

**Use of Assistive Technology for Cognition Mobile Applications by Breast Cancer
Patients Treated with Chemotherapy**

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Abstract

Difficulty thinking, remembering, and concentrating are common complaints among breast cancer patients treated with chemotherapy; however, tools and support for coping with these impairments remain limited. A previously unexplored option for managing the perceived impairments that accompany chemotherapy is the use of assistive technology for cognition (ATC), which is designed to aid memory, planning, and attention. This study seeks to understand whether women with breast cancer perceive any benefit from using two ATC apps on their smartphone and whether any gaps exist between the functionality of these apps and the needs of the participants. This two-week study examines the experiences of eight women with breast cancer before and after the use of two ATC apps (It's Done and AudioNote) using a combination of semi-structured interviews and diary entries. All eight participants were either currently undergoing chemotherapy or had been treated with chemotherapy in the past, and had self-reported cognitive impairments. Instances of forgetting and frustration observed before the introduction of the ATC apps indicated that participants' current coping strategies did not adequately meet their cognitive needs. After the It's Done and AudioNote apps were introduced, participants found aspects of the apps beneficial, such as the recurring reminders, push notifications, and audio recording feature. While most participants felt that the apps improved their quality of life in one or more areas, usability issues, lack of functionality, and lack of habitual use prevented the two apps from comprehensively addressing participant's cognitive needs. Recommendations for a single ATC app that combines and improves upon the features present in It's Done and AudioNote to better support the cognition of breast cancer patients treated with chemotherapy are discussed.

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Chapter 1: Introduction

Minor mental lapses, such as misplacing keys or forgetting someone's name, is part of everyday life. For women who have undergone chemotherapy for breast cancer, mental lapses like these frequently occur throughout the day, making the completion of daily tasks a constant battle.

Difficulty thinking, remembering, and concentrating is a common complaint among those treated with chemotherapy; so much so that it is colloquially referred to as “chemobrain” or “chemofog.” Since the etiology of the chemobrain phenomenon remains unclear, support for those affected by it is limited. Healthcare professionals are reluctant to acknowledge perceived changes in cognition, making it difficult for patients to understand and cope with their symptoms. Despite the numerous mobile applications created specifically for those with breast cancer,¹ most cancer-related mobile applications fail to address the cognitive needs of this user group.

This study seeks to explore the potential benefit of providing breast cancer patients with assistive technology for cognition (ATC) to help individuals cope with chemobrain. ATC applications are used to aid the cognitive ability of both high-functioning and cognitively impaired individuals in the areas of memory, planning, and attention. These applications range from the basic functions one might use on a mobile device, such as a calendar or alarm, to more specialized applications for those with severe cognitive deficits.

The purpose of the study was not to quantify the efficacy of the ATC apps but to assess whether the participants perceived any benefit from using them, and whether gaps existed between the functionality of the ATC applications and the needs of the participants. While experiences of CRCI is not limited to those being treated for breast cancer, the scope of this study has been limited to breast cancer patients because it is one of the most frequently occurring cancers in the U.S. and is the focus of much of the research into chemotherapy-related cognitive impairment.

¹ Mobile applications designed for breast cancer patients represent approximately 50% of current cancer related mobile applications (with an additional 30% not targeting any specific kind of cancer).

Chapter 2: Literature Review

Chemotherapy-Related Cognitive Impairment

In the U.S. alone, there are an estimated 232,670 new cases of breast cancer every year ("SEER Stat Fact Sheets: All Cancer Sites," n.d.). Approximately 12.3% of women will be diagnosed with breast cancer in their lifetime, making breast cancer the most common type of cancer for women in the U.S. ("SEER Stat Fact Sheets: Breast Cancer," n.d.). Fortunately, survival rates for this disease continue to rise, with approximately 89.2% of breast cancer patients surviving five years or more after diagnosis. Though breast cancer treatments such as chemotherapy have helped to increase the chances of survival, the benefits of treatment can come at a high cost. Aside from the physical effects, up to 75% of cancer patients experience some degree of cognitive impairment either during or soon after chemotherapy treatment (Janelins et al., 2011).

For years claims of chemotherapy-related cognitive impairment (CRCI) were primarily supported by anecdotal evidence. Patients often report difficulty with short-term memory, concentration, multi-tasking, and recalling words or names, both during and after treatment. (Munir, Burrows, Yarker, Kalawsky, & Bains, 2010; Myers, 2012; Player, Mackenzie, Willis, & Loh, 2014; Rust & Davis 2013). It was only within the last ten years that several meta-analyses provided more solid evidence, showing higher levels of cognitive impairment in breast cancer patients during and after chemotherapy in comparison to controls (Falleti, Sanfilippo, Maruff, Weih, & Phillips, 2005; Jansen, Miaskowski, Dodd, Dowling, & Kramer, 2005; Stewart, Bielajew, Collins, Parkinson, & Tomiak, 2006).² However, the domains of affected cognition differed between each of the studies. Two of the studies (Falleti et al., 2005; Stewart et al., 2006) noted deficits (with small to moderate effect sizes) in the areas of working memory, short-term memory, long-term memory, language, spatial abilities, and motor abilities. Jansen et al. (2005) found that only visual memory displayed significant impairment across all control types (i.e., control group, normative data, or baseline data), but that differences in verbal

² Studies involving CRCI often suffer from small sample sizes. Pooling data from different sources through meta-analysis increases the power of the study, making it more like to find effects if they occur.

memory, visual memory, executive function, and information processing speed were significant when comparing the results of chemotherapy patients to the normative data control.

Research concerning the duration of cognitive dysfunction after treatment also varies greatly. Longitudinal studies have shown cognitive impairment to exist in a subset of patients before the start of treatment, which may contribute to the post-treatment impairment observed in breast cancer survivors. Several longitudinal studies have compared pre- and post-chemotherapy measurements of cognitive function to that of healthy/normative controls. In these studies, 12-82% of participants demonstrated impairment in attention, memory, psychomotor speed, and executive function (Janelins, Kesler, Ahles, & Morrow, 2014). However, two recent meta-analyses seem to contradict these findings. A 2012 study of long-term (6+ months) cognitive impairment in breast cancer survivors previously treated with chemotherapy found that only the areas of verbal and visuospatial ability seem to be affected (Jim et al., 2012). A 2015 meta-analysis found no significant difference between pre- and post-treatment measurements of cognitive performance in longitudinal studies, though the time of post-treatment measurements ranged from 1-18 months after chemotherapy (Ono et al., 2015).³ In both cases, the studies do not focus on acute impairment after treatment but focus on longer-lasting effects.

Confounding Cognitive Factors During Chemotherapy

Though cognitive impairment has been shown to increase during chemotherapy, the cause of this increase remains unclear. As baseline measurements show, some people with cancer experience cognitive impairments even before the start of treatment. There are many confounding factors that can affect an individual's cognition, making it difficult to attribute any impairment to the chemotherapy treatment itself.

A cancer patient's cognitive ability during treatment is affected by a number of individual factors, making the study of chemobrain a difficult task. Confounding factors that can affect cognitive ability, during or after treatment, include cancer stage/type,

³ An examination of cross-sectional studies from the same meta-analysis revealed a significant increase in post-treatment cognitive impairment over that of healthy controls.

treatment plan, pre-existing conditions, genetic factors, socioeconomic status, menopausal status, and age (Janelins, et al., 2014). Some studies have also found fatigue to correlate with CRCI, but additional research is needed to understand how it interacts with other effects on objective cognitive performance. Psychological factors such as anxiety and depression can affect cognition at any time, though studies have accounted for this during objective measures of cognitive performance and have generally ruled it out as a contributing factor to CRCI (Hermelink et al., 2010; Janelins, et al., 2014).

Comorbid age-related cognitive impairment is one of the most commonly used explanations for cognitive deficits that occur during and after chemotherapy (Janelins, et al., 2014). Breast cancer is most frequently diagnosed in women ages 55-64, with the median age of diagnosis occurring at age 61 ("SEER Stat Fact Sheets: Breast Cancer," n.d.). With a higher age of diagnosis, there is an increased risk that symptoms of mild cognitive impairment (MCI) are caused by the beginning stages of Alzheimer's disease. Alzheimer's disease affects approximately 15% of individuals aged 65-74, though the risk of the disease increase with age. Of the people living with Alzheimer's disease, 82% are 75 or older (2015 Alzheimer's disease facts and figures, 2015).

The Gap Between Objective and Subjective Measures of Cognitive Impairment

Though many breast cancer patients report symptoms of chemobrain, research has shown that a gap does exist in the assessment of cognitive performance through subjective and objective measures (Pullens, De Vries, Roukema, 2010), suggesting that self-reported impairment does not necessarily indicate the presence of an actual cognitive deficit. A meta-analysis of studies comparing objective and subjective assessments of cognitive impairment found that 16 of the 24 studies reported no significant relationship between the two measures (Hutchinson, Hosking, Kichenadasse, Mattiske, & Wilson, 2012). In the eight studies that did find significant results, it was most commonly observed in the relationship between measures of memory and self-reported impairment in breast cancer patients. Subjective measures of cognitive impairment have been found to correlate more strongly with tests of psychological distress rather than objective measures of cognitive performance (Pullens et al., 2010; van Dam et al., 1998). Another

possible explanation for the gap is that pre-existing knowledge about chemotherapy-associated cognitive problems may increase self-reported rates of impairment (Schagen, Das, & van Dam, 2009).⁴

Despite the differences in subjective and objective measures, perceptions of impairments should not be dismissed as they can impact a person's quality of life (Shilling & Jenkins, 2007). One longitudinal study found that during the course of chemotherapy, the number of participants reporting difficulty concentrating increased from 54.5% before treatment to 81.8% during treatment (Kohli et al. 2007). Similarly, the number of participants reporting problems with memory increased from 55.9% to 85.9%. High levels of self-reported impairment may be attributed to the fact that subjective measures of cognitive performance often account for a patient's perception of impairment over time, and may detect minor changes in cognition that objective measures cannot (Janelins, et al., 2014).⁵

Effects of Perceived Impairment

The resulting anxiety and frustration over the perception of cognitive decline can affect several domains of a person's life, including their social relationships and their ability to return to work. Some survivors avoid social situations so as to not be embarrassed by their perceived cognitive deficits, leading to changes in their social relationships (Selamat, Loh, Mackenzie, & Vardy, 2014). Inability to complete daily tasks also created a feeling of disconnect between survivors and their families (Player et al., 2014). Survivors also reported decreased confidence in their ability to return to work, fearing that their cognitive abilities will affect their performance (Munir et al. 2010). Those who return to work while experiencing perceived cognitive impairment feel that they are less productive, reporting that tasks taking longer to complete due to difficulty

⁴ In this study, patients with pre-existing knowledge of chemotherapy-associated cognitive problems had higher ratings of subjective cognitive impairment than those without pre-existing knowledge. However, this study did not account for the fact that patients may have researched or asked their doctor about CRCI as a result of experiencing impaired cognition. Pre-interview priming was also shown to affect rates of self-reported cognitive impairment, but only for those with no chemotherapy experience.

⁵ Discrepancies between self-reported and objective measures of cognition have also been observed in studies conducted with individuals with other chronic diseases such as multiple sclerosis and rheumatoid arthritis (Middleton, Denney, Lynch, & Parmenter, 2006; Shin, Katz, & Julian, 2013).

concentrating, multi-tasking, and processing information (Banning, 2011; Munir et al., 2010; Selamat et al., 2014). One study suggested that an employer's willingness to make accommodations for the cancer survivor's needs was positively associated with the survivor's return to work (Bouknight, Bradley, & Luo, 2006).⁶

Support from Healthcare Professionals

Support from friends, family, and healthcare providers is a critical factor for helping individuals overcome the many side effects of chemotherapy. However, support from healthcare professionals is much more limited when it comes to a patient's perception of impaired cognition. (Myers, 2012; Selamat et al., 2014). Since the etiology of cognitive impairment during chemotherapy remains mostly unknown, patients experiencing cognitive changes during treatment are often denied the validation and support they seek from doctors. In a study of 74 breast cancer survivors experiencing post-treatment symptoms, many complained about a lack of acknowledgment by healthcare professionals concerning cognitive impairment during and after treatment (Boykoff, Moieni, & Subramanian, 2009). Participants felt that healthcare providers were often insensitive or dismissive about their experiences of chemobrain, and were quick to attribute cognitive changes to other factors such as age. Patients often receive little to no information concerning the possibility of cognitive impairment before the start of treatment (Rust & Davis, 2013; Selamat et al., 2014). This lack of information and support from healthcare professionals prevented patients from creating proactive coping strategies, and created additional stress for individuals attempting to self-manage their perceived impairments.

Tools and Strategies for Coping with Cognitive Impairment

Sites like cancer.org, mayoclinic.org, and cancer.net do provide some suggestions for coping with chemobrain ("Attention, Thinking, or Memory Problems," 2013; "Chemo

⁶ Limited research has been done to evaluate how social factors might affect survivor's employment and ability to work. Factors frequently associated with a survivor's return to work are the type of cancer, treatment, current health status, level of education, and physical workload (as required by the job). (Taskila & Lindbohm, 2007).

