<br>Emotion**: Contentment | The combination of increase HR and decreased HRV could indicate focus. Sometimes, she was sleeping and sometimes she woke up. Neutral facial expressions. Did she wake up, but with her eyes closed? |
| | | #2 | Agitation: None<br>Emotion*: Neutral (4 out of 7)<br>Emotion**: Contentment | The combination of some decreasing HR and increase of HRV values could indicate relaxation. Just before this moment, she was chatting vividly, but now she is sleeping. It could indeed be relaxation. |
| Participant was sitting in the chair; he just had lunch. Surrounding him, people are talking. Sometimes, he joins the conversations, sometimes he **seems to listen to the conversation**. |   | #3 | Agitation: None<br>Emotion*: Neutral (4 out of 7)<br>Emotion**: Contentment | The combination of stable HR and decreasing HRV could mean contentment or even focus. People around him were talking. Was he focused on the conversation surrounding him? |

## 4. Discussion

To gain understanding in the lived experience of older adults with dementia, this paper aimed to demonstrate innovative approaches this lived experiences. The lived experience consists of what people do incorporated with how they emotionally respond. In this study, a combination of (informal) interviews, observations, and biometric measurements was applied.

### 4.1 Ethical considerations

How people experience something consists of several components (social, physical, mental/cognitive). Traditionally this experience is therefore mapped using different instruments relying on cognitive or mental aspects, i.e. interviews or surveys. For people with dementia this is done but with their (in)formal carer or

using observational methods (i.e. mapping physical component). In short, research often talks about people with dementia. Of course this can also yield valuable information, but always involves the interpretation of somebody else regarding the experience of another person.

For people with dementia, specifically for those living in inpatient facilities, many assumptions are prevalent in practice and research regarding how certain 'behaviours' or 'environments' are experienced. However, the question remains whether, with the changes wrought by the dementia process, this is indeed the case. For example, assumptions were found during the selection of observational scales for this study about the definition 'inactivity'; is 'watching TV' indeed inactive? These kind of assumptions are particularly relevant for people with dementia experiencing many apathy symptoms and/or have difficulties in expressing themselves.

With advances in (biometric) technology, it is possible to retrieve more 'direct' information regarding physiological processes. Research in other target groups showed that this physiological data can give insight in bodily functioning, as well as into mood and wellbeing. Unfortunately, not much research goes into what (moderate to severe) dementia means for using biometric data. Our study tried to explore the potential of physiological measuring for this target group, combined with observational methods and informal interviews. While using only one method would be far cheaper and less time-consuming, the idea is that the combination of observational and physiological can give a more complete image of the lived experience of older people with severe dementia in nursing homes.

4.2 Four main insights

Four main insights were identified to conduct this type of research, including practical recommendations, and potential influential (technological) factors which can influence the research results: (1) combination of methods, (2) the use of multiple physiological indicators, (3) baseline development per individual participant, and (4) specify 'inactivity'-activities.

Combination of methods. Observations on behaviors and facial, body, and verbal expressions in combination with biometric data is key in interpreting the lived experience: they are interdependent and complementary. Physiological data can be used to objectively measure emotions, but you need observational (and interview) data to interpret the response. These combined data provide very valuable information, especially for this target group, where the expression of emotions is often disturbed.

Practically, observations should include *who, is doing what, with whom, in what relationship and who is the initiator, where, when and in what context, and which affective state.* It is important to register every detail. Before starting your research, you should decide carefully the method of registration (i.e., on paper in tables, or possibly using a tablet; not a computer).

Furthermore, nursing staff should be carefully involved in the whole process of the re-search; from explaining goals, to participant selection, observation procedures, application of the sensors, follow-up study. They can give important insights into the context and lives of the people they care for day in and day out. Informal interviews with them and – if possible – participants with dementia should be held upfront, during, and after

the structured observations *to collect background information, preferences, and possible incentives or explanations of behaviors.*

The use of multiple physiological indicators. The use of multiple physiological indicators turned out to be of additional value in the interpretation of affective states; especially in combi-nation with observational data. While in this study HR, HRV, PR, SCL, and skin Temperature were used as indicators, other indicators like body posture or GPS trackers might be valuable for other research goals as well.

