

Ethics and DEI

Co-creating a digital tool for assessing meaningful engagement in advanced dementia

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Purpose Individuals living with dementia who lose the ability to speak are at increased risk of isolation from the social world as caregivers struggle to communicate with them. Adaptive Interaction [1,2] provides a way to connect with people living with dementia who can no longer speak using nonverbal channels (Figure 1). AI can equip caregivers to interact with individuals who can no longer speak, but they lack a means to capture or assess meaningful engagement in these interactions. This three-part study aims to develop a measure to support ongoing opportunities for meaningful engagement, authentic caring relationships, and creating and maintaining a supportive community for individuals who can no longer speak [3]. **Method** Part 1 comprised (i) analysis of existing Adaptive Interaction data to identify key indicators of engagement in interactions between people living with dementia who can no longer speak and caregivers; (ii) a review of existing engagement measures to identify key variables operationalized to measure engagement; and (iii) two rounds of co-creation workshops with 19 experts including family care partners and long term care staff to inform development of a prototype digital tool for measuring Meaningful Engagement in Advanced Dementia (MEAD). Each workshop was video recorded. In Part 2, the prototype MEAD tool was field tested by 9 dyads, each comprising one person living with advanced dementia and one member of care staff over 7 days. A total of 63 sessions were video recorded, followed by interviews with the caregivers to examine how this tool could fit into their workflow. Part 3 is the implementation phase, which is currently in progress. **Results and Discussion** Part 1 (i) produced a behavioral coding scheme for identifying engagement within interactions between caregivers and people with dementia who can no longer speak. In Part 1(ii) we identified 21 different measures of engagement developed for use with people living with dementia, 19 of which used observation, 10 in real-time and 9 using video recording. Visual indicators of engagement included emotion, body movements, and gestures, aligning with the coding scheme developed in part 1(i). In Part 1(iii) analysis of the workshop video recordings identified three themes: a. engagement, was recognized as a collaborative concept between the person and their social environment, observed through non-verbal cues (e.g., eye gaze); b. lack of standardized tools and formal policies for assessing engagement, and c. the importance of considering contextual influences (e.g., type of activity) and personalized engagement strategies based on the person's interests. Part 2 data demonstrated that the MEAD tool was easy to use and supported caregivers to focus on nonverbal interactions. Feedback and suggestions are being incorporated into the V2 prototype. Part 3 of the project is underway with a long-term care provider to explore staff training needs and variables to be addressed to support implementation of the MEAD digital tool in routine care.

References

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Figure 1 Rubbing heads during an AI 'conversation' (permission received for publication)