Brain," 2014; "Chemo Brain," n.d.), such as working in a quiet environment, getting plenty of rest, eating a healthy diet, and using strategies to help with memory. These strategies included the use of notebooks, daily task logs, calendars, and post-it notes to keep track of important information and reminders. Though mobile devices were recommended as a way to help create and store reminders, only cancer.net suggests the use of a specific application. The cancer.net mobile app can aid cognition by allowing users to track symptoms, save information about different medications, store questions for health professionals, and record audio answers ("Mobile Applications," n.d.).⁷

M-Health Applications and Assistive Technology for Cognition

M-health Applications

The prevalence, portability, and functionality of smartphones and similar devices have made the mobile platform ideal for new health technologies. Mobile health applications (m-health apps) have been used to deliver relevant health information, monitor chronic conditions, send appointment reminders, aid with treatment compliance, or even stage medical interventions (Klasnja & Pratt, 2012; WHO, 2011).⁸ M-health apps may also contain features that can aid cognition such as navigation to medical facilities, symptom trackers, voice recorders, and medication and appointment reminders (U. S. Food and Drug Administration, 2015).⁹

Though there is a multitude of m-health applications designed specifically for people with cancer, most of these apps are designed to provide cancer-related information rather than help manage or cope with the disease. According to a 2013 study, there were approximately 295 cancer related mobile applications designed for use by the general

⁷ In addition to coping strategies, several interventions have been proposed for reducing or preventing the occurrence of cognitive deficits including cognitive behavioral therapy, brain training, physical activity and certain medications such as modafinil (Fardell, Vardy, Johnston, & Winocur, 2011; Janelisins, et al., 2014).

⁸ In a 2011 survey, the World Health Organization defined m-health as a "medical and public health practice supported by mobile devices, such as mobile phones, patient monitoring devices, personal digital assistants (PDAs), and other wireless devices" (World Health Organization [WHO], 2011).

⁹ There is an overlap in the definition of m-health apps and apps that may meet the FDA's definition of a medical device. The FDA distinguishes between mobile applications that explicitly meet the definition (and are strictly regulated) and apps that only may meet the definition.

public and available for download in the official app stores for iPhone, Android, Nokia, and BlackBerry (Bender, Yue, To, Deacken, & Jadad, 2013). Almost half of these applications (46.8%) pertained specifically to breast cancer. Most of the apps were purely informative, with 58.6% of them being used to raise awareness or provide educational material about cancer.¹⁰ An additional 23.1% of the applications promoted fundraising and charities. Only 11 of the 295 (3.7%) applications were designed to assist with disease management.

Assistive Technology for Cognition

M-health applications that contain cognitive aids, such as pill reminders and symptoms trackers, can also act as assistive technology for individuals with impaired cognition. In the Section 508 Standards for Electronic and Information Technology, assistive technology is defined as “any item, piece of equipment, or system, whether acquired commercially, modified, or customized, that is commonly used to increase, maintain, or improve functional capabilities of individuals with disabilities” (Definitions, 2000). Assistive technology for cognition (ATC) is a subset of assistive technology, referring to devices that are capable of aiding cognition during task performance (Gillespie, Best, & O’Neill, 2012). ATC can aid with memory/retrieval, time management, organization and planning, emotion regulation, attention shifting/altering, or navigation/experience of self (Gillespie et al., 2012).

ATC devices can be as simple as a calculator or alarm and can help to extend the cognitive ability of even high-functioning individuals. However, people with severe cognitive deficits (such as those with dementia, Alzheimer’s disease, intellectual disabilities, stroke, and traumatic brain injury) often require far more specialized applications. One such example is the Planning and Execution Assistant and Trainer (PEAT) application. PEAT is a customizable smartphone application designed for people with impaired memory and executive function (Levinson, 1997; Modayil, Levinson, Harman, Halper, & Kautz, 2008). PEAT can monitor user activity and provide reminders

¹⁰ There is also some concern as to quality of cancer-related applications, as many are designed without scientifically valid information or medical professional involvement (Mobasheri et al., 2014; Pandey, Hasan, Dubey, & Sarangi, 2013).

and contextual cues to help users complete important activities. The PEAT application's comprehensive features allow it to act as a cognitive orthotic for people with Traumatic Brain Injury (TBI) and other severe cognitive deficits.

Cognitive Aids for Use During Cancer Treatment

Though there has been a lack of ATC apps designed for patients with cancer, there is a need for cognitive aids that can assist with tasks like *oral chemotherapy adherence* and *symptom tracking*.

Patients receiving oral chemotherapy ingest the treatment via a pill instead of receiving it intravenously at a medical facility. While oral chemotherapy provides greater patient convenience, it often requires adherence to a strict drug regimen. Complex treatment schedules are associated with lower treatment adherence (Schneider, Hess, & Gosselin, 2011), and may be particularly challenging to follow for individuals experiencing cognitive impairment. Missed doses can reduce the efficacy of the treatment while doses taken too close together can increase its toxicity (Ruddy, Mayer, & Partridge, 2009). Several mobile applications are available as pill reminders; however none have been designed specifically for patients undergoing chemotherapy.

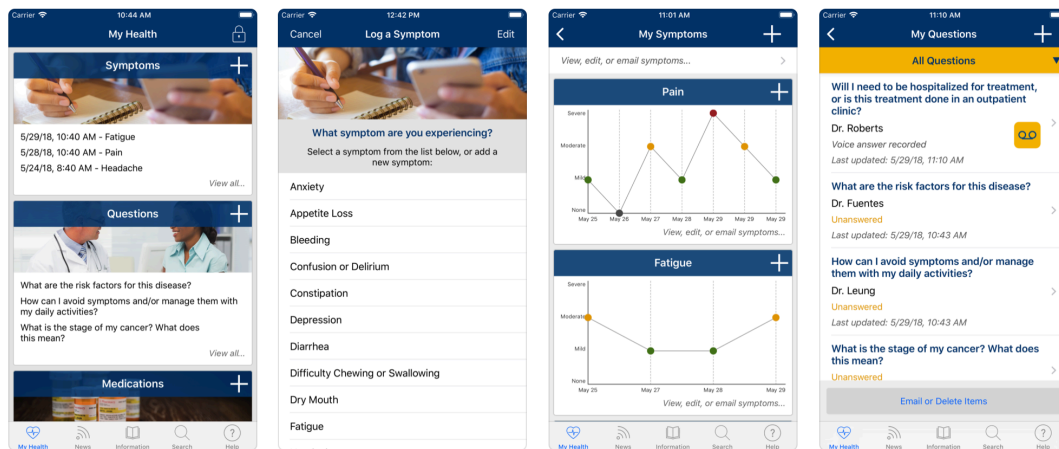


Figure 1: Screenshots of Cancer.net app on iPhone (“Mobile Applications,” n.d.).

Symptom tracking is also crucial to cancer care as it can help increase the reporting accuracy of side effects experienced during treatment. Delayed reporting (i.e., waiting until the next doctor's visit) often results in symptoms being reported as less frequent or severe than they are (Coolbrandt et al., 2011). Applications like the Cancer.net app (help patients record the time, frequency, and severity of their symptoms). Accurate symptom reporting is critical for healthcare professionals to make proper treatment decisions.

Methods and Best Practices for Studying Mobile Application Usage

Accuracy of Self-Reported Data

Studying the use of mobile applications by participants in a research study can be a significant challenge. Aside from data logging (which provides quantitative feedback), researchers often rely on self-reported data in order to collect detailed information about user experiences. Obtaining accurate self-reported data can be difficult as participants' memories are subject to trace decay and recall biases (Baddeley, Eysenck, & Anderson, 2009; Lazar, Feng, & Hochheiser, 2010). Examples of this have been observed in several studies with cancer patients, where participants underestimated the frequency and severity of their symptoms, and overestimated their prescription adherence (Coolbrandt et al., 2011; Schneider et al., 2011).

Diary Studies

Researchers can often increase the accuracy of self-reported data by employing research methods that rely on immediate (rather than delayed) recall. One way of doing this is through the use of diary studies, which reduce recall biases by having participants record their experience at frequent intervals or after specific events (Lazar, Feng, & Hochheiser, 2010). Though diary studies may reduce the occurrence of certain recall biases, diaries still suffer from many of the inaccuracies of self-reported data. One study that used data loggers to compare actual and self-reported usage found that participants tended to overestimate the amount of time they spent using applications, while only

recording approximately 40-70% of the times they used the applications (Möller, Kranz, Schmid, Roalter, & Diewald, 2013).

Diary studies have been used to study forgetfulness by having participants mark times they have misplaced or forgotten something (Terry, W.S. 1988). However they are generally not used to study individuals with self-reported cognitive impairment, likely because the effects of mild cognitive impairment can potentially affect the quality of data obtained from the study. Difficulty with concentration, multi-tasking, short-term memory, and verbal memory can potentially make traditional diaries difficult for some users with cognitive impairment. Fortunately, diary studies can be highly customized using current technology to accommodate the needs of both participant and researcher.

Reminders and Self-Reporting

Participant reminders are necessary for improving rates of self-reporting. Voluntary diaries have been shown to have lower rates of self-reporting than interval studies in which daily reminders were sent when an entry had not been made for that day (Möller et al., 2013).¹¹ In mobile phone studies, researchers can make use of a phone's features, such as texting, email, and calls, to remind a participant to report or to follow up on entries. Though reminders can help increase self-report rates, other research methods such as interviews or data loggers may be necessary to enhance the quality of the data (Palen & Salzman, 2002).

Effects of Media Type

A study by Carter & Mankoff (2005) found that the type of media used for diary entries can affect which events are captured, as well as the participant's ability to recall an event at a later time. Photo entries were observed to be the easiest to create and provided sufficient context for later recall. Audio entries, though less effective for

¹¹ In the case of event studies, capture rates also decrease when participants are asked to record an event that often occurs, as frequent entries are viewed as burdensome (Möller et al., 2013). In some cases, the need for frequent entries also changed the participant's behavior (e.g., avoiding tasks which require diary entries).

recognition and recall, could be created more covertly, causing participants to create entries for events that they may have not otherwise recorded.

Similarly, Palen & Salzman (2002) found that voicemail diary entries were useful for capturing experiences as they occurred. Participants can call a number and leave a message, allowing them to resume their activities more quickly than they would if they were using a paper diary. Participants also provide richer detail when creating audio entries rather than written ones. Though voicemail studies can be used to create highly structured entries, Palen & Salzman recommended doing this only for larger studies that involved less interaction with participants. Voicemail diaries can be particularly useful when conducting mobile phone studies, as participants can create entries using devices they already carry.

The use of “snippets” is helpful in encouraging participants to record events that may be deemed too trivial for a full diary entry (Brandt, Weiss, & Klemmer, 2007). Snippets are images or short pieces of text or audio that are created at the time of an event and are later reviewed and used in the creation of a full entry. The use of snippets has been shown to increase entry length and accuracy. Additionally, hybrid studies that use multiple media types (i.e., audio, text, and images) can help recall and maximize the amount of detail captured (Brandt, Weiss, & Klemmer, 2007; Carter & Mankoff, 2005).

Chapter 3: Methodology

Design

Selection of Methods

The study design utilizes multiple data collection methods, including surveys, semi-structured interviews, and a diary study to collect qualitative data from a small group of participants over the course of several weeks.

Surveys were used at the beginning and end of the study to collect screener data, demographic information, and responses to the modified Perceived Deficits Questionnaire (PDQ), Assistive Technology Quality-of-Life (ATQoL) Scale, and the System Usability Scale (SUS). Since participants in the study could potentially suffer from impaired retrospective memory, it was essential to choose a methodology that could capture in-the-moment experiences, reducing the amount of recall required. Though in-person ethnographic techniques would have been suited to the goals of the study, the participants' locations across the United States made this unfeasible. Instead, a combination of remote semi-structured interviews and diary entries were used. The semi-structured interviews allowed the researcher to explore past experiences in detail, while the diary entries captured day to day events which may have otherwise been forgotten by the participant. A diary study alone would not have been sufficient for data collection as the cognitive challenges faced by the participants would likely affect how often they remember to create an entry for the target event. However, the diary study was structured so that participants could create entries based on what was most convenient for them at the time, thus reducing the burden on the participant. Participants were able to create entries via text, email or phone call.

Sampling and Sample Size

A sample size of eight was selected due to the exploratory nature of this study. The inherent sensitivity of medical information made members of this population challenging to identify and contact. Due to limited access to the population, probability

sampling techniques were not used. Instead, the study used a convenience sample made up of women who met the criteria set forth by the study and who were willing to participate.

Timing of Data Collection

In order to assess whether the participants perceived any benefit from using ATC apps, and whether gaps existed between the functionality of the applications and the needs of the participants, it was necessary first to explore participants' experiences before using the ATC apps. As such, the study was split into two parts, pre- and post-ATC app introduction. The first part of the study focused on participants' experiences of impaired cognition and their current coping tools and strategies. In the second part of the study, after the apps were introduced, the research focused on participants' use and overall impressions of the two apps.

Materials

Stimuli

After reviewing more than a dozen ATC mobile apps, two were selected for use in this study. The It's Done app and the AudioNote app were chosen based on functionality, ease of use, and device compatibility. Both apps are listed as memory aids on abledata.com, a site for assistive technology information that is maintained for the National Institute on Disability and Rehabilitation Research ("AudioNote - Notepad And Voice Recorder," n.d.; "It's Done," n.d.)

