Developing a caregiver feedback response system using a home-based sensor platform
L. Ault, A. Kachala, F. Knoefel, A. Frank, B. Wallace, R. Goubran, J. Kaye, C. Trudel, N. Thomas

Purpose As the aging population increases, more individuals with dementia will be cared for by spouses and family members. The role of the caregiver is associated with higher levels of stress, depression, and reduced sleep quality, factors that are associated with higher caregiver burden (Farina et al., 2017). Current caregiver assessment includes diaries, which can create added stress (Välimäki et al., 2007), and other forms of self-report questionnaires (Deeken et al., 2003), that can be affected by inaccuracies in self-reporting. Home-based, technology-assisted assessment platforms could provide a novel approach to measure time and effort related to caregiving tasks (Thomas et al., 2019). For this information to help caregivers identify higher levels of stress and respond early, methods for providing feedback on sensor-based outcome measures related to a caregiver's health and daily activities need to be developed. **Methods** A pilot study enrolling individuals with cognitive impairment living with a caregiver is already collecting data on health and activity measures using the Collaborative Aging Research Using Technology (CART) sensor platform. Sensor data from the system provides information on daily activity level, sleep measures and time spent together. Through surveys and focus groups we aim to determine the information on daily activities and burden derived from the system that is most relevant to caregivers. The second aim is to ascertain the best method to summarize and provide this information to caregivers. Surveys were initially collected from caregivers of individuals seen at the Bruyère Memory Program. Focus groups and surveys are now being completed online due to current physical distancing measures. Relevant themes extracted from the focus group sessions and survey data will inform development of a preliminary version of a feedback system for caregivers. **Results and Discussion** The sensor system is currently installed in the homes of 3 care dyads and collecting data continuously on daily functional activities. The caregiver's average age is 61.7 years and sensor data has been collected for a total of 18,768 hours. Caregiver opinions have been collected from online focus groups (n=5) with further sessions scheduled. Survey responses have been obtained (n=4) and collection is ongoing. Initial responses from the surveys and focus groups indicate that access to this information could be helpful in identifying stress levels, and could also be relevant to share with their physician. Objective information obtained from the sensor system could help to more accurately identify stress and burden experienced by caregivers. Providing feedback information to caregivers directly could help them to identify changes in their level of caregiving activities and seek assistance from health care or community supports earlier.

References
Deeken, J. F., Taylor, K. L., Mangan, P., Yabroff, K. R. & Ingham, J. M. (2003). Care for the caregivers: a review of self-report instruments developed to measure the burden, needs, and quality of life of informal caregivers. Journal of pain and symptom management, 26(4), 922–953. https://doi.org/10.1016/s0885-3924(03)00327-0
Farina, N., Page, T.E., Daley, S., Brown, A., Bowling, A., Basset, Banerjee, S. (2017). Factors associated with the quality of life of family carers of people with dementia: A systematic review. Alzheimer's & Dementia,13 (5), 572-581. https://doi.org/10.1016/j.jalz.2016.12.010
Thomas, N., Lindauer, A. & Kaye, J. (2019). EVALUATE-AD and Tele-STAR: Novel Methodologies for Assessment of Caregiver Burden in a Telehealth Caregiver Intervention - A Case Study. Dementia and geriatric cognitive disorders, 47(3), 176–184. https://doi.org/10.1159/000497805
Välimäki, T., Vehviläinen-Julkunen, K. & Pietilä, A. M. (2007). Diaries as research data in a study on family caregivers of people with Alzheimer's disease: methodological issues. Journal of advanced nursing, 59(1), 68–76. https://doi.org/10.1111/j.1365-2648.2007.04273.x
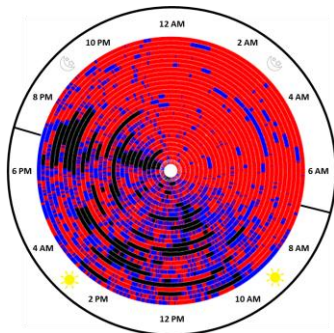
Figure 1. Plot of sensor data illustrating the time spent together (red), apart (blue) and out of the home (black) for one house for one month