

SELF-TRACKING TECHNOLOGY FOR DEMENTIA CARE: A COLLABORATIVE PERSONAL HEALTH INFORMATION PRACTICE

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Abstract

This is a position statement for the PIM workshop of Successfully Aging with Our Information and Our Information Tools, reflecting the authors' position regarding the possibility of self-tracking technology for dementia care. It also describes relevant background and potential discussion topics.

Keywords: self-tracking, collaboration, dementia care, personal health information management

1. Introduction

1.1. Background

Dementia is an important public health concern considering the ongoing worldwide increase in older adults (Brayne and Miller, 2017). Individuals with dementia typically experience progressive deterioration in cognitive functioning that is worse than what might be expected from “normal aging”; the impaired domains such as memory, thinking, comprehension, and orientation frequently affect their ability to perform everyday tasks independently and lower their quality of life (Alzheimer’s Association, 2022). As a result, people with dementia often need continuing and complex care, which is primarily provided by unpaid caregivers such as family members and friends, the majority of whom consider their health and social life to suffer because of the substantial care burden (Alzheimer’s Disease International, 2019). Due to the inevitable trend of aging population and the lack of a cure for dementia, it is important to support persons with dementia and their caregivers by facilitating their well-being and improving their quality of life. According to the recently published mDementia program handbook by the World Health Organization (WHO), mobile technology for health (mHealth) has the potential to play an essential role in this process (WHO, 2021), as it can be designed to help those individuals with dementia in their self-care, and to facilitate care from caregivers.

Currently, the prevalence of smartphones and wearables equipped with sensors enable the naturalistic collection of personal health-relevant data in an extremely granular, unobtrusive, and affordable way (Aung et al., 2017); their data-capture capabilities and interactive affordances, have altered how we monitor and influence personal behavior in everyday lives (Lupton, 2016), and have emerged as a kind of personalized health information resource for the management of chronic illness among seniors (Caldeira and Chen, 2019). Such devices with self-tracking exemplify the use of mHealth – “the use of mobile and wireless devices to improve health outcomes, health care services, and health research” (National Institutes of Health, 2013). Self-tracking, provided as personal informatics systems (Li et al., 2010), is emerging as a type of mHealth intervention with great potential for improving the quality of life for persons with dementia and their caregivers (Nunes and Fitzpatrick, 2015). In our case, we therefore pay our attention to the self-tracking technology for dementia care.

1.2. Problem Statement

Self-tracking has grown in popularity as a method of managing chronic illnesses outside of clinical settings, with most research focusing on individuals' engagement with their tracked personal data (Katz et al., 2018). Recent research indicates, however, that this engagement is highly *collaborative*, involving coordination and communication among various parties, including healthcare professionals, caregivers, patients, and others (Murnane et al., 2018). Based on our observation from prior studies, much of our current insights of collaboration in the context of self-tracking stems from studies of self-tracking for chronic conditions that can be managed or controlled (e.g., diabetes, bipolar disorder), with the know-how of when, how, and what types of personal health data to track, what types of information to generate from tracking, and subsequent behaviors to engage in as a result of the tracking. In light of the collaborative nature of dementia care, little is known about the role that self-tracking may play in helping elderly dementia patients and their caregivers to cope with such an inevitable degenerative illness.

Self-tracking is currently the main way for individuals to access their personal health data. However, it is not just technology in and of itself; it can also be conceptualized as a health information practice related to collecting, organizing, making sense of, and acting on the tracked personal health data, given that tracked personal health data are new types of information about one's health (Feng and Agosto, 2019). We believe self-tracking for dementia care can be viewed as a collaborative personal health information practice, considering that dementia care is an interpersonal process in which people with dementia and their caregivers continuously balance and negotiate their needs (Hwang et al., 2020). In this regard, we believe that an exploration of the types of tracking-related information desired, how they are desired, and by whom they are desired can enhance our understanding of the extent to which current self-tracking technologies may or may not support dementia care. To investigate our position, we examine dementia care tracking-related posts in online dementia care communities as part of our study. The following is a condensed version of the findings that we would like to share and feel it very relevant to this workshop.

