Chapter 5
Smart Lifelogging Technology for Episodic Memory Support

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ABSTRACT

Recent episodic memory impairment (EMI) affects over 26 million individuals with Alzheimer's disease. Smart lifelogging technologies can capture a log of the user's personal experience using wearable or embedded recording devices and present elements of that log as cues that can support memory recollection for people with EMI. In this chapter, the authors describe their design process for developing and evaluating a smart lifelogging system specifically designed to help people with mild EMI remember their experiences better and reduce the burden on their caregivers. The authors' design process includes two formative field studies to understand both what lifelogging data is most effective for supporting memory and how to present these data. The authors found that their self-guided approach was more effective at supporting people's ability to retain a detailed memory of their experiences, to feel more confident about their memory abilities, and to reduce the additional burden placed on the caregiver than a caregiver-guided approach.

INTRODUCTION

Ubiquitous computing technology has the potential to assist, compensate, and even enhance our natural cognitive abilities. Traditionally, computers are particularly well-suited for faithfully keeping records of vast amounts of information and providing us programmatic access to these records when we need it. Thus, computing can play a vital role in compensating for problems such as episodic memory impairment (EMI) common in individuals with neurological conditions such as Alzheimer's disease by keeping an account of the episodes in an individual's life. Advances in ubiquitous computing extend the ability of systems from simply storing information to capturing high-fidelity representations of an individual's life experiences unobtrusively.

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In this chapter, we discuss the design process of how we developed a smart lifelogging system to assist people with episodic memory impairment to recollect the details of recent personal experiences. We followed a user-centered design principle to understand the needs of users and designed a system to fit these needs and maximize the potential for adoption of our technology. Our formative field studies were invaluable for helping us generate design guidelines for developing a system that worked within the constraints of the abilities of users and complexities within the caregiver/care-recipient social relationship and environment. We developed our system and tested it with individuals with representative users and found that our system supported memory well and imposed less of a burden on the caregiver. In addition to developing a smart lifelogging system that has the potential to improve the quality of life of individuals with episodic memory impairment, our research process of in-situ field studies to understand current practices, discovering the implicit notions of what users actually want (or should have), and designing a system that meet these needs can be followed for other smart healthcare technologies.

BACKGROUND

We depend on our episodic memory to help us remember our recent experiences. We can remember having a good conversation with a close friend last week and can pick up where the conversation left off. We can remember buying milk and bananas from the market in the morning so we do not have go out and buy them again in the afternoon. We can remember having dinner at a new restaurant and can relive the experience of how delicious the food tasted by simply thinking about it. We can remember spending an evening reading a favorite book in the safety and comfort of our home. Recent episodic memory supports our sense of self (Clare 2003) by enabling us to mentally travel back in time and relive our pleasant experiences and to feel socially and physically engaged in our lives.

Episodic memory impairment (EMI) is the main symptom associated with Alzheimer's disease, a common neurodegenerative disease that affects over 26 million people worldwide, with this number expected to quadruple by 2050 (Alzheimer's Association, 2008). Recent episodic memory impairment dramatically changes the lives of individuals with the impairment. Individuals struggle with the need to constantly readjust their own expectations of what they can and can no longer remember. EMI can lead to a loss of autonomy and control in individuals' lives, resulting in feelings of uncertainty, irritation, and frustration as they attempt to compensate for their memory loss but repeatedly fail. They may withdraw from interacting socially with others to avoid appearing incompetent and as a result may even develop depression (Steeman, DeCasterle, Godderis, & Grypodonck, 2006). They must rely on others for support and often must repetitively ask their family caregivers (such as a spouse or an adult child) for information about current and recent events. The lives of their family caregivers are also dramatically changed as caregivers become overburdened with providing support for both the cognitive and physical needs of their loved one and can themselves develop depression or burnout which can lead to reduced quality of care (Almbert, Grafstrom, & Winblad, 1997). Thus, individuals with EMI and their caregivers struggle to regain a sense of normalcy—how things were before the onset of the disease—in their lives (Butcher, Holkup, & Buckwalter, 2001; Clare 2003). In other words, their ideal situation would be to turn back the clock and live in a time before the disease changed their lives, when their lives were "normal." Restoring normalcy in their now changed lives involves restoring the memory abilities and independence that the disease took away from them.