Digital phenotyping for changes in activity at the end of life in people with dementia

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Purpose Almost 90% of people with dementia develop behavioral and psychological symptoms (BPSD) such as apathy, agitation, and sleep disturbances (Sandvik, et al., 2016). Recent research shows that data acquired from mapping the physical, mental, and functional activities of a person can serve as a marker for conditions including BPSD (Au-Yeung et al., 2022; Husebo et al., 2019; Vahia et al., 2019). The application of digital phenotyping to people with dementia is still mostly unexplored. There is therefore value in investigating whether digital phenotyping can enhance the objectivity of measuring activity and symptom changes during the last period of life. We hypothesize that use of sensing technology will enable better estimation of time of death, facilitating improvement of end-of-life interventions and directives for people with dementia. **Method** DIgital PHenotyping in DEMentia (DIPH.DEM), a 3-year prospective cohort study (N=25), will monitor participants living in a nursing home at baseline, and every 6-months (7-days), up to 1-year. The objective of the study is to use sensing-based digital phenotyping (Somnofy and Garmin Vivoactive 5), combined with validated assessment tools, to describe the activity trajectory and associated processes of the end of life in persons with dementia. Parameters included are heart rate (HR)/heart rate variability (HRV), accelerometry (32 Hz) (activity levels), sleep stages, sleep length, sleep quality, and respiration. Raw accelerometry data will be processed using a high pass filter at 0.25 Hz (MATLAB) within 24 hr timeframes. Euclidean Norm Minus One and Mean Amplitude Deviation methods will be used to calculate cut-off points for assigned activity levels (very low activity, low activity, high activity). (Bakrania et al., 2016) Rest-activity rhythm amplitude and fractal complexity of daily physical activity will be calculated based on methods from previous literature (Feng et al., 2023). HR, HRV, sleep parameters (including sleep regularity index scores) will be analyzed based on manual inspection of the data (MATLAB) and established thresholds from previous literature (Winfred et al., 2024). **Results & Discussion** Preliminary results are currently being analyzed and will include development of models based upon descriptive statistics (linear and non-linear regressions, STATA) and digital and traditional outcome measure data at an individual and group level. The use of digital phenotyping can provide more precise knowledge on living, and dying, with dementia. This can improve directives and provide guidance for timely, appropriate interventions, including referral to palliative services and pharmacological interventions.

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