The "It's Done" app is designed for those who need assistance planning their day and remembering daily tasks, such as taking medication or locking the door. The app uses daily to-do lists and has prompting features that alert users when they are supposed to complete a task. The app can also automatically text or email others (such as a caregiver) when the user has completed their task. The "AudioNote" app is for those who have difficulty recalling details from a conversation, or have difficulty concentrating while others are talking. It allows users to record lectures or conversations, and take notes or photos during the recording. The text, photos, and audio recording are all saved together

in one document. When the user taps a section of the text, it automatically brings the user to the point in the recording where that note was written, allowing users to note important sections of a recording.

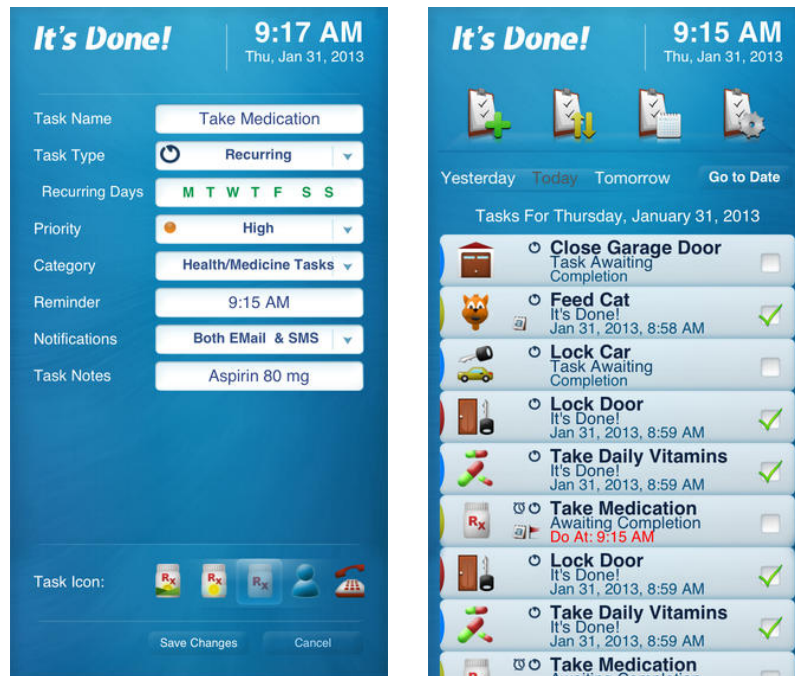


Figure 2: Screenshots of It's Done app on iPhone ("It's Done!" n.d.)

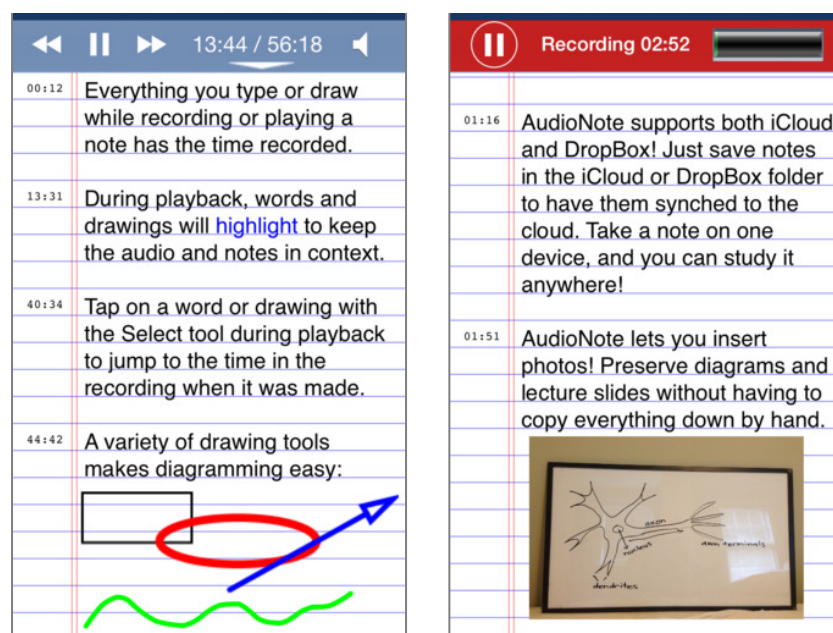


Figure 3: Screenshots of AudioNote app on iPhone ("AudioNote," n.d.).

The applications' streamlined interface and simple functionality made them optimal for use by individuals with cognitive impairment. While there were many commercially available applications to choose from, the complexity of most applications often made them ill-suited to the study. While popular applications like Evernote can help users with planning and organization, its multitude of available features and settings make it potentially difficult to use by individuals with cognitive impairment. Additionally, specialized ATC applications, such as those designed for users with TBI, were not considered as they sought to address more extreme cognitive deficits that were not expected to be present in chemotherapy patients.

Device compatibility was another important consideration in the selection process. The study was designed to allow participants to use their smartphones in order to increase familiarity and ease of adoption, so the applications needed to be compatible with both Android and iOS devices. The applications were chosen because they are available for download from both the Apple App Store (for iOS devices) and the Google Play Store (for Android devices).

Data Collection Tools

Google Forms was used to collect data for the surveys, while Google Voice and Skype were used to conduct and record the remote interviews. Google Voice and Gmail were used to capture text messages, voicemails, and emails from participants during the diary study.

Measures

Modified Perceived Deficits Questionnaire (PDQ). During the initial recruitment process, potential participants were asked to complete a modified PDQ as part of a larger demographic survey. The PDQ was modified to include only ten questions (instead of the original 20) in order to reduce the cognitive burden placed on participants. The questionnaire was designed to assess a participant's perceived ability in the areas of attention/concentration, retrospective memory, prospective memory, and planning/organization (Sullivan, Edgley & Dehoux, 1990). The questionnaire lists typical examples of mild cognitive impairment, such as forgetting names or appointments. The

participant is then asked to rate the frequency of the event on a 5-point Likert scale (0 = Never, 4 = Almost always). Though designed to measure perceived cognitive impairments in individuals with Multiple Sclerosis (MS), the PDQ was used as an appropriate recruitment measure due to the overlap in symptoms of mild cognitive impairment experienced by both breast cancer patients undergoing chemotherapy and individuals with MS (Chiaravalloti & DeLuca, 2008).

Modified Assistive Technology Quality-of-Life (ATQoL) Scale. A modified version of the ATQoL scale was administered to participants after the final interview. The scale was initially designed to assess the effect of assistive technology on quality of life in large-scale surveys of older adults (Agree & Freedman, 2011). The original scale consists of seven questions; four with a negative orientation and three with a positive orientation. The scale assesses how participants' feelings and performance of daily activities have changed since using AT devices; specifically, in the areas of safety, control, participation, pain, tiring, time, and reliance on others. The scale was modified in two ways for this study. First, the responses were modified to include both positive and negative responses to account for a potential decrease in any of the mentioned areas. Secondly, the question regarding feelings of physical pain was removed as it was not appropriate for a study regarding assistive technology for cognition.

System Usability Scale (SUS). Though qualitative data regarding usability was collected for both apps, the SUS was also used as a measure of global usability for the It's Done and AudioNote apps (Brooke, 1996). This 10-question survey was administered twice, once for each app. The final SUS scores were then calculated for each participant and averaged.

Participants

Recruitment

Recruitment criteria for this study were as follows:

- Women who received chemotherapy treatment as a result of being diagnosed with breast cancer

- Currently experiencing instances of confusion, difficulty concentrating, or difficulty remembering
- Under 65 years of age
- Own a smartphone which was either an Android or iOS device
- Currently in control of all their decisions regarding treatment

Only participants with self-reported cognitive impairments were recruited, as it was unlikely that participation would cause these individuals to become aware or alarmed by the presence of possible cognitive impairments during the course of the study. As part of the initial recruiting process, individuals interested in participating in the study were asked to complete the modified Perceived Deficits Questionnaire as part of a larger screener/demographic survey.

To reduce the risk of any confounding age-related cognitive impairments, participants had to be under the age of 65. Additionally, only participants who made all of their own treatment decisions were selected for the study, to ensure that any possible cognitive deficits were not severe enough to interfere with the participant's ability to consent to the study.

A request for participation in this study was posted to social media and on several online forums for individuals with breast cancer.¹² Individuals were able to indicate their interest in participating in the study by completing an initial survey which included screener questions. Respondents who met the criteria set forth by the study were contacted by the researcher.

Demographics

The study consisted of eight female participants with self-reported cognitive impairments, two who were currently undergoing chemotherapy, and six who had been previously treated with chemotherapy.¹³ Of the eight participants, six were white/Caucasian, one was black/African American, and one was African-American and Native American. Ages of participants ranged from 28 to 52, with a median age of 43.

¹² The request for participation was posted in forum threads related to research studies and posted with the approval of site moderators.

¹³ See Table 9 in the appendix for demographic information on each participant.

Two participants worked full-time, two participants worked part-time, one participant went to school full-time, and three participants were not currently working as a result of their illness. Regarding smartphone ownership, six participants had an iOS device while two participants had an Android device. Participants used these devices during the latter part of the diary study.

Procedure

Initial Interview

During the initial remote semi-structured interview, participants were asked about their experiences of cognitive impairment, strategies they used to help overcome these impairments, and any prior knowledge they had relating to chemobrain. Participants were also asked about their daily tasks/routine and the types of activities they perform on their phone.

Diary Study

As previously mentioned, the research was split into two parts, pre- and post-ATC app introduction. The first five days of the diary study sought to establish a baseline for each participant by gaining a better understanding of the cognitive difficulties they were experiencing. During this time, participants were instructed to either call, text, or email the researcher when they experienced difficulty thinking, remembering, or concentrating and to provide a description of the event. Participants were sent daily emails reminding them to submit any additional diary entries they may have forgotten to send/complete from earlier that day.

Once the first part of the diary study was completed, participants were asked to download the It's Done and AudioNote app and were given a quick tutorial by the researcher on the features of each app. After that, participants continued the diary study for another ten days. During this time, participants were instructed to either call, text, or email the researcher each time they used either one of the apps and to provide a quick description of how the app was used.

Final Interview

During the final interview, participants were asked to discuss how they used each of the two ATC apps, provide details on key entries from the diary study, explain what worked well and what did not for each app, and give their overall impressions of each app experience.

Final Survey

Participants were administered a final survey which included a SUS questionnaire for each app, as well as the modified Assistive Technology Quality-of-Life (ATQoL) Scale.

Data Analysis

Once the interviews and diary study were completed, audio recordings were transcribed and used to create affinity diagrams and frequency tables, which identified key trends and themes.

Chapter 4: Results

Study Pre-test

The initial interview and first week of the diary entries captured participants' experiences of perceived cognitive impairment, in addition to the tools and strategies used to cope with the impairment. This initial study period served to establish a frame of reference for each participant before introducing the ATC applications.

Perceived Frequency of Cognitive Dysfunction

Prior to the initial interview, participants were provided with ten situations that may be common to a person with memory, attention, or concentration deficits. They were asked to rate the frequency at which they experienced these events in the past four weeks (see Table 1). The following five situations had median scores in the 'Often' category:

- Losing train of thought when speaking
- Forgetting what you came into the room for
- Trouble concentrating on what people are saying during a conversation
- Forgetting if you have done something
- Trouble holding phone numbers in your head, even for a few seconds

Few participants recorded responses in the highest frequency category ('Almost Always'), suggesting that while participants may perceive deficits as common, they may not be severe in the sense of being ever-present. The situation occurring least frequently, with the lowest median score, was forgetting to take medication, though it is unclear if this was due to participants having methods in place to ensure medication adherence.

Initial In-Depth Interview

Perception of Cognitive Impairment

Consistent with previous research on chemobrain, participants reported increased difficulty with short-term memory, concentration, and multi-tasking since undergoing chemotherapy.

Difficulty remembering. All eight participants felt that they struggled to remember tasks and events, and struggled to keep things in their mind, even for a short period of time. Instances of forgetting included: forgetting to attend an outing with friends, leaving important items at home (i.e., grocery lists, coupons, phone, ID badge),

Table 1

Perceived Frequency of Cognitive Dysfunction

	Never	Rarely	Sometime	Often	Almost Always
How often do you lose your train of thought when speaking?	0	0	3	5	0
How often do you have difficulty remembering the names of people, even ones you have met several times?	0	3	3	2	0
How often do you forget what you came into the room for?	0	1	1	6	0
How often do you have trouble concentrating on what people are saying during a conversation?	0	0	3	4	1
How often do you forget if you have done something?	0	0	3	5	0
How often do you miss appointments and meetings you had scheduled?	2	1	4	1	0
How often do you forget what you did the night before?	0	3	2	3	0
How often do you forget to do things like turn off the stove or turn on your alarm clock?	1	2	5	0	0
How often do you have trouble holding phone numbers in your head, even for a few seconds?	0	0	2	3	3
How often do you forget to take your medication?	0	4	3	1	0
Total	3	14	29	30	4

Note. Bolded numbers indicate the median score for that question. Two bolded numbers in the same row indicates that the median exists between these two scores. This questionnaire was adapted from the Perceived Deficits Questionnaire developed by Sullivan et al. (1990), focusing on the attention/concentration, retrospective memory, and prospective memory subscales.

walking into a room and forgetting what they needed, and difficulty remembering the way home from a familiar location.

“All day long I forget.” -P01

“I’ve been forgetting things more often lately.” -P04

Difficulty focusing and concentrating. Six of the eight participants felt that they struggled to focus/concentrate, and were easily distracted. Participants described their thoughts as “scattered.” One participant felt uncomfortable driving because she “spaced out” so easily. Four of these six participants described feelings of mental foggy and being in a daze, which made regular mental tasks challenging to complete.