Some potential influential (technological) factors should be considered in future research concerning the physiological indicators. For example, more information about the effects of age, dementia and medication (e.g., heart medication) on indicators, such as HR, HRV, skin Temperature, and SCL, is necessary for even better interpretation (Perugia, 2018); since, for example, the algorithmic models for the interpretation of the data are now primarily based and trained with data from healthier and younger individuals. Furthermore, the application of the sensor may also affect data quality, due to the nature of changing conductivity of older skin (Barontini, et al., 1997) and due possible shifts of the sensor during movement. Lastly, one should be aware that some sensors need continuous Bluetooth connection, which requires a mobile phone to be in close contact with the participant throughout the movement.

Baseline development per individual participant. Whereas shorter measurements of physiological and observational data can give insights into people's stress response during a particular activity, more measures and longer measurements turned out to be important to interpret the readings by developing a baseline. Specifically, with (positive or negative) stressful activities, longer measurements can indicate whether the activity was stressful or strenuous: i.e., the longer it takes for HRV to recover, the more physically taxing the activity was. Furthermore, if after these activities HRV becomes very high, it may indicate that the previous activities were enjoyed.

The baseline should be constructed using the combination of physiological and behavioral methods, including the informal interviews. An average of physiological data can be calculated over the longer period of time and the data of the OERS and MEDLO scales can be plotted over this period of time. This makes it possible to interpret peaks and drops of data. This re-quires longer periods of observations, since it is also important to notice what participants say; because this could yield information about their emotions and mood (see section 'Baseline development' for an ex-ample). In addition, the baseline development includes knowledge about the type of dementia, because this could influence the mood (for example, possibly rapidly changing emotions in frontotemporal dementia). A complexity of constructing a baseline for people with severe dementia is the real life situation in a collective living room instead of a controlled laboratory free of (environmental) influences.

Practically, it is important to develop a *baseline per participant* with multiple and longer biometric measurements and observations, to interpret the biometric values of a particular activity. Beforehand, the most suitable indicators related to the research goal and best suited sensor for the individual participant should be selected and tested. The constructed baselines and specific activities should be *mapped and timed*

*carefully over time to link the data*. During the measurements, one should also systematically keep track of who wore which sensor and when.

Specify 'inactivity'-activities. In this study, the category 'inactivity' was more specified accord-ing to the activity, e.g., sleeping, sitting and looking around, watching TV. Biometric data dif-fered during these activities; which could better nuance the lived experience of these types of activities. However, the duration of these activities turned out the be difficult to map.

## 5. Conclusion

In conclusion, the combination of spatial, behavioral, and biometric data using (informal) interviews, observations of activities and facial/body/verbal expressions, and multiple physiological indicators via wearable sensors provide a more detailed and nuanced image of the lived experience of people with dementia in nursing homes. While it is difficult to conduct research with people with severe dementia, it is extremely necessary and useful to gain proper understanding about their lived experience. In this paper, we would like to help future researchers by sharing our experiences and translating them into practical recommendations. Figure 5 shows the overview of the recommendations to construct the lived experience.

