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Suvien: Impact, Usability and Effectiveness

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Suvien: Impact, usability and effectiveness

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About the Sheridan Centre for Elder Research

The Centre for Elder Research conducts innovative Lab to Life™ research that enhances the quality of life of older adults while serving as an education and research hub for Sheridan and the broader community.

The Centre for Elder Research was launched in 2003 at the Oakville, Ontario campus of Sheridan College. The Centre has an established track record in applied research and a reputation as a leader that challenges traditional thinking, creating possibilities that transcend historical boundaries.

The applied research conducted at the Centre has contributed to the implementation and evaluation of programming at all levels of society, from the general public, to industry partners, all the way to regional and municipal policy-makers.

Embracing an interdisciplinary approach and, working with faculty and staff from all departments of the college, the Centre is able to directly support the scholarship of teaching and learning at Sheridan, enhancing the student experience and giving all students the opportunity to broaden their horizons through applied research.

Our applied focus, Sheridan's institutional strengths and our strong network of community and industry stakeholders positions the Centre to ensure that knowledge is effectively translated into goods, services, programs and policies that directly benefit older adults and their families.

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Suvien is a new tablet-based app that can display personalized multi-media content to facilitate conversation with an individual who has dementia. The Sheridan Centre for Elder Research, in partnership with the Ontario Brain Institute and the Alzheimer Society of Ontario, conducted a small 6-week pilot study to evaluate the impact, usability and effectiveness of the app on the caregiving process. Participants agreed to use the app over the course of their regular caregiving duties for at least a 2-3 times per week. A total of seven family caregivers (5 female, 2 male) and a program worker who used the app with three older adults attending a day program participated in the pilot. Participants completed pre and post measures about their caregiver experience, their use of technology, frequency and quality of interactions and emotional affect. They were provided with a journal to record their observations. At the end of the 6 weeks participants attended a debriefing interview about their experience with the app. Results showed that the app provided an easy-to-use, accessible and enjoyable conversational tool with potential as a mood changer, a distractor, and a prompt for storytelling. Interface issues identified in the trial were conveyed to the Suvien team for consideration before a public launch.

1. Introduction

1.1. Background

It is well established that the risk of Alzheimer's disease and other forms of dementia increases significantly with age. Currently, the likelihood of developing Alzheimer's doubles about every five years after age 65 (World Alzheimer Report, 2012). According to the World Health Organization (2015), 47.5 million people worldwide are living with dementia, or more than the total population of Canada. Over the next 16 years, if nothing changes, the number of Canadians living with Alzheimer's disease and other dementias will grow to 1.4 million (Alzheimer Society of Canada, 2012).

It is also well documented that family members provide the majority of support and care for people with dementia. Most people with dementia have at least one individual providing unpaid care. Almost half the informal caregivers in Canada (43 per cent) are between the ages 45 and 54, and over 200,000 people providing care are over the age of 75. Primary caregivers are most often spouses (31%) or adult children and in-laws (54%; Statistics Canada, 2008).

Although the caregiving role can be very satisfying for family members it generally becomes increasingly demanding as the disease progresses. Those providing care for individuals living with dementia often have high levels of stress and are at increased risk of health issues associated with the demands of caregiving. Up to 75 per cent will develop psychological illnesses; 15 to 32 per cent will experience depression (World Health Organization, 2012).

While the concerns of caregivers of individuals with Alzheimer's disease and related dementia are similar to other caregivers, there are also specific challenges that are unique to dementia. Dementia-related conditions typically advance through several stages, each with increasing loss of memory, decreasing the individual's ability to think clearly, communicate with others, and perform everyday activities. One of the most distressing symptoms is the progressive loss of the ability to communicate (Alzheimer Society Ontario, 2012).

