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HEALTH LITERACY

Bethany Figg, Column Editor

GreyMatters: An Interactive Tool for Patients and Their Caregivers

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ABSTRACT

Every person needs communication. When the ability to communicate is lost, quality of life declines. Hearing loss, visual deficits, mobility issues, and cognitive decline all impact the communicative abilities of people and the quality of their communication. Dementia is one of the chronic health conditions that greatly and negatively impacts communication on all levels. A graphic artist with family affected by dementia developed an application to give dementia patients and their family, friends, and caregivers the opportunity to have meaningful interactions. *GreyMatters* is a health literacy tool to improve communication and quality of life in these patients.

KEYWORDS

Communication; dementia; health literacy; health tools; quality of life; relationships

Introduction

Communication is an integral part of everyday life. Isolation resulting from the inability to effectively communicate is devastating. Dementia may cause serious interruptions in communication which makes interactions with family members, friends, patients, and caregivers tedious. Problems with communication can vary with each type of dementia, but typically they cause problems with language, attention, focus, and awareness. Not only does this affect simple conversation and an individual's ability to relay needs, but it can make moments with a loved one or patient stressful and emotional. The *GreyMatters* Apple app for the iPad was designed to assuage this situation.

According to the Alzheimer's Organization, Alzheimer's disease is the sixth leading cause of death in the United States and the only top ten cause of death in America that cannot be prevented, cured, or slowed (Facts and Figures 2015). Alzheimer's accounts for an estimated 60–80% of all dementia cases. This is not the only type of dementia that can be diagnosed. Given an individual's particular symptoms and presentation, a diagnosis of vascular dementia, previously known as multi-infarct or post-stroke dementia, accounts for 10% of cases. Other types such as Lewy Body dementia,

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frontotemporal dementia, and Parkinson's dementia occur less frequently (Facts and Figures 2015). These types of dementia have more obvious symptoms whereas an Alzheimer's disease is a slow, progressive decline over time. Other conditions that fall under the category of dementia and cause many of the same issues (i.e., cognitive decline, mobility difficulty, self-care deficits, communication issues) are Creutzfeldt-Jakob disease and normal pressure hydrocephalus (Facts and Figures 2015).

The creator of the *GreyMatters* app, Jenny Rozbruch, had a personal experience with this devastating disease when her grandmother, Frieda, was diagnosed with vascular dementia and suffered for seven years (About Us 2015). Typically, in vascular dementia there is a coexistence with Alzheimer's disease. Vascular dementia occurs after a vessel blockage in the brain leads to strokes or bleeding in the brain. The location, number, and size of injuries to the brain determine whether dementia will be the end result and how the patient will present. Most often, the patient has impairments in judgment and an inability to make decisions, plan, or organize. Thinking and physical function can also be affected (Facts and Figures 2015). It is within this realm that the decline in communication is displayed. Recalling events in the short term, recognizing faces, knowing names, or even knowing how to engage in simple conversation can be greatly diminished in a dementia patient. This makes the daily life confusing and frustrating for the patients as well as their family and caregivers. When wants and needs cannot be expressed, the flow of a conversation is lost.

Background

After witnessing her grandmother struggle with vascular dementia for seven years, Jenny Rozbruch created and founded *GreyMatters*. Although Frieda received care from her family and professional aides, the loss of her short-term memory and independent functioning continued to decline. During visits, Jenny noticed that Frieda's long-term memory and spirit improved dramatically during simple activities such as looking through photos from her youth, listening to familiar music, and hearing stories from her life described back to her. This realization allowed Jenny's family to reconnect with Frieda by tapping into the remaining abilities she had. These memories gave her family and caregivers the access to the relationship that was once treasured.

GreyMatters Overview

Currently, the free *GreyMatters* app is only downloadable through the Apple App Store for the iPad. There are options for in-app purchases, and the user would need an active iTunes account. *GreyMatters* is designed to be personalized for the specific needs of a dementia patient while also aiding the



Figure 1. Welcome screen.

caregiver in improving patient care. *GreyMatters* can be beneficial in home settings but also can be tailored to larger care facilities. An option is available to use the app for as few as one or two patients or as many as dozens, because a profile with information for each individual patient is created and stored (see [Figure 1](#)). Patients suffering from dementia need engagement, communication, and personal relationships to promote quality of life. Based on *GreyMatters*' philosophy of "people with dementia are 'still here'" those things should not be lost (Grey Matters to Us 2016).