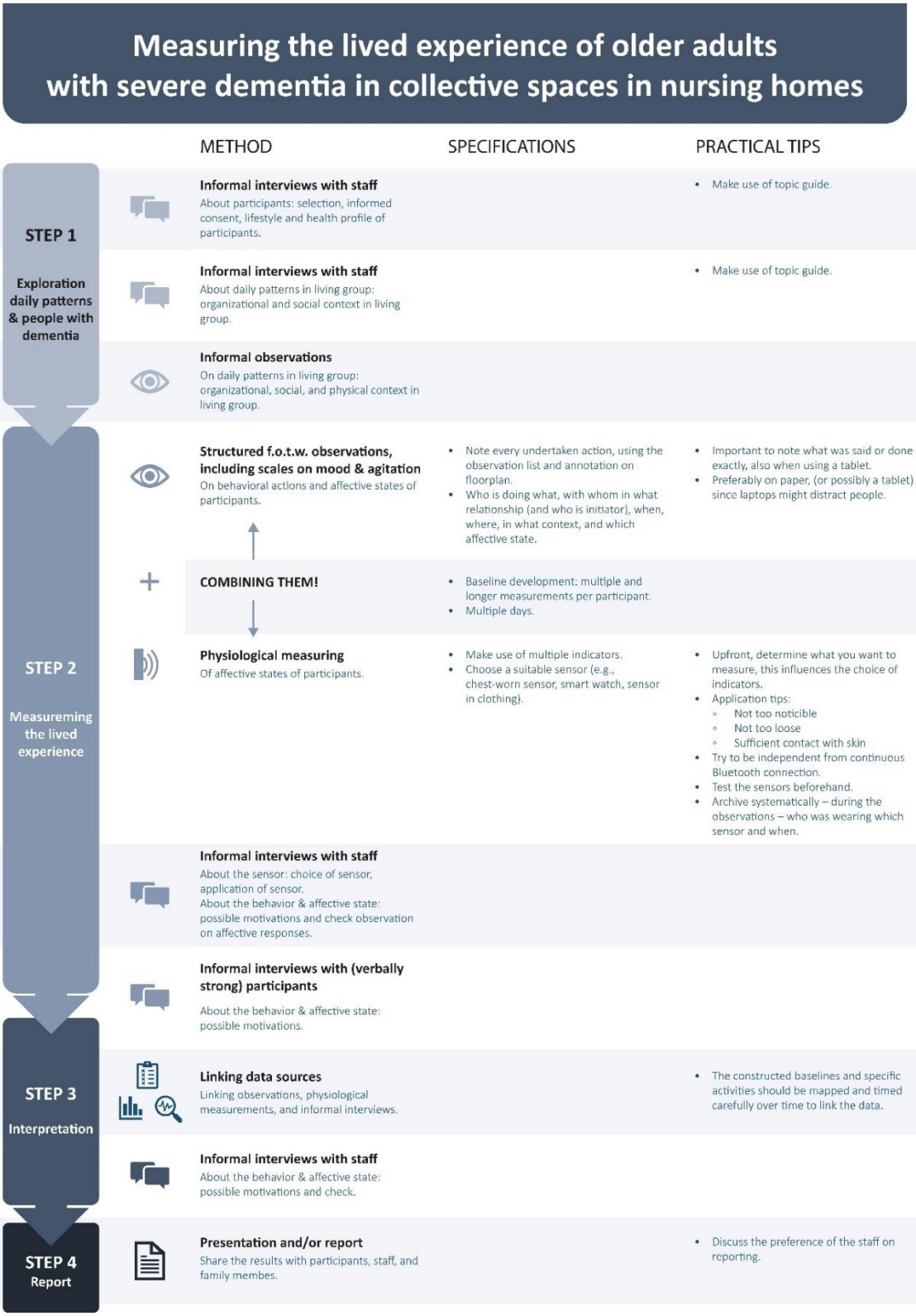



Figure 5. Recommendations to measure the lived experience of older adults with severe dementia in collective spaces of nursing homes

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## Appendix I | Observation list (including 'what')

| DATE: | | | LOCATION: | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| nr | time | who | what | with whom | initiated by | what context | where | Mood 1 | Mood | Agitation |
| 1 | | | | | | | | | | |
| n | | | | | | | | | | |

| Category | Subcategory | Activities |
|---|---|---|
| Inactivity | No activity | Doing 'nothing' |
| | Watching TV | Watching TV |
| | Sleeping | Sleeping |
| Activities of Daily Life (ADL) | Personal hygiene | Personal hygiene (e.g., washing hands) |
| | | Put on glasses |
| | | Put on hearing aid |
| | | Taking drugs |
| | | Wipe hands |
| | Go to bathroom | Go to bathroom |
| | Eating and drinking | Eating |
| | | Drinking |
| | Mobility | Physiotherapy |
| | | Transfer from point A to point B |
| | | Looking at info signs and landmarks (for wayfinding purposes) |
| | | Pronouncing aloud destination (for wayfinding purposes) |
| | | Trying to open doors (for wayfinding purposes) |
| | | Help of care professional / informal carer / fellow resident (e.g., p help, providing directions) (for wayfinding purposes) |
| | | Arrival at destination (for wayfinding purposes) |
| | | Traveled route (for wayfinding purposes) |
| | | Stops on the route (for wayfinding purposes) |
| Instrumental Activities of Daily Life | Domestic activities | Setting the table |
| | | Cleaning (e.g., sweeping, washing/drying dishes, dusting) |
| | Preparing food and drinks | (Helping with) preparing food (e.g., washing, peeling, cutting) |
| | | Stir into drink with a spoon |
| Communication & hobbies | Communication | Verbal communication |
| | | Non-verbal communication |
| | | Visit |
| | | Phone call (including video calls) |
| | Hobbies | Individual activities (e.g., reading, crafting, looking at pictures, etc.) |
| | | Organized activities (e.g., sporting at the table, making music, gard playing games) |
| Remaining | - | - |

