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Enabling Self-Care and Shared Decision Making for People Living with Dementia

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Abstract : People living with dementia should be at the centre of decision-making regarding goals for daily living. These goals include basic activities (dressing, hygiene, and mobility), advanced activities (finances, transportation, and shopping), and meaningful activities that promote well-being (pastimes and intellectual pursuits). However, there is limited involvement of people living with dementia in the design of technology to support their goals. A project is described that is co-designing intelligent computer-based support for, and with, people affected by dementia and their carers. The technology will support self-management, empower participation in shared decision-making with carers and help people living with dementia remain healthy and independent in their homes for longer. It includes information from the patient's care plan, which documents medications, contacts, and the patient's wishes on end-of-life care. Importantly for this work, the plan can outline activities that should be maintained or worked towards, such as exercise or social contact. The authors discuss how to integrate care goal information from such a care plan with data collected from passive sensors in the patient's home in order to deliver individualized planning and interventions for persons with dementia. A number of scientific challenges are addressed: First, to co-design with dementia patients and their carers computerized support for shared decision-making about their care while allowing the patient to share the care plan. Second, to develop a new and open monitoring framework with which to configure sensor technologies to collect data about whether goals and actions specified for a person in their care plan are being achieved. This is developed top-down by associating care quality types and metrics elicited from the co-design activities with types of data that can be collected within the home, from passive and active sensors, and from the patient's feedback collected through a simple co-designed interface. These activities and data will be mapped to appropriate sensors and technological infrastructure with which to collect the data. Third, the application of machine learning models to analyze data collected via the sensing devices in order to investigate whether and to what extent activities outlined via the care plan are being achieved. The models will capture longitudinal data to track disease progression over time; as the disease progresses and captured data show that activities outlined in the care plan are not being achieved, the care plan may recommend alternative activities. Disease progression may also require care changes, and a data-driven approach can capture changes in a condition more quickly and allow care plans to evolve and be updated.

Keywords : care goals, decision-making, dementia, self-care, sensors
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