“Your brain is foggy and you don’t remember, so sometimes I feel like I’m always in a fog.” -P07

“Things are foggier, difficult to remember.” -P01

Difficulty keeping up a conversation. Four of the eight participants struggled when talking to others, either because they lost their train of thought, couldn’t find the right words to express themselves, or had difficulty processing what was happening in a conversation when multiple people were involved.

“I just trail off, I forget what I say.” -P07

Difficulty multi-tasking. Two participants stated that they could not multi-task as well as they could before.

Poor organization. One participant stated that it was more difficult to stay organized now.

Emotional Impact of Perceived Cognitive Impairment

Participants were often frustrated by frequent experiences of cognitive impairment, especially as they remember that mental tasks did not use to be as difficult. For the participants who had already completed chemotherapy, they were uncertain of how much longer it would be before they felt “back to normal.”

“You think ‘Oh it’s just a little memory loss, it will come back’...even though I haven’t been in chemotherapy, it doesn’t come back. Well my hair came back but it doesn’t come back the way you remember it. You do remember how you were, that part you don’t forget. You do remember...and that’s frustrating too, I almost wish that I didn’t remember how I used to be.” -P04

“I am having lots of trouble remembering certain things as it relates to things at work or at home and in general. It comes and goes even though I am a year into it. Even though I’m almost a year into it and they say slowly but surely everything will come back to how it’s supposed to be, I still haven’t got back to where I was beforehand.” -P05

Awareness of Chemobrain Before Treatment

Participants were asked about any prior knowledge they had regarding either chemobrain or the possibility that they might experience cognitive impairment during or after chemotherapy. Six of the eight participants received warnings from their doctor’s that they may experience cognitive difficulties. Two participants mentioned that their experience of cognitive impairment was worse than what was described by their doctors.

For the six participants who were informed about the possibility of cognitive impairments before chemotherapy, only one participant had a doctor who provided specific suggestions for managing the impairment. This participant’s doctor suggested she write everything down to help her keep track of things she needed to remember. Two participants received suggestions to help manage their perceived impairment after reporting their symptoms. One participant’s doctor recommended that she go to a

cognitive therapist, while another participant's therapist recommended she write everything down and play memory games to mitigate her impairments.

Coping Strategies

The coping strategies used by participants to manage their perceived cognitive impairments were largely self-determined and not suggested by medical professionals. Only one of the eight participants researched “chemobrain” and how to cope with it. Other than that, participants did not specifically search for tools or strategies to cope with their impairments. Instead, they relied more heavily on existing cognitive aids or reminder strategies that had developed prior to chemotherapy. Strategies used by participants to cope with their cognitive impairment can be grouped into five categories:

Immediate task completion. Participants tried to complete tasks immediately when possible. Reducing the time between acknowledging the task and completing it decreased the time the participants needed to hold the task in their short-term memory.

Set a single important place. One participant designated a place in her house to keep important items and reminders from her husband. Checking this place acted as a sort of to-do list, in that the participant could check to see if she had tasks to complete that day.

Help from friends and family. All participants received help from their friends and family to cope with their perceived cognitive impairments. Help from friends and family came in the form of frequent written and verbal reminders, taking notes during doctor's appointments, and checking in with participants throughout the day to see if certain tasks have been completed. Seven participants lived with one or more family members. One participant lived alone, though her daughter sometimes stayed over at her home.

Create reminders. Participants relied heavily on reminders to complete tasks and attend events during the day. Written reminders were the most common type of reminders, though some participants took pictures of items they needed to remember, recorded audio notes for themselves, or arranged items in a way or place that acted as a reminder. Creating a reminder as soon as the task was acknowledged was critical to task completion, as it was unlikely the participant would remember to write down or complete

the task later. As a result, participants had to use alternative methods for creating reminders when otherwise occupied, like when driving. Participants also created cues to remind them of tasks. Examples include setting an event notification on their phone's calendar or arranging items in a way that triggers a memory (e.g. a grocery list placed on top of a purse would remind the participant to go to the grocery store that day).

“If I have an idea or something that I know I don’t want to lose...I know if I don’t get it down right that minute, that in five minutes I might not be able to remember.” -P06

Participants created three types of reminders: events, task, and list reminders. Events were places the participant needed to be at a specific time, such as doctor's appointments or a child's soccer game. Paper calendars, digital calendars, paper planners, and specific apps helped participants keep track of events they needed to attend. Tools used to manage digital calendars included native calendar apps on iPhone and Android, Microsoft Outlook, or Google Calendar. Two participants managed their doctor's appointments specifically using the MyChart app.

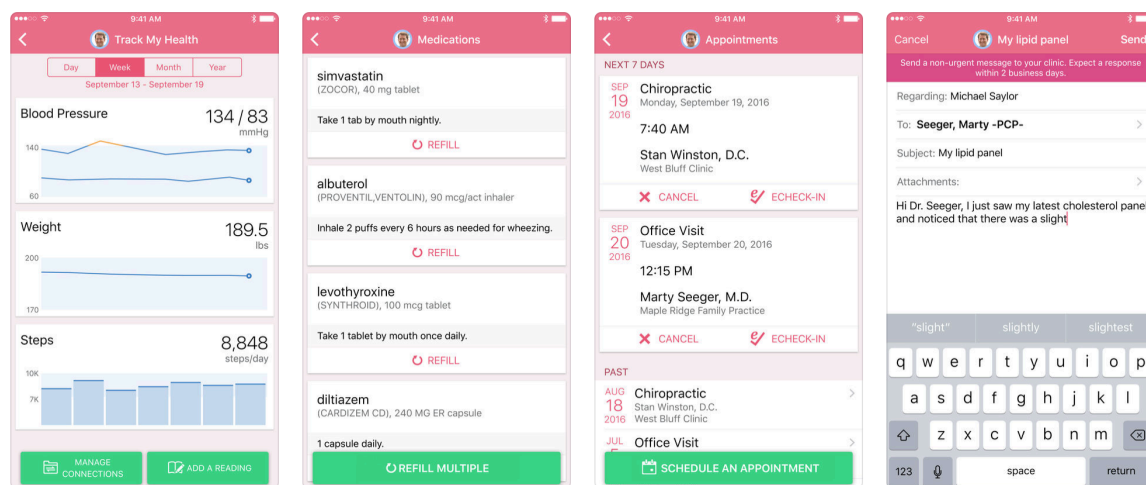


Figure 4: Screenshots of the MyChart app on iPhone (“MyChart,” n.d.).

Tasks represent a single item of work to be done, such as take daily vitamins or pay a bill. Participants used sticky notes, scrap paper, notebooks, logs, planners, texts,

emails, digital pictures, voice memo and note apps native to their smartphone, Microsoft OneNote, and the task feature in Microsoft Outlook to create this type of reminder.

Participants used lists to capture a set of steps needed to complete a single task or to capture a series of tasks that needed to be completed (e.g. grocery list, to-do list).

Participants used scrap paper, notebooks, logs, planners, and note apps native to their smartphone in order to create lists.

Tools Used to Execute Coping Strategies

All participants used a combination of handwritten reminders and digital tools to carry out their coping strategies.

Handwritten reminders. Participants often used multiple types of handwritten reminders in order to prompt themselves to complete tasks and attend events throughout the day. Sticky notes and paper calendars were common handwritten reminders. Three participants kept a notebook on them in which they used to document tasks and to-do lists. Some participants even used scrap paper to create reminders, though these reminders were occasionally lost or misplaced.

Digital tools. Most digital tools used were smartphone apps and features, though some participants used multi-platform tools like Google Calendar and Microsoft OneNote. All eight participants used their smartphone in some capacity to cope with their perceived impairments. These participants often relied on the features and apps that come standard on smartphones, such as:

- Notes app—used to create task reminders and to-do lists
- Text and email—participants texted or emailed themselves reminders
- Calendar app
- Voice memo, and dictation—used to create reminders when driving
- GPS—used to navigate when forgetting the way home
- Timer—used to help set periods of concentration

In addition to default smartphone apps, two participants downloaded the MyChart app on a recommendation from their doctors. The MyChart app was used to schedule and keep track of appointments, though it was also used to view health records and test results, renew prescriptions, and communicate with doctors. Though not directly related

to managing cognitive impairment, three of the eight participants used one or more of the following fitness tracking apps to monitor their diet and exercise: MyFitness Pal, Running for Weight Loss, Fitbit, and Nike+.

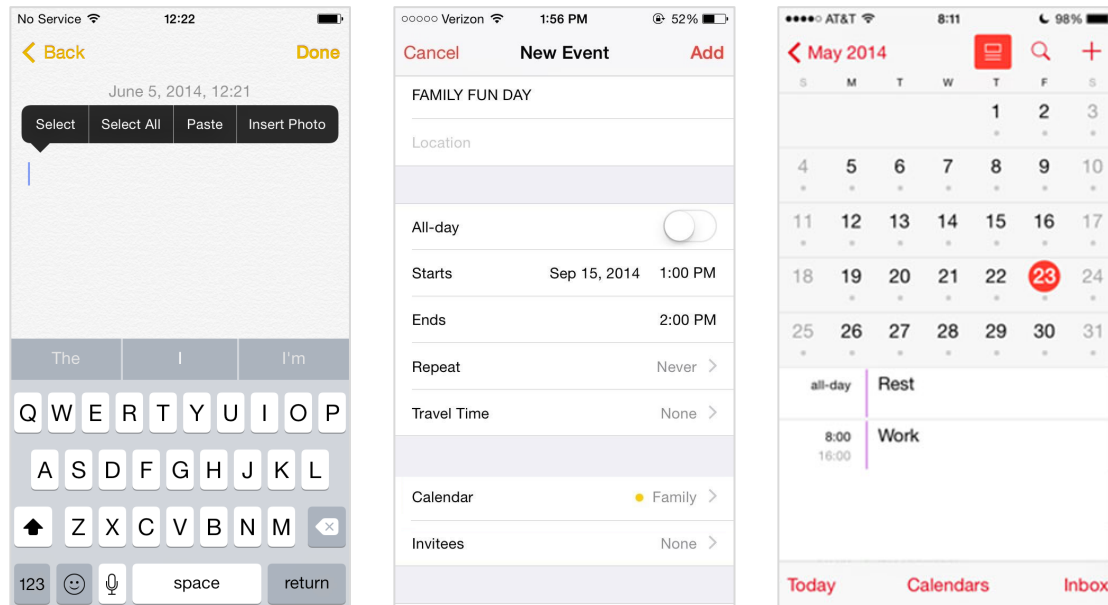


Figure 5: Screenshots of standard iPhone apps used by participants. Notes app (left) and calendar app (middle and right).

Reminder preference: handwritten vs. digital. Preference of handwritten or digital reminders was situational,¹⁴ based on one or more of the following factors: location, type of reminder, convenience, and smartphone familiarity. Participants often used their mobile phone to create reminders when on the go, and used handwritten reminders more when in the home. Some participants relied exclusively on their phone to create event reminders but used notebooks to create task and list reminders. Since participants had to write down reminders as quickly as possible to avoid forgetting, participants often opted for the medium that was closest to them. For example, a participant may choose to write a reminder on a piece of scrap paper if it was closer to her than her phone.

¹⁴ Only one of the eight participants stated a preference for one type of reminder over the other. This participant preferred digital reminders.

Though all participants in the study were smartphone users, smartphone savviness varied within the group. The most mobile-savvy participant worked in the tech industry and used several digital tools on her phone and laptop to manage her cognitive impairments. The least mobile savvy user had just recently started using a smartphone. Participants who were infrequent or unfamiliar smartphone users relied more on paper reminders than digital phone reminders.

Table 2

Tools Used by Participants to Cope with Cognitive Impairment

Coping Tool	Used by how many participants
Calendar app on smartphone	7
Notetaking app on smartphone	6
GPS app on smartphone	6
Paper Calendar	6
Sticky Notes	5
Google Calendar	4
Paper Planner	4
Notebook	3
Email app on smartphone (sends email to self)	2
Text Messages (sends texts to self)	2
Camera on smartphone (take pictures as reminders)	2
Voice memo feature on smartphone	2
Dictation feature on smartphone	2
Microsoft OneNote	1
Timer app on smartphone	1
To-do lists in Microsoft Outlook	1

Habituation of Coping Strategies

Coping strategies were often imperfect, in that instances of forgetting still occurred. The creation of habits to support coping strategies helped participants improve the effectiveness of their reminders.

Checking to-do lists at specific times during the day. Though the use of to-do lists helped participants to remember tasks that needed to be completed, the success of this technique relied on participants remembering to check their list. Checking to-do lists every morning and every night helped some participants to complete all their daily tasks, though fatigue sometimes caused participants to forget to check their list before they went to sleep.

Using a consistent medium for capturing reminders. Participants who created a majority of their reminders on a single medium, such as a phone or notebook, had an easier time keeping track of their daily tasks and events. Participants who used multiple mediums, such as post-it notes, scrap paper, planners, and notebooks had more difficulty keeping track of reminders, resulting in reminders being misplaced, lost, or left at home. Overlapping mediums also caused issues, such as when participants kept multiple calendars. Instances of forgetting occurred when not all calendars were up to date.