My Life

After downloading the app and loading the information about the patient, families and caregivers will see a screen to choose a category (see [Figure 2](#)). Once selected, the window is darkened and the application opens. The patient



Figure 2. Categories.

and their family member/caregiver can begin to share and make memories. The customizable feature of *GreyMatters* makes the application unique. Group activities within a care facility tend to be generalized in an attempt to meet the needs of many people at one time. In the home or private setting, it would be much easier to engage a dementia patient with activities, photos, or music, but may be daunting for a family member or caregiver to recognize where or how to begin. The “My Life” sections allow for a history of the individual patient’s life and experiences. Family members are able to upload photos and news articles familiar to the patient. Families and/or caregivers can also record simple voice narration and add text to evoke memories. The goal is to trigger memories and foster quality communication. Simplicity is important for patients with dementia, so it is imperative to keep the messages short and specific. Any text should be in contrasting color for easy reading (see [Figure 3](#)).

My World

The “My World” tab within the *GreyMatters* app allows families to use preloaded content pages to appeal to the patient’s interests on a generational level. As an example, one could choose a list of movies and actors or actresses that were popular during a particular decade. Photos of those individuals and scenes from the movies can be added. On each page, the patient has the option to choose “I Remember” or “Remind Me” by pressing a button on the screen. The purpose is to initiate conversation. As in [Figure 4](#), a photo of a music artist may trigger a memory that would encourage a conversation about the artist and subsequently, moments of the patient’s life related to that



Figure 3. My Life.



Figure 4. My World.

artist. Music can be uploaded and played from a different location in the app. Some options available for purchase within the app are films, music, and sports from the 1940s and 1950s.

Record and Share New Memories

During the course of a visit with a patient using the *GreyMatters* app, certain moments or events of the patient's past might be recalled. Should this happen, the recollection could be shared in the present time and then shared with family members. When a particular image is shown or a story is told to the patient and a memory is evinced, there is an icon in the lower right hand corner that can be pressed. A new video or photo of the patient talking about it can be uploaded. This gives the patient the opportunity to live in the current time as well as remember the past. Due to many types of dementia affecting the short term memory, recent events are the most difficult to evoke. According to the *Alzheimer's Disease—Questions and Answers (2015)*, previous life events are important and may launch a meaningful conversation and visit (See [Figure 5](#)).

Music and Games

The population of the United States is aging, and with the growing Baby Boomer population the odds of encountering someone in health care 60–65

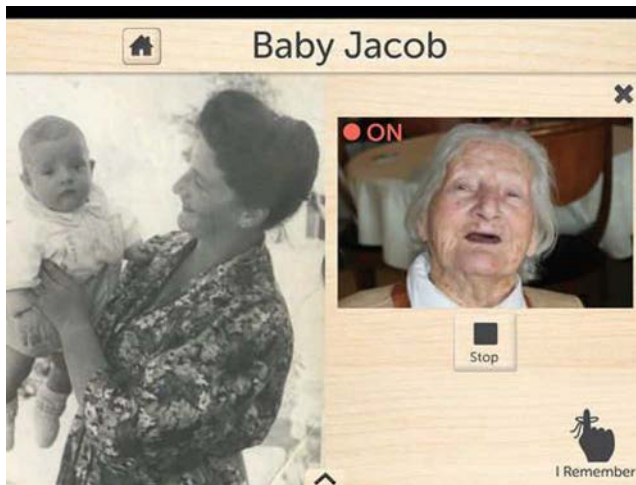


Figure 5. New memories.

years and older are very high. According to the Texas Department of Health Services (DSHA) in 2015, an estimated five million people age 65 and over have been diagnosed with Alzheimer’s Disease alone in the United States (Facts and Figures 2015). The Texas DSHA further elucidates the prevalence of Alzheimer’s Disease by noting that 1 in 9 people over 65 have Alzheimer’s and one-third of people over 85 have Alzheimer’s. This is reflected by the iTunes account that the most popular eras accessed in the *GreyMatters* “Music and Games” section, range from the 1930s–1950s. iTunes also reveals that some of the most popular in-app purchases are films of the 1940s and films and sports of the 1950s (Top In-App Purchases 2016). Additionally, users may load music and games (i.e., Memory Pages) from other decades. These provide the opportunity for stimulating memories, encouraging conversation, and reassuring the dementia patient. The significant effect music can have on a patient is evident in testimonials of caregivers and families. Caregivers note behavioral changes in both the meaningful relationship with patients, and a reduction in dealing with behavior issues (Music Therapy for Dementia 2013).

Caregivers and family members may choose to play a game of memory cards with their loved ones featuring familiar content from the patient’s life. The patient can select a category, and that topic will be the feature of that memory card round of play (see Figures 6 and 7).