As the disease progresses and the person with dementia faces growing challenges in communication, conversations eventually lose the 'turn-taking/turn-making' feature of human interaction. Together with the progressive decline in cognitive functions these changes alter the nature of relationships with family and friends. It is not uncommon for others to view the person differently, thinking the disease strips people of their identity or sense of self, often resulting in the assumption that the person is gone. This contributes to the erroneous belief that there is little point in trying to interact with the person. The impact of the social isolation that can occur as a result includes withdrawal, depression, and overall decreased quality of life (Alzheimer Society of Canada, 2012).

Myser (2007) argues that this fading identity needs to be constantly re-constructed and restored with the assistance of caregivers and others in society. Smale and Dupuis

(2004) suggest that it is these emotional dimensions of the disease that caregivers find the most difficult.

A number of interventions to provide education and support for caregivers have been developed but there has been limited research on interventions to enhance communication with people with dementia, in particular, interactions that attempt to engage the person in a meaningful way.

Some studies suggest that reminiscence activities using photo albums, music or artifacts from the person's past can trigger memories and that those remote memories may be used to stimulate interactions. There is some evidence that memories that place value on a person's unique life experience and sense of self can improve mood and some cognitive abilities, such as those used for conversation (Cotelli, Manenti, and Zanetti, 2012; Myser, 2007).

Given the many demands on caregiver time and energies, practical and easy-to-use interventions are needed to stimulate and support conversations with the person with dementia. Electronic devices and applications are increasingly available and with their flexibility and portability, have the potential to provide opportunities to support caregiving.

1.1. Current Project

Having experienced the impact of Alzheimer's disease in their own families, a group of individuals who work in the technology field formed a non-profit group, Suvien, derived from the French word for memory. Recognizing that electronic applications and devices are increasingly available and have the potential to support caregiving, they developed a tablet-based app (currently designed for the Apple iPad) that could curate personalized multi-media content to facilitate conversation with individuals who have dementia. Partnerships through the Ontario Brain Institute and the Alzheimer Society of Ontario led to an informal pilot of the app at adult day programs run by Alzheimer Society Peel. Encouraged by the positive response to their app in the day program the Suvien team approached the Sheridan Centre for Elder Research to conduct a more formal research evaluation of their product. This resulted in the current pilot study conducted by the Sheridan Centre for Elder Research in partnership with the Alzheimer Society of Ontario and the Ontario Brain Institute. This study has been approved by the Sheridan Research Ethics Board.

The specific purpose of this study was to evaluate the impact, usability and effectiveness of the tablet-based app called Suvien on the caregiving process for those caring for an individual with dementia. According to Steve Collins (Suvien, 2014), one of the Suvien developers, the intent of using the app is to "provide familiarity and comfort for the person with dementia, by drawing out memories from their own life history." Caregiver participants in the study were asked to use the app as part of their regular caregiving routine over a 6 week period, evaluate its effectiveness and suggest ways that it could be made more useful for them. The results from this study will be used by the Suvien team to improve the app for a broader public launch.

2. Methodology

2.1. Sample and Procedure

2.1.1. Sample

Participants who were caregivers for older adults with dementia were sent an information flyer (Appendix A) through the Sheridan Centre for Elder Research email database and the database maintained by Acclaim Health Seniors Day Program (located on campus). The first 10 participants who responded were invited to an orientation session. Two participants withdrew before this session due to scheduling issues and another failed to attend. When this latter person could not be reached, one person on the waitlist was contacted and invited to participate.

Additionally a program worker at the Acclaim Health Seniors Day Program used the Suvien app with 3 clients attending the day program. Personal and pre/post data were not collected from those clients but the program worker did participate in one of the debriefing interviews.

A profile of the participants is provided in Table 1. Although this pilot study was small the participants reflect the demographic for caregivers providing care for those with dementia in the Canadian population.