“Sometimes I can even write it down and I still don’t remember...sometimes I write it down and I can’t even find the paper I wrote it on.” -P05

Diary Study Part I: Behavior Before the Introduction of ATC apps

The majority of diary entries centered around instances of forgetting items, tasks, or events, though some participants reported instances involving difficulty focusing, concentrating, or holding a conversation.

Impact of Instances of Reported Cognitive Impairment

For most instances, the impact of the cognitive impairment was minor, in that the outcome was mild frustration, annoyance, or inconvenience.

"I was cooking and cleaning out the fridge at the same time and accidentally threw away the cheese and herbs I was going to use in my recipe :(" -P03

"I was late for an appointment because I forgot the time." -P6

A few participants noted more severe incidents, such as leaving the stove on, forgetting to lock the house, and forgetting to take medication, which had the potential to negatively affect the health and safety of the individual. One participant could not remember if she had already taken her medication or not.

Table 3

Diary Study Part I: Self-Reported Instances of Cognitive Impairment

Instance of Cognitive Impairment	# of participants who reported it
Forgot to complete a task	7
Forgot belongings somewhere (e.g. at home, in a store)	6
Misplaced an item	6
Failed to hold information in memory for a short period	5
Forgot about an event	5
Forgot to take medicine	3
Difficulty focusing or concentrating	3
Forgot to turn hot item off (e.g. stove, hair curler)	3
Can't remember words or names	2
Lose train of thought during a conversation	2
Did not know what day it was	2
Could not recall if a task had been completed	2
Forgot what someone had told them	2
Forgot to lock/unlock house	2
Could not recall how to get to a familiar location	1

“So far I've forgot pot on stove.” -P05

“I forgot to close the garage door and the house ended up being open for 4 hours while we were gone.” -P04

I forgot to take my probiotics this morning and now my stomach kills while I'm driving for an hour to pick up my son from camp.” -P04

“I put a pain pill out and put it over where I put my cup on the side of the bed, and I must have took it...I ran around for about 40 minutes looking for it, I still ain't found it. I said god I must have took it but I don't remember taking it. I took my water, all I got is ice in my cup, so I had to have taken it.” -P02

Some participants were impacted financially, have to pay late fees or pay more money to complete a task due to forgetting.

“I forgot to drop off the water bill and had to pay a late fee of \$30 dollars” -P07

“I forgot to sign an important document and it came back to me as being late and now I have to pay a late fee.” -P04

Instances of forgetting also took an emotional toll. Participants were frustrated after instances of forgetting and difficulty concentrating. For one participant, the severity of her perceived cognitive impairment contributed to her feelings of stress and depression. Three participants described family members being annoyed or mad at them when they forgot to do tasks that were expected of them.

“I left my coupons at home and I am just about to lose my mind.” -P01

“I left my hair iron on this morning and my husband got really pissed when he got home :/” -P07

Diary Study Part II: Behavior After the Introduction of ATC apps

Participant Use of the It's Done App

Participants primarily used the It's Done app to create recurring reminders for daily tasks, such as take medication, feed the dog, and water the plants. Two participants used the app to keep track of minor tasks that occurred several times a day, such as locking the doors to the house or car. Medication adherence was the most common use case for the recurring task feature, with seven out of the eight participants creating one or more recurring reminders for their vitamins and medication. Recurring reminders were often created by selecting one of the default/pre-loaded tasks in the It's Done app. Participants also used the It's Done app to create in-the-moment, one-off reminders, such as pick up medicine or pay a bill. One-off reminders were always custom tasks (not selected from the list of pre-loaded tasks) as they were highly specific and situational. Participants only occasionally used the app to create reminders for future tasks and events, such as meetings or appointments. Three participants did use the app to create a reminder for a future doctor's appointment. During the diary study, one participant commented that she could not figure out how to create a reminder for a future event in the app.

"[It's Done] was definitely task oriented, that's something I tend to be weak at, like in life at general, like remember to call to make an appointment, or if I have to call about a certain thing or send in the paper work, or take care of a bill...I set reminders for things like that."-P06

All participants used the "reminder" feature to set a time when a push notification would alert the user to complete the task. Two participants used the "notification" feature, which sends an email or text notification when a task has been completed. These participants used the notification feature to communicate to their husbands that specific tasks had been completed.

Participant Use of the AudioNote App

AudioNote was primarily used to document lists or capture quick task reminders. Creating a grocery list was the primary use case for the app, with four of the eight participants using the app for this purpose. Participants also used the app to document tasks and to-do lists. Lists were created using either the text or audio recording feature. Two participants used the app to record other people talking so they could listen later. Examples of this included recordings of church sermons, conversations, and doctor's appointments. While several participants felt that the recording feature would be useful for recording and taking notes during doctor's appointments, only one participant remembered to do so. Only one participant used the photo feature in AudioNote, which she used to take pictures of the covers of books she was reading. Under the pictures, she would write notes about that book. Overall, participants used AudioNote less than the It's Done app, with some stating they did not have daily need for it.

Post-Diary Study Interview

Perceived Benefits of the It's Done App

Participants had mixed reactions to the It's Done app. Though not all participants found the app to be useful as a whole, individual features were perceived as beneficial, including its recurring tasks feature, default/pre-loaded tasks, push notifications, and the visibility of completed tasks.

The ability to set recurring reminders was particularly helpful, as participants could automate aspects of creating their daily to-do list. Additionally, the recurring task feature expanded the types of tasks participants would traditionally capture using reminders. Previously participants used handwritten and digital reminders to capture one-off tasks, which lead to participants forgetting to accomplish simple tasks that occurred daily, such as locking the door or watering plants. The recurring task feature was particularly useful for daily medication adherence.

"There were a couple reminders to do on a daily basis so it was good to remind me of those." -P04

“This is the most compliant I have ever been in taking my vitamins.” -P01

“It reminds me to check everything. I'd left my car doors unlocked, so it's very helpful when you're not thinking correctly.” -P02

“The It's Done app, I really used it a lot, it really helped me out...some of the things I did daily I would forget so with that app it allowed me to be able to remember so I wouldn't have to be in the situation where I didn't remember.” -P05

The benefit of It's Done's default/pre-loaded tasks was three-fold. Not only did it save participants time when creating a new task, but it also helped them create reminders for tasks they might have otherwise forgotten about, such as taking their daily vitamins. The default tasks also helped participants get started with the app, showing them the types of daily tasks that might be helpful to track.

“I like that it had some suggestions like lock door or lock car.” -P08

“It helped me to come up with more things to kind of put on the list, like simple things that before I thought maybe it was stupid to write even though no one will see my calendar or my tasks, it made me feel like it was ok to write more of those kind of things, and then I started using it more for that.” -P06

“Some of the settings it already had on there like locking the door and taking my vitamins, I never wrote those things down and especially taking vitamins is a good idea, and I always forget to lock the back door...so it helped me remember to do things like that.” -P07

It's Done also helped participants keep track of which tasks had already been accomplished by displaying completed tasks alongside uncompleted tasks. Seeing

uncompleted tasks was a useful feature since prior to the introduction of the ATC apps, participants experienced instances when they could not remember if a task had been completed.

“When I went back in to check something else off I was like oh cool I already did that.” -P01

Push notifications were helpful to participants, especially those who had not previously relied much on their phone for reminders. With push notifications, participants were reminded to complete time-sensitive tasks without having to refer to the full to-do lists. Though only two participants used the feature which notified another person by text or email when a task had been completed, these participants found this feature useful for communicating with her their husbands.

“It was the notification in the it’s done app that helped me because it made me like more responsible.” -P07

“I liked being able to send notifications when it was complete it kind of saves me of having to do an extra step with my husband and letting him know that it is complete... it was more of a job complete feeling than having to report like a little child because of that feature.” -P07

Some participants voiced feelings of safety and assurance, knowing that they could rely on the It’s Done app to remind them of all the things they needed to do that day. The assurance of knowing they will be reminded helped participants free up mental energy, as they knew they did not have to worry or focus on remembering minor tasks.

“I do feel like it has freed up some mental energy...checking things off the list was motivating me to dilly dally less” -P06

“I feel more safe because it helps remember to lock the house, especially on my chemo days when I don’t feel good and don’t feel like doing anything.” -P02

“You can let the app kind of be your brain taking over the little things and your other brain can enjoy life...it was nice not to have to cram my brain with all these other little things, so I can focus my energy and my mind on the bigger things” -P01

“I know I am going to be reminded of everything and won’t neglect anything...I can be assured that I will be reminded.” -P08

Issues with It’s Done App

During the diary study and the final interview, participants reported several issues which made the app difficult and unappealing to use.

Creating a task was cumbersome. When creating a new task, participants are presented with 8 form fields which capture details about the task and allows them to set up notifications. However, for participants wanting to quickly document a task before forgetting it, the eight form fields felt overwhelming. Though not all of the form fields were required, reading through all of the fields felt cumbersome. Additionally, participants felt that the priority and category fields were unnecessary, as none of the participants used them during the study.

“I have a hard time using things like that because even though set up is simple I feel like it takes me a lot of time to input everything...I have to fill all this in and it’s like not a big deal but for some reason in my mind it feels like this huge task so having to select everything every time and what type of reminder, maybe if it was a little more streamlined for me that would be easier to use on the fly.” -P06

“The it’s done app has a few too many things, sometimes I just like to add a quick note and move on, but it takes a little longer to enter.” -P04

“There was too much information to put it in...too many steps and I can’t really see myself having to fill in so many things in order to just put an event in. I also didn’t like too many drop downs in order to add what you want to add...I thought it was easier to add a quick reminder on your phone even.” -P07

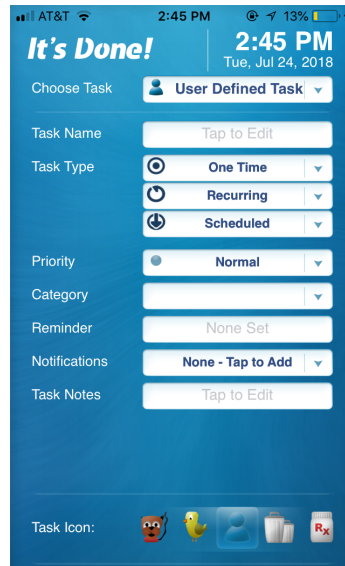


Figure 6: Task creation screen in the It's Done app.

Uncompleted events did not carry over to the next day. Unlike a traditional to-do list, which has a single running list of tasks, the It's Done app creates separate to-do lists for each day. In other words, if a participant did not complete all their tasks on Monday, these tasks would not roll over to Tuesday's to-do list. Furthermore, uncompleted tasks from previous days could not be checked off or moved to a different day. If participants wanted to add an uncompleted task from a previous day to the current day's to-do list, they had to manually re-add it. This created an additional burden on participants and made it more likely for uncompleted tasks to be forgotten.

“You can’t check things off for the previous day. I forgot to check something off but I actually did it and you can’t go back and say oh I did this yesterday...I thought that was really annoying.” -P03

“I wish that the task would carry over to the next day if it is not checked off.”

-P04

“I wish there was a way to go back to the day before and check things off or have an option to carry the task onto the next day. That is what I do with my calendar.”

-P07



Figure 7: Checking off and editing task in the It's Done app ("It's Done!" n.d.).

Creating and viewing reminders for future tasks and events was confusing.

One participant struggled to figure out how to create reminders for future tasks or events. This issue was because the It's Done app distinguishes between a one-time task that occurs on the current day (labeled as a "one-time" task) and a one-time task that is set to occur on a future date (labeled as a "scheduled" task). Participants expected the ability to set a date within the "one-time" task feature, and did not expect they would have to change the task type in order to do this. Additionally, the "scheduled" task type did not immediately resonate as a place to go in order to create a future task or event.

“I thought it was weird the difference between one-time, recurring, and in the future because a scheduled task could be a one-time task in the future, I thought that was really confusing, that's why I had such a hard time with it. You have two

things that do the same thing but one is for right now and one is for the future... You should be able to select and then schedule a task for that date, not select a date and then task type. That was kind of weird.” -P03

Three participants found it difficult to see when these future tasks were set to occur. Participants expected a calendar feature which would allow them to see what days they have tasks on, however they were presented with a native date picker instead (see Figure 8). This interface made it difficult for participants if they did not know the exact date an event was on. For example, if a participant wanted to see when their next doctor’s appointment was, they had to essentially guess what day the event might be on, and use the date picker to select the month, day, and year. Selecting a day would bring them to the to-do list for that day. If the appointment was not on the day they selected, they had to individually check the to-do lists for other days in order to find the next appointment.

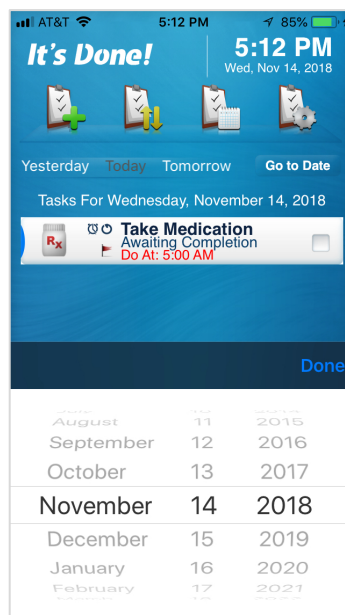


Figure 8: A native date picker appears when clicking “Go to Date.”