Reminders

Dementia disrupts nearly every aspect of the patient’s daily life. As it continues to advance, the ability to speak, feed, and dress oneself deteriorates and eventually disappears. Throughout the progression of the disease, daily



Figure 6. Memory card sets.

tasks become increasingly difficult and even annoying to the patient. From one hour to the next, patients may forget they are being cared for and living in a facility which is not their own home, or they may be unable to perform usual tasks. Even the act of taking medications or bathing can cause resistance and uncooperative behavior toward the caregiver. *GreyMatters* can alleviate this by providing reminders in calm, loving, familiar voices. Another option available is to remind the patient that they are in a safe place and that the family member that is speaking loves them. Family members and caregivers can tailor the “reminders” to answer the questions that are most frequently requested by the patient. If they are concerned about where they are, asking to go home, wanting to know who the people taking care of them are or where

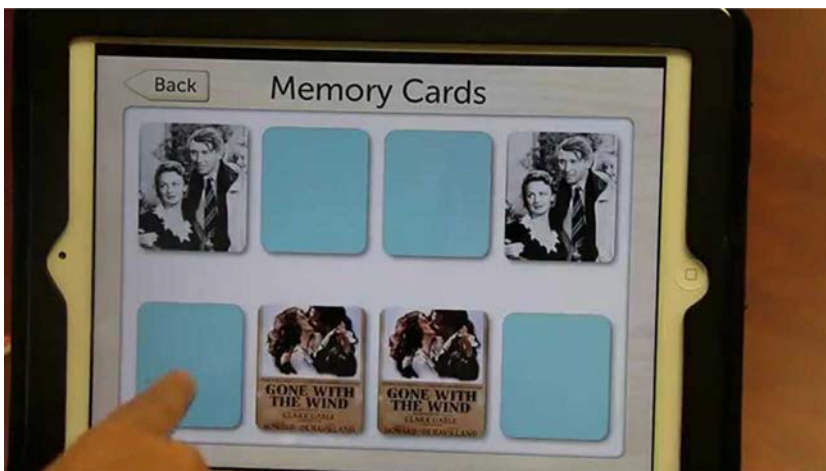


Figure 7. Memory game.

a specific family member is, short sentences to calm and reassure the patient can prove to be an invaluable tool. Even the patient can add their own “reminders” about photos.

Accessibility

Any chronic health condition requires each patient to be treated as an individual. Traditional approaches to management do not always produce the same results in every case. Often, a successful intervention will not achieve the same outcome the next day. Caregivers must be able to adapt to the patient and their moods. *GreyMatters* is uniquely designed based on the patient’s own life. Their personal experiences are embraced to guide them through a very confusing time in their lives and allow family and caregivers to participate. Each profile is customizable by choosing earth tones for men, more feminine colors for females, and blues or greens for screen color. The size of the screen is dependent upon the size of the iPad, but still large enough to be visible; the icons and windows are large enough to be touched. The screens within the app are designed simply and cleanly. Too much stimulation can be detrimental to the dementia patient and counter-productive to quality communication.

GreyMatters Health Literacy Tools

GreyMatters is a prime example of what a health literacy tool should be. Patients have a right to be informed of all of their medical care and to understand all the information presented. Informed decisions cannot be made unless there is understanding. Sadly, when dementia is present, a patient’s ability to obtain and process basic health information is severely disrupted. Caregivers may find it difficult to choose the appropriate words to guarantee that the patient comprehends what is being said and how they should proceed. With *GreyMatters’* assistance, reminders and cues are given to the patient in a way that makes them comfortable and alleviates distress. This will provide the best hope that the patient will have as much of an understanding of their health condition as possible, and that the patient’s family can feel that they are contributing to their loved one’s care. The flexibility of the app makes it most helpful to the patient, the family, and caregivers.

Conclusion

The statistics clearly demonstrate the pervasiveness of dementia in the lives and medical care of those living in the United States. Many of these numbers have been documented in this article. The progressive nature of the disease makes daily life extremely difficult and may give family and caregivers the feeling that it is impossible to manage. Communication is one aspect of life

that is affected nearly from diagnosis. Understanding that patients need sufficient time and opportunity to express themselves, that simple language with clear/direct words are most effective can be helpful (Facts and Figures 2015). Accompanying these words with gestures, pictures or verbal cues is what the *GreyMatters* app will add in an effort to enhance the communication and interactions of dementia patients and their families. Several research studies have been conducted with positive results regarding the use of simple technology like *GreyMatters* with dementia patients. Jane Flinn, coauthor to one of these studies said, “The more you can activate the brain, the better ... If [apps] keep the caregiver engaged, then that’s helpful, because it’s something the caregiver can do with the other person” (*GreyMatters* App Aims to Help People Connect with Loved Ones Suffering from Dementia 2015). The uniqueness of *GreyMatters* is not its streamlined appearance or simplicity of use, but its personalized life scrapbook that is customizable for each patient struggling with dementia.

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