## Appendix II | OERS & MEDLO

Observational scales on mood

Table 1. Observed Emotion Rating Scale (OERS) (Lawton, et al., 1996)

| Category | Signs |
|---|---|
| Pleasure | Smile, laugh, stroking, touching with "approach" manner, nodding, singing, arm or hand outreach, open-arm gesture, eye crinkled |
| Anger | Clench teeth, grimace, shout, curse, berate, push, physical aggression or implied aggression, like fist shaking, pursed lips, eyes narrowed, knit brows/lowered |
| Anxiety/fear | Furrowed brow, motoric restlessness, repeated or agitated motions, facial expression of fear or worry, sigh, withdraw from other, tremor, tight facial muscles, calls repetitively, hand wringing, leg jiggling, eyes wide |
| Sadness | Cry, tears, moan, mouth turned down at corners, eyes/head down turned and face expressionless, wiping eyes, horse-shoe on forehead |
| Interest | Eyes follow object, intent fixation on object or person, visual scanning, facial, motoric or verbal feedback to other, eye contact maintained, body or vocal response to music, wide angle subtended by gaze, turn body or move toward person or object |
| Contentment | Comfortable posture, sitting or lying down, smooth facial muscles, lack of tension in limbs, neck, slow movements |

Table 2. Maastricht Electronic Daily Life Observation Tool (MEDLO) (de Boer, et al., 2016)

| | Descriptive expressions |
|---|---|
| Negative: a negative mood can be characterized by groaning, moaning, crying, screaming, shouting, tensed facial expression or tensed body language. Furthermore, the content and tone of the verbal or nonverbal interactions gives information regarding the negativity of the mood. | |
| 1 | Great signs of negative mood (sadness, displeasure, anger, worries, fear, boredom or discomfort). |
| 2 | Considerable signs of negative mood (sadness, displeasure, anger, worries, fear, boredom or discomfort). |
| 3 | Small signs of negative mood (sadness, displeasure, anger, worries, fear, boredom or discomfort). |
| 4 | Neutral: a neutral mood is scored if there is no positive or negative mood observable, e.g. gazing or sleeping. |
| Positive: a positive mood can be characterized by smiling, laughing, chuckling, humming a tune, relaxed facial expression or relaxed body language. Furthermore, the content and tone of the verbal or nonverbal interaction gives information regarding the positivity of the mood. | |
| 5 | Small signs of positive mood (contentment, happiness, pleasure, relaxation, comfort). |
| 6 | Considerable signs of positive mood (contentment, happiness, pleasure, relaxation, comfort). |
| 7 | Great signs of positive mood (contentment, happiness, pleasure, relaxation, comfort). |

Observational scale on agitation

Table 3. Maastricht Electronic Daily Life Observation Tool (MEDLO) (de Boer, et al., 2016)

| | Deviating verbal expressions | Motoric agitation | Aggressiveness | Resistance to care (professional) |
|---|---|---|---|---|
| 0 | Not present | Not present | Not present | Not present |
| 1 | Low volume, not disruptive in milieu, including crying | Pacing or moving about in chair at normal rate (appears to be seeking comfort, looking for spouse, purposeless movements) | Verbal threats | Procrastination or avoidance |
| 2 | Louder than conversational, mildly disruptive, redirectable | Increased rate of movements, mildly intrusive, easily redirectable | Threatening gestures; no attempt to strike | Verbal/ gesture of refusal |
| 3 | Loud, disruptive, difficult to redirect | Rapid movements, moderately intrusive or disruptive, difficult to redirect | Physical toward property | Pushing away to avoid task |
| 4 | Extremely loud screaming or yelling, highly disruptive, unable to redirect | Intense movements, extremely intrusive or disruptive, not redirectable verbally | Physical toward self or others | Striking out at caregiver |