“I tried to go to the day I set the appointment for and I don’t think it was showing up and I don’t know where it went...I didn’t know if I had done something wrong...It should have been like a calendar where you add it and you are done, and I would have liked to have seen a format like a calendar too.” -P07

“When I add a note for a different day, it doesn't show so I don't know if it actually is in there. That's pretty frustrating.” -P04

No option to set both an event time and reminder time. Currently, the It's Done app only allows users to select the time when they want to be reminded about a task or event; it doesn't have separate option to capture when the event should occur. While not all tasks need a separate event and reminder times (i.e., medication reminders), others require advanced reminder times to prepare the user for the event. For example, one participant wanted to capture the time of her doctor's appointment while also receiving a reminder the previous day so she could plan the day accordingly. While participants could capture additional details for a task or event using the notes area, information in the notes was not readily visible and more difficult to access. Additionally, long task names were cut off in the daily to-do list view, so participants could not enter the time of the event in the task name field without risking having their text truncated.

“If the it's done app had the option to set multiple reminders...that would make it better...Sending the reminder before the day is important to me, like reminding me I have an appointment the day before instead of the day of, both is ideal for me, so I can't accidentally plan badly.” -P06

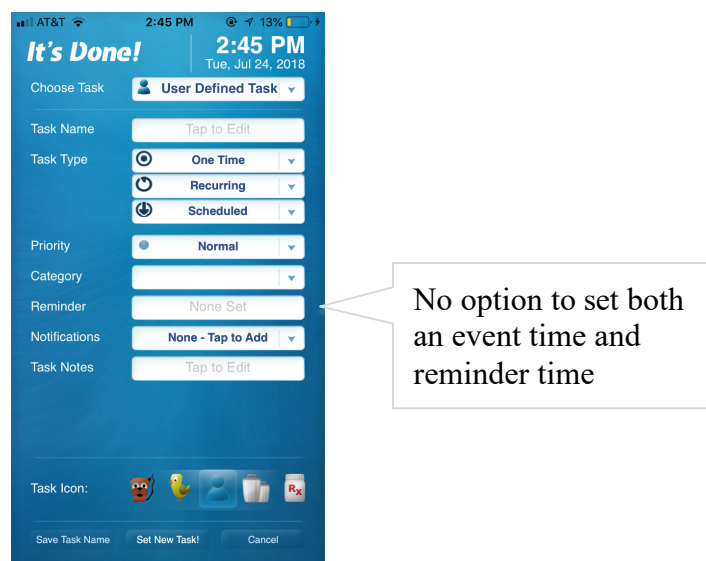


Figure 9: Task creation options in the It's Done app.

Could not “snooze” reminders. Though participants found the push notifications helpful for reminding them to complete a task, participants felt they were likely to forget a task if they did not complete it at the time they were notified. If the push notification occurred when they were busy, participants felt that they would not remember the task later. Participants wanted the ability to “snooze” notifications so that they would receive another reminder later.

“I noticed that if I didn’t complete a task I couldn’t move it to a different day or snooze it, I have to add it in again the next day and I would never want to do that.” -P7

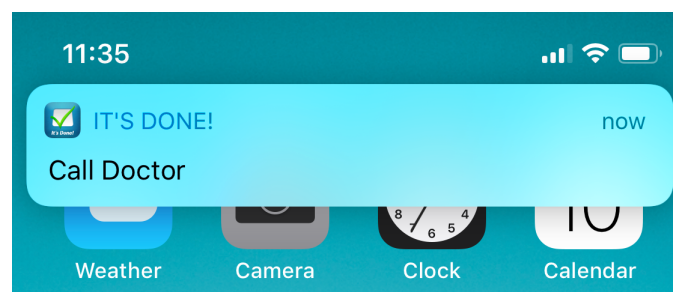


Figure 10: It's Done iPhone notification.

Text in the app was too small. Two participants reported trouble reading the text in the app and wanted the option to make the text size larger.

“The task name field is really small.” -P03

“It’s a little small, I would like for the fonts to be bigger...everything is so tiny, even the drop downs are tiny.” -P08

Overall Impressions of the It's Done App

While the app’s core functionality as a checklist/to-do list helped participants keep track of daily tasks, in the context of their current tool ecosystem, some felt that the app did not create an added benefit. Usability issues made creating one-off tasks

cumbersome and confusing, which meant it was the most suited for daily reminders, which only had to be set up once. However, participants did not want to use multiple apps to capture daily and one-off reminders.

Participants who frequently struggled to remember everyday tasks, such as locking the door, benefited from the use of It's Done. Similarly, those who had previously relied more on paper reminders benefited from It's Done's push notification reminders. Conversely, more mobile-savvy users did not feel like It's Done was worth the effort of using, especially since the standard note and calendar apps on their phone were so simple and easy to use.

"It's Done seems like an overly complicated calendar/checklist... I did like the reminders that came with it though" -P03

"There's things I really like, the different options you have of how you send yourself a reminder and that you can send it to other people but like the interface is sort of funny to me...it didn't feel intuitive for me." -P06

Perceived Benefits of the AudioNote App

The flexibility of AudioNote's note-taking medium made it helpful to some, and difficult to use for others. The ability to write freeform text made AudioNote useful for creating lists and quick task reminders, especially as participants felt that creating task reminders in the It's Done app was cumbersome. Participants tried using the pen feature in the app to create "handwritten" notes in the app, yet they found this feature time-consuming and challenging to use without a stylus.

While not all participants found the recording feature beneficial, those who did enjoyed how easy it made it to create lists and task reminders. For these participants, it was easier to talk than type, especially when tired. One participant commented that the act of speaking her to-do list out loud even helped her remember the tasks later, even without the use of the app.

“For me the convenient part was speaking into the recorder and recording what I needed to say and going back and listening to it. I look for the things that are more easy or more convenient for me because my energy levels are still so low.” -P05

“I really like being able to have the multi-media integrated into the notes, and that makes me want to use it because for some reason it just feels exciting to me...I used it to record things that were interesting and clear my mind of space because I knew things were noted somewhere so I didn't have to be drilling it into myself or trying to remind myself to remember.” -P06

“It allows me to remember what was said by my Dr and any one else. I can use it all my appointments.” -P02

“It was faster and easier for me to record it instead of writing it down or texting it.” -P04

“I used it even more for really quick reminders...I used it in that way instead of making a task because I didn't like the cumbersome feel of the it's done.” -P03

Issues with the AudioNote App

Difficulty using auditory input and output in different environments.

Participants felt uncomfortable creating recordings when other people were around and struggled to listen to recordings when in noisy environments. Additionally, participants did not want to listen to recordings in public without headphones.

“If it's an audio thing I am not going to hit play while I am in the grocery store.” -P01

No dictation feature. In some situations, participants wanted to create reminders in audio form and have them automatically transcribed into text. While creating audio

reminders was sometimes easier than writing them out, it was often easier for participants to refer back to a written reminder.

“I think this app is good for something quick fast and easy. And then the person can go back and write down what they record. I think the app would have been better if while recording it also took the text down in the notepad.” -P05

“I don’t know if I would want to listen to myself in that recording again, like hear the whole thing over again. So that was kind of the issue with that.” -P04

“The one feature I was disappointed of not having which I would have found useful was that you couldn’t even talk into it for it to write out what you wanted to say, you just had to record it. In a text message you can record your voice and send it as a text message so if I am not going to write it out which the microphone allows you to write out the text message, then I really don’t even see a point to it.” -P07

“It would be nice that if you make an audio note if it would transcribe it.” -P08

Forgetting to use the app. Though participants used the app to capture tasks and lists, they sometimes forgot to check the app, leading to instances of forgetting. For example, one participant described creating a grocery list using AudioNote but then forgetting to use the list when she was at the grocery store. With no native alert features such as push notifications, participants needed to have habits for using the app in place in order to use it as an effective reminder tool.

“One time I made a record of things to get at the grocery store but forgot to use it.” -P03

“I used the AudioNote app to write lists down but a lot of times I forgot that I wrote it in there.” -P07

Factors Affecting App Adoption

Overall, participants struggled to use both apps frequently and effectively. In addition to usability issues, several factors appeared to play a part in the lack of app adoption by the participants.

No guidance on how to integrate coping strategies into their daily routine.

Though participants were given a walkthrough of the app's functionality when they first downloaded the app, participants were not provided guidance as to how they should use the app in their daily life. As a result, some participants were left feeling unsure of how to use the app to help them remember. This was especially the case for AudioNote, which had a more open, less directed feel than the It's Done app. Additionally, the It's Done app had task examples that helped participants understand how to use the app and helped give them a jump start on creating daily reminders.

"The app wasn't very necessary. The recording feature was pretty cool but I don't know what I would use it for." -P07

Participants did not develop habits for using the app. Participants did not consciously develop habits around using the apps, and as a result, would forget to use them when appropriate. For example, while participants felt the AudioNote app would be helpful for recording doctor's appointments, they would forget to use the app when at the doctor's office. The need to report back daily on the use or non-use of apps appeared to encourage habitual use among some participants, as did the daily reminders they set up in the It's Done app.

"Remember that I can use them all the time is a conscious effort...I think it would really help me so I want to put myself in the habit of using it. I like the idea of it very much and I think parts of how it functions are really helpful." -P06

The apps were not comprehensive. Participants felt that neither app was comprehensive, with AudioNote lacking a reminder feature and It's Done being too

cumbersome to use for simple tasks. As a result, participants still had to use their own tools to help them remember.

“I wouldn’t want to use two different apps, one for a calendar and one for daily reminders, I would want it all to be in the same app...if it was all done in one app it would be a good feature to have...but the iPhone does have an app like that that comes with the phone too.” -P07

Other apps on their phone were easier to use. Several participants compared the design and functionality of the It’s Done and AudioNote apps to the apps already on their phone. Some felt that the ATC apps were busier and less clean than the calendar and note apps that come standard on their phone. For the AudioNote app specifically, some did not feel that the app was all that different in regard to functionality to the notes app already on their phone.

“[The iPhone calendar] has almost as many options as the It’s Done app but it doesn’t look as busy for some reason that the way that It’s Done looked. I didn’t like that visually because it was so busy.” -P04

“Neither of them had a very pretty or clean UI, that would impact me using them, I don’t like to use software that doesn’t look good or feel fun to use, and neither of them had that. If you think about the note taker app just in your iPhone, it looks clean.” -P03

“The iPhone already has in that system where you can do voice and save the note so I didn’t really see a whole bunch of difference there...I don’t know how much different it would be for me if I got in the habit of using the notes that came with the iPhone.” -P01

Using a phone for reminders is not appropriate in all situations. One participant described that it was difficult for her to take notes with her phone because of how it would appear in meetings, making written notes a better option in that situation.

“It definitely wouldn’t have been appropriate for me to pull out my phone, so I would have used the app a lot more if I was able to use my phone at work.” -P03

Final Survey

System Usability Scale (SUS) Scores

After averaging the SUS scores for both apps, the It’s Done app received a score of 64.06, and the AudioNote app received a score of 70.63 (See Tables 4-7). While SUS scores are generally used as a point of comparison rather than an absolute judgment of usability, research by several scholars has provided insight into the meaning of individual scores.

Sauro (2011) determined that the average SUS score is a 68, having averaged the scores of over 5000 participants across 500 SUS studies. Both ATC apps scored close to this average, with the It’s Done app falling just below 68 and AudioNote just above. Research into acceptability standards of SUS scores conducted by Bangor, Kortum, & Miller (2008) suggests that the It’s Done app has marginal acceptability regarding usability while AudioNote barely crosses the threshold into an acceptable level of usability. Additional research by Bangor, Kortum, & Miller (2009) found that SUS scores correlated with an adjective-anchored Likert scale rating the user-friendliness of the product. Based on the mean SUS scores associated with each point on the adjective-anchored Likert scale, the scores of both ATC apps fall between “OK” and “Good.”

Table 4

System Usability Scale (SUS) Scores for It’s Done App

P01	P02	P03	P04	P05	P06	P07	P08	Mean	SD	95% CI [LL, UL]
100	32.5	32.5	50	90	57.5	57.5	92.5	64.06	26.86	[43.41, 84.72]

Table 5

System Usability Scale (SUS) Frequency of Responses for It's Done App

	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
I think I would like to use this app frequently	1	1	1	2	3
I found the app unnecessarily complex	3	0	0	2	3
I thought the app was easy to use	1	1	0	3	3
I think I would need the help of a technical person to use this app	3	3	1	1	0
I found the various features in this app were well integrated	1	0	2	4	1
I thought there was too much inconsistency in this app	1	4	1	2	0
I imagine that most people would be able to learn this app very quickly	0	1	1	3	3
I found the app very cumbersome to use	2	1	1	4	0
I felt very confident using this app	0	0	4	2	2
I needed to learn a lot of things before I could get going with this app	4	1	0	2	1

Table 6

System Usability Scale (SUS) Scores for AudioNote App

P01	P02	P03	P04	P05	P06	P07	P08	Mean	SD	95% CI [LL, UL]
82.5	87.5	75	45	60	90	32.5	92.5	70.63	22.43	[51.86, 89.39]

Table 7

System Usability Scale (SUS) Frequency of Responses for AudioNote App

	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
I think I would like to use this app frequently	0	3	3	0	2
I found the app unnecessarily complex	4	1	1	2	0
I thought the app was easy to use	0	1	1	3	3
I think I would need the help of a technical person to use this app	4	2	1	1	0
I found the various features in this app were well integrated	0	1	1	5	1
I thought there was too much inconsistency in this app	4	3	0	1	0
I imagine that most people would be able to learn this app very quickly	0	0	1	5	2
I found the app very cumbersome to use	3	3	0	2	0
I felt very confident using this app	0	2	0	4	2
I needed to learn a lot of things before I could get going with this app	3	1	1	2	1

Assistive Technology Quality-of-Life Scores

Seven of the eight participants indicated that using the ATC apps had improved their quality of life in one or more of the following areas (see Table 8).