2. Our Current Study Summary

Through a series of thematic analysis, we recognized four types of tracking metrics are desired for nine types of information: *safety alert* for wandering, falls, and strangers; *reminders* of daily life activities and medical and health related activities; *monitoring* data related to daily life activities and data related to health status, and *remote control* for patients' daily life activities and financial safety.

In addition to dementia care tracking metrics and information, we analyzed roles in dementia care tracking practice to understand how collaboration might manifest in this regard. Our findings indicate that patients, caregivers, family members, and community members contribute differently to tracking practice in dementia care, whereas health care providers, who have been extensively mentioned in self-tracking for other types of chronic illness management, participate less in dementia care.

- *Working with tracked data to reassure*: caregivers and family members played critical roles as *data consumers*, interacting with tracked patient-generated data to provide better care to people with dementia. Additionally, community members involved in dementia care tracking were social workers or private caretakers hired by dementia patients' family members. As hired caregivers, community members played a participatory role similar to that of caregivers and family members, as data consumers who worked with patients' tracked data to provide better caregiving.
- *Tracking as provision and participation*: dementia patients wanted to keep tracking. In this sense, therefore, dementia patients acted as *data creators*, authorizing third parties with whom they had a trusting relationship (i.e., family members and caregivers) to handle their tracked personal data. Noted that active data creators accounted for a very small percentage of the total in our thematic analysis. Many persons with dementia were more likely to participate passively in tracking by using devices or tools given to them by family members or caregivers without explicit consent. At the same time, because community members were performing close caring work, they were data creators, in that their personal data (e.g., image, voice, behavioral data, etc.) might be passively

tracked by dementia patients' family members. Thus, dementia patients and community members, as data creators in tracking, can also be considered as *data subjects* (Ruppert et al., 2017); they generate data, and they are directly impacted by the decisions made about data and its outcomes. However, they have limited direct interactions with the tracked data.

We found two primary challenges in self-tracking for dementia care that cannot be ignored:

- *Technological challenges in addressing information wanted for tracking*: this challenge involved family members' difficulties in deciding what self-tracking tool to use and how to track what type of data for dementia care. Specific technical challenges are centered around (a) limited features to support *integrating tracking information wants* and (b) difficulty in *managing the entire tracking process, which stymies communication*.
- *Data work challenges resulting from roles in tracking*: since we observed that tracking-related information for dementia care can be categorized as tracked data about patients' daily life activities, personal health, and finances. These patient-generated data can be captured if patients consent to having their data sensed or passively collected via wearable devices or smart tools. However, because many dementia patients in our data were either uninterested in or frustrated by such technology, difficulties in (a) *seamless data creation* made the collection of patient-generated data a significant challenge. Additionally, as family members found it difficult to collect necessary tracking information while still protecting the patient's privacy, (b) *data collection with only necessities* became quite challenging. Moreover, (c) *interpreting data* was quite challenging because issues frequently arose to ensure that tracked data could be easily understood by caregivers with less technical expertise and by patients with impaired comprehension and decision-making ability. These challenges in data work placed a strain on the entire caregiving process.

3. Expectations & Desire for workshop

In this study, we have identified desired information about dementia care tracking. Considering the tracking categories and the desired information that we have identified, family members, caregivers, and community members can better structure their collaborative use of self-tracking technologies to support people living with dementia. Given these observations, we are exploring the possibility of self-tracking technologies be implemented in dementia care through collaboration, with the recognition of different types of information as well as different roles involved and with particular attention paid to different types of data work and related roles in data work. We have outlined a number of challenges that existing self-tracking technologies may present for collaborative tracking in dementia care. As we argue that self-tracking for dementia care is a collaborative personal health information practice, we believe that our research findings demonstrate that it is a unique problem that intersects collaborative information behavior and personal health information management that has been understudied by information science researchers. We hope to initiate a discussion on these issues at this PIM workshop and to contribute ideas and discussions on how "collaborative tracking" can be generalized and applied to a broader context of health management for normal aging.

*Notes: Both Ning Zou and Daqing He are able to attend the workshop in person.

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