Table 1: Profile of Participants

Caregiver Age/Gender	Care Recipient/Age	Care Recipient Accommodation	Computer Use	Length of Caregiving
56/F	mother/92	on own in home	yes	4 months
62/F	mother/85	with daughter in home	no	20 months
66/F	mother/94	on own in condo	yes	2.5 years
49/F	mother/80	couple in own home	no	3+ years
88/M	wife/82	with spouse in home	yes	5
86/M	wife/74	with spouse in home	no	5+
68/F	uncle/95	retirement home	no	8 years

A total of 7 caregiver participants (female=5, male=2) began the study. They ranged in age from 49 to 88 years of age (average age=68). The care recipients ranged in age from 74 to 95 years of age (average age=86). Two of the participants were providing care for their wife, four were daughters providing care for their mother and one female participant was providing care for an uncle. One of the participants was caregiver for both parents although her primary role for the purpose of this trial was with her mother.

Of the six care recipients who lived in the community in their own home or condo, two lived on their own, three lived with their spouse and one with a daughter. One care recipient lived in a retirement home. There was a variation in how long the caregivers had been providing care, ranging from 4 months to 8 years, with the overall average being 3.6 years. All but one of the community dwelling participants received additional caregiving assistance, primarily from other family members. Five also received

community support services from personal support workers, and/or attended the Acclaim Health Senior Day Program.

Four of the caregivers did not use any technology to assist with caregiving and did not use a computer. Two caregivers made limited use of a computer for email, YouTube videos, iPhoto, slideshows and Facebook. One spouse caregiver was an active computer user of email, Skype, music, medical websites and Facebook. Care recipients had limited or no prior use of technology. One care recipient had used a cell phone and a computer for email but became too frustrated to continue. In spite of their limited use, limited knowledge and insecurities with technology, all participants were very receptive and eager to try the app for this study.

Participants provided a wide range of reasons for their interest in joining the study. These reasons primarily related to enhancing the quality of life for the person with dementia by providing an easy to use tool to stimulate interactions in an enjoyable and positive way. Most felt that their care recipient would be interested. One daughter wrote that it would “make her mother happier and calmer”, adding it could provide “a distraction that brings a positive state of mind”. Three caregivers identified value in the app being able to help others in the future. Two caregivers made reference to the pilot being a way for them to learn to use technology and as a way for them to keep their brain active. Two forecasted that retirement and long term care centre residents would benefit from Suvien since it is simple to set up and use. One identified that gathering multi-media content in one place would be a benefit for many people. One participant credited the cost (free) as a factor.

Participants gave an equally broad list (Table 2) of expected outcomes from the trial. These mostly related to their expectation for positive interactions and connections, being able to provide an activity that would create interest, enjoyment and positive feelings for the care recipients and for the caregiver, and an overall enhanced quality of life. Comments suggested that they expected the use of the app would provide opportunities for meaningful interactions with the person with dementia. It could be inferred from their statements that they were facing challenges with losing an essential component of their relationship with the care recipient.

Table 2: Expected Outcomes from Trial

Mostly adding interest to her day and so improving her quality of life (5)	Something to do when care recipient does not feel like doing anything (4)
Use the app when study ends (2)	Pleasure for me as caregiver
Enjoyment with the increased attention and associated close connection (3)	Spouse would enjoy it, be happier, remember old memories
'Interview' mom about her 'life and loves'	Getting my spouse more engaged, more stimulated
Find out what music she likes and adding that to our list of activities	An app that relates (she likes photo album) to my mom, she would then get enjoyment from the iPad

Before taking the iPad home for the 6 week trial, the participants were asked how they anticipated using the app. Their answers were consistent with those listed above in that they expected positive interactions with the care recipient for themselves and others, including grandchildren and a respite caregiver. One caregiver hoped that using the app would help build a repository of family history to record for future generations. An underlying theme was a desire for connections on an emotional level. Participants wrote of sitting with the care recipient, engaging them with photos and music in order to generate overall good feelings. One participant wrote that she hoped the app could “help turn negative days/moments into positive ones by showing mom her accomplishments and really connecting emotionally”.