Safety. Four of the eight participants felt that the apps improved their safety (see Table 8). The one participant who responded that the apps made her feel “a lot more” safe stated that the It’s Done app had improved her safety by helping her remember to

lock her house. Three of the eight participants did not feel that the two ATC apps were relevant to their day to day safety, and responded with “Does not apply.”

Control. Six of the eight participants of the participants felt that the apps provided more control of their daily activities. Interviews with participants suggest this was because the apps gave them the power to better keep track of and remember tasks.

Participation. Most participants felt that the ATC apps did not affect how often they took part in activities they enjoyed, as five of the eight participants selected the “No More, No Less” option, and one participant responded “Does not apply.” However, two participants felt that the apps allowed them to take part in activities they enjoy “a lot more” because the apps allowed them to spend less time and energy on having to remember tasks and more on their friends and family.

Tiring. Four of the participants felt that the ATC apps did not affect how tiring their daily activities were.¹⁵ Two of the participants felt that the apps made their daily activities a little less tiring because they did not have to put as much effort into remembering to complete tasks. One participant felt that using apps made their daily activities more tiring because of how difficult it was to enter tasks into the It’s Done app.

Reliance on others. Five of the eight participants felt that they relied on others less after the introduction of the ATC apps, with two of those five participants stating that they relied on others “a lot less” than before. Interviews with participants indicate this is because the apps provided reminders so that the participants’ friends and family did not have to.

Time. Half of the participant felt that the ATC apps made their daily activities take less time. Interviews with participants indicate this was because they did not have to spend as much time trying to remember all the things they had to do each day. However, one participant felt that the ATC apps made her daily activities take more time due to the time it took to create tasks in the It’s Done app.

¹⁵ One additional participant selected “Does not apply” when asked: “Because you use these apps, how much less tiring is it for you to do your daily activities?”

Table 8

Quality of Life Questions Relating to Assistive Technology Use: Participant Responses

	P01	P02	P03	P04	P05	P06	P07	P08
Because you use these apps, how much safer do you feel when you do your daily activities?	Does not apply	A lot more	Does not apply	No More, No Less	A little more	Does not apply	A little more	A little more
Because you use these apps, how much more control do you have over your daily activities?	A little more	A lot more	No More, No Less	No More, No Less	A little more	A little more	A little more	A lot more
Because you use these apps, how much more often do you take part in activities you enjoy?	A lot more	A lot more	No More, No Less	No More, No Less	No More, No Less	No More, No Less	No More, No Less	Does not apply
Because you use these apps, how much less tiring is it for you to do your daily activities?	Does not apply	No More, No Less	A little less	A little more	No More, No Less	A little less	No More, No Less	No More, No Less
Because you use these apps, how much less do you rely on others in your daily activities?	A little less	A lot less	A little less	No More, No Less	No More, No Less	Does not apply	A little less	A lot less
Because you use these apps, how much less time does it take for you to do your daily activities?	A little less	A lot less	No More, No Less	A little more	A lot less	A little less	No More, No Less	No More, No Less

Note. This questionnaire was modified from the Assistive Technology Quality-of-Life (ATQoL) Scale, which was originally designed to assess the effect of assistive technology on quality of life in surveys of older adults (Agree & Freedman, 2011).

Table 9

Quality of Life Questions Relating to Assistive Technology Use: Frequency of Responses

	A lot less	A little less	No More, No Less	A little more	A lot more	Does not apply
Because you use these apps, how much safer do you feel when you do your daily activities?	0	0	1	3	1	3
Because you use these apps, how much more control do you have over your daily activities?	0	0	2	4	2	0
Because you use these apps, how much more often do you take part in activities you enjoy?	0	0	5	0	2	1
Because you use these apps, how much less tiring is it for you to do your daily activities?	0	2	4	1	0	1
Because you use these apps, how much less do you rely on others in your daily activities?	2	3	2	0	0	1
Because you use these apps, how much less time does it take for you to do your daily activities?	2	2	3	1	0	0

Note. Bolded numbers indicate the median score for that question. Two bolded numbers in the same row indicates that the median exists between these two scores. This questionnaire was modified from the Assistive Technology Quality-of-Life (ATQoL) Scale, which was originally designed to assess the effect of assistive technology on quality of life in surveys of older adults (Agree & Freedman, 2011).

Chapter 5: Discussion

Perceived Benefit of ATC Mobile Applications

Whether it was the cognitive aids already on their smartphone or those introduced during the study, it is clear that participants found value in using ATC apps to cope with their perceived cognitive impairments. The native functions leveraged by the It's Done and AudioNote apps, such as audio recordings and push notifications, helped participants remember daily tasks and supported their cognition in ways that handwritten reminders could not.

While individual aspects of the It's Done and AudioNote apps were perceived as helpful, as a whole these apps were unable to fully address the needs of breast cancer patients with perceived cognitive deficits. Both apps suffered from usability issues which made the apps challenging to use for this audience. Excellent usability is crucial for apps made for those with cognitive impairments, yet AudioNote and It's Done received SUS scores on the lower end of acceptable usability. Additionally, neither app could capture all three types of reminders created by participants, i.e., tasks, events, and lists. For example, the It's Done app was helpful for creating task reminders, but it could not adequately capture lists and events. Conversely, the AudioNote app was well suited for creating lists but lacked the functionality to create event reminders and mark tasks as complete.

Looking at the functions of AudioNote and It's Done that participants found beneficial, we must acknowledge that these features are not unique to these apps. Smartphones come pre-loaded with apps that support cognition in many of the same ways that It's Done and AudioNote do. A combination of the iPhone's calendar, notes,¹⁶ voice memos, and reminder app can accomplish most of what is possible with It's Done and AudioNote.¹⁷ With this in mind, it was not surprising to observe that participants who

¹⁶ At the time the research was conducted, Apple's iOS 8 operating system came standard with a voice recorder app, a calendar app with notifications, and a notes app that could capture pictures and text. Only a few months later, in Apple's iOS 9 update (see Figure 11), the notes app added a checklist and drawing function.

¹⁷ This is not to imply that using multiple cognitive aids is an ideal solution for users with perceived cognitive impairments as the burden of learning, adopting, and checking multiple new apps is high.

habitually used their calendar and notes apps on their phone benefitted less from the introduction of It's Done and AudioNote. On the other hand, those who had previously relied heavily on handwritten reminders appeared to benefit more from the introduction of the ATC apps as it provided them with novel tools for coping with cognitive impairment.

Though It's Done and AudioNote may not be perfect apps for this user group, the benefit of ATC for breast cancer patients treated with chemotherapy is clear. Entries from Part I of the diary study highlight the gap that exists between the needs of breast cancer patients treated with chemotherapy and the strategies they have adopted to cope with their perceived cognitive impairment. ATC apps have the power to not only mitigate instances of forgetting but to reduce the frustration and anxiety that arises as a result of experiencing these perceived impairments, thus improving quality of life.

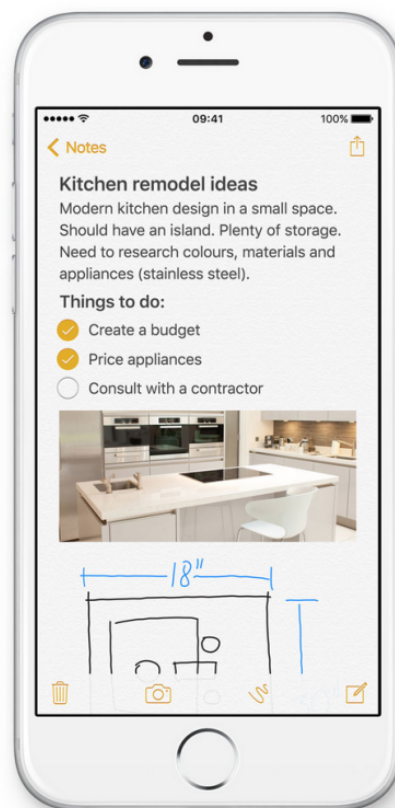


Figure 11: Apple's iOS 9 notes app.

Recommendations for an ATC app Designed for Breast Cancer Patients with

Perceived Cognitive Impairments

Findings suggest that the creation of a single ATC app that combines and improves upon the features present in It's Done and AudioNote would suit the cognitive needs of breast cancer patients undergoing chemotherapy. The following recommendations address the gap that exists between the functionality of the It's Done and AudioNote apps and the needs of participants in this study.

Make the app clean and simple. Visual clutter is difficult to process for users who have struggled with concentration. Streamlining the app experience will help users focus on the elements required to complete their task.

Provide in-app walkthroughs or how-to videos. A walkthrough of the app can help users who struggle with remembering and concentrating to become familiar with the app more quickly. How-to videos can also serve as an example of how the app can be used in everyday life, which may improve app adoption.

Ensure that the app is intuitive. Apps with a steep learning curve are not suitable for this user group as they struggle with remembering and concentrating. Even with an initial walkthrough/how-to video, participants may forget about features that aren't readily apparent or intuitive to use.

Optimize for the creation of all three types of reminders. Users need the ability to easily create three types of reminders: tasks, events, and lists. In this study, standard smartphone apps and the ATC apps used by participants were only suited to create one type of reminder, forcing participants to adopt multiple tools. In order to create a single ATC app that suits the needs of the target audience, the app must contain several features that allow for optimal creation and management of all three reminder types. Specifically, the app should use a calendar feature to create events, a checklist feature for creating and managing tasks, and a multimodal note feature to create lists.

Eliminate unnecessary fields and use progressive disclosure during the task creation process. Reducing the user's cognitive load is essential when designing for a group who may have little time or energy when using the app. Providing users with

advanced task options can support the creation of data-rich reminders that benefit the user later on, however, presenting too many fields at once makes the process of creating a task feel overwhelming and burdensome. To simplify the task creation process, eliminate unnecessary form fields, such as the priority or category fields found in the It's Done app. Then, use progressive disclosure to show only the most critical fields first, with an option to expand the task reminder to include advanced fields if needed. Progressive disclosure will allow users to create quick reminders when tired or on the go, and create detailed reminders when they have more time.

Provide relevant, pre-programmed tasks and events. Allowing users to select from a list of common tasks and events will save them time and effort when creating reminders. Examples of a relevant task for this group may be “take medicine,” while a common event may be a doctor’s appointment. Pre-programmed/default tasks also serve as an example of how the app can be used and may prompt users to create reminders for tasks they may not have remembered on their own. Additional research may be needed to identify common tasks and events for this user group.

Support multimodal notes and reminders. Flexibility of the reminder medium is vital to supporting participants with varying levels of cognitive ability. For example, audio reminders require less time and energy to create than text reminders, however they may not be appropriate to create in certain environments. Photo reminders require the least amount of cognitive effort to create but cannot be edited in the way a text reminder can. Supporting audio, photo, and text reminders would allow users to capture notes in the modality that best suits the information being recorded, their environment, and the user’s current mental energy level.

Additionally, with photo reminders, participants could take pictures of their handwritten reminders, allowing them to store digital and written reminders in a single location. With recorded notes, users could record conversations, lectures, and doctor’s appointments and listen to them later. This would help individuals who feel that they get lost during conversations.

Support location-based reminders and notifications. Creating reminders did not always ensure that a task would be executed, or that a list would be remembered. For example, participants would create reminders to ensure they brought their coupons to the

grocery store, but then would forget to use the coupons at checkout. By associating reminders with a specific location, users could receive contextual notifications that are triggered when they arrive at that location. In the grocery store example, a user could create a “use coupons” reminder and set the location as the local grocery store. When entering the grocery store, the user would receive a notification reminding them to “use coupons” which would allow them to get the coupons out before they forget about them. Location-based notifications would also help users remember to record their doctor’s appointments. Some participants described wanting to record their doctor’s appointments but forgetting to do so when they arrived. If the user created a reminder to record her doctor’s appointment and entered the address of the doctor’s office into the reminder, later she could be sent a notification reminding her to record the appointment when she arrived at the office.

Support dictation, transcription, and handwriting recognition features. The modality that is easiest for a user to create a reminder with (i.e., audio, photo, or text) is not always the easiest for the user to later experience the reminder. For example, while it takes less time and effort to create an audio reminder than a written one, audio reminders cannot be quickly scanned in the way a written reminder can. Dictation and transcription features would allow users to easily create reminders using audio while providing them a textual output that can be quickly read later on. Similarly, intelligent character recognition (ICR), could extract the text from photos of handwritten reminders so that it is editable.

Encourage habit creation through the app. As observed in the research, coping strategies fell short when they were not habituated. To this point, downloading a highly usable ATC app will not help users cope with their cognitive impairments if they don’t develop a habit of using the app. Designing the experience to support habit creation takes the burden of habituating coping behaviors off of the user. According to Nir Eyal’s Hook Model, building a habit-forming product involves leveraging internal and external triggers to encourage the user to perform an action which generates a reward (Eyal & Hoover, 2014).. Then the user must put forth an investment in the product, in the form of additional time, effort, money, data, or social capital. The investment makes the habit loop more likely to occur again, as it can result in a more engaging trigger, a more

exciting reward, or it can make future actions easier to perform. The Hook Model in an ATC app could look like the following: A daily notification reminds users to check their to-do list. When the user checks off tasks on their list, they are rewarded with a celebratory animation. Appealing to users' desire for completion and competence, the app celebrates when all to-do lists tasks have been checked off (Eyal & Hoover, 2014). Users are then given the option to save tasks so that they can be easily re-used in the future.

