Monitoring challenging behaviors in dementia with sensor technology

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Purpose People with dementia (PwD) often present Behavioral and Psychological Symptoms of Dementia, which include agitation, apathy, and wandering amongst others, also known as challenging behaviors (CBs). These CBs worsen the quality of life (QoL) of the PwD and are a major source/ reason of (increased) caregiver burden. The intricate nature of the symptoms implies that there is no "one size fits all solution", and necessitates tailored approaches for both PwDs and caregivers. To timely prevent these behaviors assistive technology can be utilized to guide caregivers by enabling remote monitoring of contextual, environmental, and behavioral parameters, and subsequently alarming nurses on early-stage behavioral changes prior to the presentation of CBs. Eventually, the system should propose an intervention/action to prevent escalation. In turn, improvement in QoL for both caregivers and PwD living in nursing homes (NHs) is expected. In the current project "MOnitoring Onbegrepen Gedrag bij Dementie met sensortechnologie" (MOOD-Sense), we aim to develop such a monitoring system. The strengths of this new monitoring system lie in its ability to align with the individual needs of the PwD, utilization of a combination of wearables and ambient sensors to obtain contextual data, such as location or sound, and predict or monitor CBs individually rather than in groups, thus facilitating person-centered care, based on ontological reasoning. The project is divided into three parts, Toolbox A, B and C. Toolbox A focuses on obtaining insight in which behaviors are challenging according to nurses and how they are described. Previous studies utilize clinical terminology to describe or classify behavior, we aim to employ concrete descriptions of behavior that are observable and independent of clinical terminology, aligning with nurses who are often the first to notice behavior and can be operationalized such that it can also be aligned with sensor data. As a result, an ontology will be developed based on the data such that sensor data can be integrated into the same conceptual information that standardizes the communication in our monitoring system. Toolbox B focuses on translating data coming from various sensors into the concepts expressed in the ontology, and timely communicate situations of interest to the caregivers. In Toolbox C the focus is exploring interventions/actions employed in practice to prevent CBs. Method In Toolbox A we used a qualitative approach to collect descriptions of CBs. For this purpose, we employed focus groups (FGs) with nursing staff who provide daily care to PwD. In Toolbox B pilot studies were conducted. A set of experiments using sensors in NHs were performed. During each pilot, multiple PwD with CBs in NHs were monitored with both ambient and wearables sensors. The pilots were iteratively approached, which means that insights from previous pilot studies were used to improve consecutive pilot studies. Lastly, the elaboration of Toolbox C is ongoing. Results and Discussion Regarding Toolbox A four FGs were conducted during the period from January 2023 to May 2024. Each FG was comprised of four nurses (n = 16). From the FGs we gained insights into behavioral descriptions and the context of CBs. Although data analysis has to be performed yet, there are indications that changes preceding CBs can be observed, such as frowning or clenching fists for agitation or aggression. Further results will be available soon. Regarding Toolbox B a monitoring system, based on sensors, is developed iteratively (see Figure 1) and piloted in three consecutive NHs from January 2021 to December 2023. Each pilot was comprised of two PwD (n = 6). Analysis of sensor data is ongoing.

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Figure 1. MOOD-Sense architecture for monitoring and behaviour registration