2.1.2. Procedure

All participants who responded to the recruitment email were invited to an orientation session with the Suvien team at the Sheridan Centre for Elder Research. In this two-hour session, the project was explained; participants were given a letter of information (Appendix B), provided informed consent (Appendix C) to be part of the project, and completed a series of surveys and assessments. These same measures (described in more detail below) were completed at the end of the project. Participants were also given a journal and asked to regularly write about their experiences using the app. They were provided with journal prompts to guide their entries and the journals were collected at the end of the pilot and reviewed by the researchers. After the 6 week study period, participants were invited to attend a debriefing interview about their experiences with the app.

Participants who agreed to participate in the project were provided with an Apple iPad on loan for the duration of the study. They were asked to collect photos, videos and/or pieces of music that could be uploaded to the app, along with short captions that could serve as conversation prompts. In the orientation participants learned how to upload the content to the app and configure it to suit their needs (please refer to Appendix D for the Suvien user guide document). The Suvien team provided technical support for this process throughout the study while ensuring that all content remained completely private.

2.2. Measures Used

2.2.1. Demographic Survey

This survey collected personal information about the caregiver and the nature of their caregiving relationship including other supports provided as well as questions about their use of technology and their expectations of the study (please refer to Appendix E).

2.2.2. Pre/Post Measures

The pre and post measures included five questions asking caregivers to rate the quality and frequency of interactions with the care recipient, as well as their mood and level of engagement over the previous week using a 5-point scale (please refer to Appendix F). Participants also completed the 20-item Positive and Negative Affect Schedule (PANAS)

to rank their positive and negative affect before and after the 6 week trial by rating to what extent they have experienced certain feelings recently (please refer to Appendix G).

2.2.3. Journal

Participants were given a set of prompts to guide them in the completion of their journal (please refer to Appendix H). Five participants submitted their journals at the end of the trial.

2.2.4. Participant Debriefing Interviews

Each participant was asked a series of questions about their positive and negative experiences with the app (please refer to Appendix I). Participants were also asked for their suggestions about how to improve and to promote the app.

Of the 7 participants (female=5, male=2) who began the study, four caregivers (female=2, male=2) used the app regularly over the 6 weeks, completed the post-measures and took part in an hour long debriefing interview. Observations were also provided by the program worker for three older adults attending the Acclaim Health Seniors Day Program.

Of the three participants who did not fully complete the study, one of the participants who attended the orientation and completed the pre-measures did not use the app because of unexpected personal constraints on her time which limited her caregiving visits. Another factor for her was the lack of Wi-Fi in resident rooms at the retirement home where her care recipient resides. A second participant stated his use was much less than intended due to his unexpected illness during the 6 week trial period. One participant was unavailable to complete the post measures or attend the debriefing interview but brought her journal entries a few weeks after the pilot ended.

3. Results

3.1. Impact

3.1.1. Mood changer/distractor

Although the numbers are much too small for any statistical analysis, there was a slight positive change in the pre and post measures on the PANAS scale. The 20-item PANAS comprises two mood scales, one measuring positive affect and the other measuring negative affect. Each emotion or feeling is rated on a 5-point scale ranging from 1 (very slightly or not at all) to 5 (extremely) to indicate the extent to which the respondent has felt this way in the indicated time frame. Scores can range from 10 – 50, with higher scores representing higher levels of positive affect.

Table 3 compares the overall positive score to the overall negative score for each of the four participants and shows a change in a positive direction for three of the four participants suggesting that their positive feelings had increased by the end of the 6 weeks. A number of journal entries noted how much the care recipient enjoyed looking at the photos and reminiscing even if they did not recognize the images accurately. One

caregiver noted that it was the extra attention and focused interactions that the care recipient was happy about. Both caregivers and care recipients enjoyed listening to the uploaded music and one care recipient sang along with the songs.