Support the input of handwritten reminders. The prominence of handwritten reminders observed in participants' coping strategies suggests that it is unlikely that users will rely solely on digital reminders. However, spreading reminders over multiple mediums also made it more difficult for participants to keep track of tasks, events, and lists. Designing the app to support input from handwritten reminders through the use of photos allows users to store all their reminders in one place, even if created on different mediums. Additionally, it may ease the transition into digital reminders for less savvy mobile users.

Support integration with virtual assistants. Virtual assistants allow users to create reminders on their smartphone or smart home devices,¹⁸ even if they are busy with other activities such as cooking or driving. Integration with smart home devices would also allow users to create reminders when they are not near their phone, maximizing the number of reminders that are captured within the app.

Allow friends and family members to share reminders using the app. Participants in this study relied on reminders from friends and family to help them complete tasks throughout the day. While the It's Done app allowed participants to alert their friends and family when a task was completed, the burden to create these reminders was placed solely on the participant. By implementing a feature that allows for the sharing of tasks, events, and lists, the app can spread the burden of reminder creation across the users' support network. Reducing the cognitive burden required to use the app may increase its adoption and ease of use.

Work with medical professionals to recommend the app to their patients. Most participants relied on cognitive aids they used before chemotherapy to cope with their

¹⁸ Examples of virtual assistants include the iPhone's Siri, Microsoft's Cortana, and Amazon's Alexa.

perceived impairments, rather than researching new tools and strategies. As such, it is unlikely that an ATC app designed specifically for breast cancer patients would have even been downloaded by these participants. However, if the medical professionals providing care to these individuals recommended the app, it would increase the app's awareness possibly help adoption; similar to how participants downloaded the MyChart app when instructed by their doctor.

Areas for Future Research

The next step of this research is to design an ATC app for breast cancer patients with perceived cognitive impairments based on the recommendations presented. Since much of the functionality recommended in this research is already present in other standard smartphone apps, the ATC app could leverage APIs and act as a single portal that connects several assistive technology apps on the phone in a more cohesive way. Conversely, the app may need to be built independent of other apps in order to maintain consistency and simplicity. Additional research is needed to understand the technical feasibility and user value of both options. Either way, to ensure that the needs of the audience are being met, iterative testing with the target user group should occur throughout the design process.

Another line of research to explore is the perceived benefit of wearable devices for women with breast cancer who have been treated with chemotherapy. With device proximity being critical to the effectiveness of time-sensitive notifications, wearable devices such as smartwatches can reduce the frequency at which the notification is out of sight or audible range. Smartwatches allow users to view or create reminders without having to find their phone, and tethered smartwatches can alert the wearer when they are walking out the door without their smartphone. Smartwatches also possess features that track aspects of a user's health, such as their heart rate, activity level, and nutrition, all of which may prove beneficial to this target user group.

Chapter 6: References

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Chapter 7: Appendix

Glossary

AT – Assistive Technology

ATC – Assistive Technology for Cognition

ATQoL – Assistive Technology Quality-of-Life (scale)

TBI – Traumatic Brain Injury

MCI – Mild Cognitive Impairment

CRCI – Chemotherapy-Related Cognitive Impairment

M-Health – Mobile Health (in regard to mobile health applications)

PDQ – Perceived Deficits Questionnaire

Participant Demographics

Table 10

Participant Demographic Information

	Age	Ethnicity	Work Status	Chemotherapy Status	Smartphone Type
P01	43	White/ Caucasian	Not currently working	Treated within the last 6 months	iPhone
P02	52	Black/ African- American	Not currently working	Currently in Treatment	Android
P03	28	White/ Caucasian	Working full-time	Currently in Treatment	iPhone
P04	43	White/ Caucasian	Working part-time	Treated within the last 6 months	iPhone
P05	39	African American and Native American	Working full-time	Treated more than 6 months ago	Android
P06	28	White/ Caucasian	Full-time student	Treated more than 6 months ago	iPhone
P07	43	White/ Caucasian	Not currently working	Treated within the last 6 months	iPhone
P08	45	White/ Caucasian	Working part-time	Treated within the last 6 months	iPhone

Personas

The following personas were created based on the findings from the initial semi-structured interviews. Quotes and stories were pieced together from participants to create four personas that are representative of a majority of challenges experienced by the participants as well as the coping strategies used. The personas are intended for use in designing applications to aid the cognition of breast cancer patients undergoing chemotherapy treatment.



Photo by Max Pixel / CC0

"I don't remember anything helpful."

About Robin

Robin lives at home with her husband, 8 year old son, and her sister. Since Robin's husband frequently travels for business, Robin's sister moved in to help her out around the house and babysit her son while she is at appointments. Despite finishing treatment just under six months ago, she still feels that she has significant difficult concentrating and remembering. Though her doctor warned her that she may experience cognitive difficulties both during and after treatment, she never expected it to be as extreme as she has experienced.

Coping Strategies

Written Reminders
Robin's doctor instructed her to write everything down, and so she does. Robin relies heavily on written reminders, and uses calendars, planners, to-do lists, and sticky notes to help her remember. She carries a notebook with her so she can write and remember things when she is out.

MyFitnessPal App
Robin uses My Fitness Pal to track her exercise and stay motivated by connecting with friends on the app. Exercising helps Robin relieve stress. She turned off notifications for this app as they become too "annoying".

Dictated Emails, Texts, and Notes
When on the go, Robin will use Apple's dictation feature to create and then send herself reminder emails or texts. She also started using the dictation feature to create notes on her phone after she found audio reminders too difficult to listen to and use.

iPhone Calendar
Robin likes the iPhone's ability to show a list view of all upcoming calendar events.

Reminders from Family
Robin's husband will write her sticky note reminders and put them on her keys.

Her Daily Challenges

- Struggles to concentrate while driving
- Loses her train of thought often
- Can't multi-task and has a limited attention span
- Becomes fatigued when writing and reading lists/reminders.
- Writes down reminders in so many different places that it is difficult to keep track of all of them.

Robin

Age: 45

Job Status: Previously worked in HR, now is a stay at home mom.

Lives with: Husband, son, sister

Devices used: desktop, laptop, iPhone, and iPad

Use of tech in coping strategies: Robin uses physical written reminders at home, but uses digital reminders when on the go.

Figure 12: Persona #1 – Robin.



"I've been forgetting things more often lately."

Kim

Age: 30

Job Status: Currently working while undergoing chemo

Lives with: Fiancé

Devices used: iPhone, iPad, and laptop

Use of tech in coping strategies: Kim relies heavily on her iPhone calendar synced with her work calendar to keep track of events.

About Kim

Kim is in the "thick" of chemotherapy while balancing wedding planning, volunteering, and her full-time job in the tech industry. Kim has always been a "list person" when it came to staying on top of things. However, now that she is in treatment she realizes that tools she previously used for occasionally reminders (i.e. lists and calendars) are now critical keeping her on track during her day.

Her Daily Challenges

- Forgets what she is saying mid-conversation
- Forgets about plans she has made with friends
- Writes lists (e.g. grocery/pharmacy lists, gifts for people) and forgets them at home
- Difficulty focusing, multi-tasking, and problem solving
- Often late to meetings because she has forgotten about them

Coping Strategies

Written Reminders
Handwritten lists and paper logs help Kim keep track of work activities, wedding planning, and every day tasks. Though she uses a lot of handwritten reminders, Kim also uses Microsoft OneNote to take free-form digital reminders.

Phone Calendar
Since starting chemo, Kim has relied heavily on her phone calendar. Her phone calendar helps her keep track of all her doctors appointments and her volunteering commitments. In addition to putting events directly in the phone, work events are synced on her iPhone through Outlook. Kim also uses a wall calendar at home but she doesn't use her paper calendar as much as the calendar on her iPhone.

Help from Family
Kim finds herself leaning more on other people due to a lack of energy and time. Her fiancé will help remind her of things she needs to do, like take her daily medicine.

Figure 13: Persona #2 – Kim.



Photo by CDC/Judy Schmidt / CC0

Michelle

Age: 50

Job Status: Lost her job as a bus driver due to her illness

Lives with: Daughter and granddaughter

Devices used: iPad, Android phone, laptop

Use of tech in coping strategies: Michelle uses her devices primarily for browsing and social media; not for alerts or reminders.

"Sometimes I don't want to think, my brain comes on in and says I don't want to play."

About Michelle

Michelle is a mother of two and a grandmother of three living in a small town. On top of managing a chronic illness, Michelle was diagnosed with breast cancer this year. She depends a lot on her family members to help her out as her severe fatigue makes every day tasks difficult.

Her Daily Challenges

- Walks into a room and can't remember what she needed
- Writes down what she needs to remember but often can't find the paper she wrote the reminder on
- Has experiences where she knows she needs to do something but can't remember the details, i.e., she knew she needed to download an app but couldn't remember which one
- Has forgotten to take medicine and turn off the stove
- Forgets the questions she wants to ask the doctor when she goes in for appointments

Coping Strategies

Written Reminders
Michelle relies primarily on written reminders as opposed to digital ones. She uses multiple paper calendars as well as sticky notes to help her remember to accomplish tasks throughout the day.

Help from Family
Michelle's family plays a big role in helping her cope. Michelle's sister takes her to the doctor and takes notes during the appointment. Michelle's daughter helps keep Michelle on track, reminding her when it's Sunday so that Michelle can attend church. Michelle describes her granddaughter as her "little helper" because she assists Michelle with minor tasks around the house.

MyChart App
The MyChart app is one of the only instances of Michelle using technology to cope with perceived impairments. Though she can keep track of doctor's appointments with the MyChart app, she primarily uses the app to message her doctor.

Figure 14: Persona #3 – Michelle.




Photo by Max Pixel / CC0

Nadine

Age: 41

Job Status: Taking a leave of absence from her position as a school teacher

Lives with: Husband and son

Devices used: iPhone and laptop

Use of tech in coping strategies: Has begun to use technology with the purchase of her new iPhone, but still primarily uses physical rather than digital reminders

"All day long I forget. Things are foggier, harder to remember. I don't know how anyone could work through this."

About Nadine

Nadine was working as a school teacher when she was diagnosed with breast cancer. Nadine took a leave of absence to undergo treatment and recover from her illness. Nadine has since finished treatment but still feels that her memory is foggy. Her day to day life is filled with doctors appointments, errands (such as grocery shopping and going to the bank), driving her son to different events (such as camp), helping her dad with his business, and going to her personal trainer who specializes in training breast cancer survivors.

Her Daily Challenges

- Forgets grocery coupons at home or forgets to pull them out at checkout
- Occasionally forgets to mail bills
- Struggles to keep track of grants she is applying for
- Forgets grocery lists at home

Coping Strategies

Written Reminders
Paper calendars, sticky notes, paper planners, and to-do lists help Nadine keep track of what she needs to do each day.

GPS
Nadine sometimes struggles to remember how to drive to familiar places, so she uses her iPhone as a GPS system when driving.

MyChart App
Nadine uses MyChart to schedule appointments with her oncologist, review test results, view billing statements, receive health reminders, and exchange messages with her doctor.

Siri / Notes App
When Nadine remembers something while driving, she uses Siri to create notes through dictation. This allows her to safely document a reminder before she forgets it.

Memory Cues
Nadine will leave items in peculiar places or groupings as reminders for herself of a task she needs to complete (e.g. hairdryer near the phone = make hair appointment).

Reminders from Family
Nadine's husband and son frequently remind her of things she needs to do that

Figure 15: Persona #4 – Nadine.

IRB Approval Letter



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March 12, 2015

Caitlin Rinn
Division of Science, Information Arts and Technology
University of Baltimore
1420 N. Charles Street
Baltimore, MD 21201

Dear Ms. Rinn:

This letter serves as official confirmation of the Institutional Review Board's approval of the renewal your protocol for the study entitled "Use of Mobile Assistive Technology for Cognition Applications by Breast Cancer Patients Receiving Chemotherapy," submitted for review on January 28, 2015 and revised February 26, 2015.

The Institutional Review Board reviewed your application via expedited review (Research category #7) and concluded that your protocol poses no more than minimal risk to participants and adequately protects participant confidentiality. As a result, the Institutional Review Board approved your proposal.

Approval of this protocol will expire on March 11, 2016 unless an application to continue the protocol is submitted to the IRB. It is your responsibility to assure that project activities are not conducted past the end date.

Investigators are responsible for reporting in writing to the IRB any changes to the human subject research protocol, measures, or informed consent documents. This includes changes to the research design or procedures that could introduce new or increased risks to human subjects and thereby change the nature of the research. In addition, you must report any adverse events or unanticipated problems to the IRB for review.

If you have any questions, please do not hesitate to contact me directly by phone or via email.

As authorized by P. Ann Cotten, C.P.A., D.P.A.
Chair, Institutional Review Board

A handwritten signature in blue ink, reading 'Jocelyn L. Klucar'.

Jocelyn L. Klucar, CRA
Coordinator, Institutional Review Board

Cc: K. Summers

University of Baltimore
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