Table 3: Calculated Change Score for Emotional Affect (post-positive score minus pre-positive score)

Participant (N = 4)	Pre-positive affect score	Post-positive affect score	Change Score
DAS5	30	38	+8
DAS7	23	26	+6
DAS8	35	39	+4
DAS11	38	35	-3

There was a similar slight positive shift in the nature and frequency of interactions and the care recipient's mood at the end of the trial period. These positive moods are supported by caregiver journal entries when using the app. One caregiver wrote the app was a "Lifesaver!" by providing a "good distraction from an argumentative mood". Another journal entry reported the app was "very helpful to combat boredom." One caregiver summed it up by writing in her journal towards the end of the 6 weeks: "Overall, best used as a mood changer/distractor."

One participant acknowledged the benefit of the app as an easy to use and available distraction when she was exhausted after a restless night with her care recipient. She found she could "use the app to focus attention" so she could just "chime in to prompt and answer questions without having to engage her 100% myself."

3.1.2 Conversational engagement

A recurring theme throughout this pilot was the desire for enjoyable interactions and connections with the person with dementia. Both the journal entries and interview responses indicated that use of the app provided comfort and pleasure for both care recipient and caregiver. Caregivers identified that the photos sometimes resulted in prolonged story-telling and enhanced interaction. One care recipient, who did not usually take the initiative, began to randomly choose a photo to talk about. One caregiver described her enjoyment at "gaining an understanding of the person's thought processes in more detail and depth."

Several caregivers reported that the iPad was more interactive and stimulating than a regular photo album. One caregiver liked being able to "do away with the paper" of a photo album.

One caregiver reported in her journal that throughout the pilot she used the iPad and the app "every time I visited to engage in conversation, twice a week, for about 5 – 10 minutes". On two occasions the conversation extended for over an hour and on a later day for two hours. Over time she noticed her care recipient incorporated the header

phrase from the opening screen of Suvien, “It’s a lovely day” into their regular vocabulary, often greeting people with this expression.

It is to be noted that these positive interactions did not happen every time the caregiver used the app. About the same number of journal entries described times when the care recipient had no interest in using the iPad, or lost interest in a few minutes. The app was another tool in the toolbox of possible interventions for caregivers and they “let it go” when it did not have a positive response.

3.2 Usability

3.2.1 Connectivity and user interface

Several caregivers reported some connectivity issues, particularly when it came to accessing wireless internet. These will likely resolve as consumer demand continues to increase and the Internet is more widely available. Currently Wi-Fi in retirement homes does not extend beyond the public areas of the home. One caregiver whose mother did not have Internet service connected the iPad to the Internet though her cell phone.

All participants reported a number of user interface issues (Table 4). The most frequent one related to the size of the photos, preferring 2 at most per screen (as opposed to the current display parameters that show 6 images at a time).

Table 4: User interface issues

New uploaded pictures were randomly cropped (e.g. cut off at a person’s waist). (One caregiver made a game of guessing who it was.)	Random projection/selection of pictures (more a concern for caregivers but one care recipient wondered what she had done wrong when the photos moved)
Unable to select a specific photo or “go back” to a previous one	Font size not customizable for impaired vision
Difficulty uploading pictures and music, both initially and throughout the trial	Could not access YouTube videos
Inability to adjust size of the pictures – wanted to make them larger on screen	Wanted to be able to toggle between picture and text (or turn text off)
Screen would go black at times for no apparent reason	Care recipients could not swipe across the screen
Wanted to upload digital magazines	Wanted control over the timing
Best to let the care recipient take the lead as pictures popped up randomly	Being able to add text to the video icon to name the video, or add a photo to describe a music file

A number of unexpected outcomes were identified by the caregivers during the debriefing interviews and throughout the journals. Some of these related to the iPad itself. Four caregivers reported awkwardness and frustration with holding the iPad, both for themselves and their care recipients (fingers pushed the “On/Off” button). This seemed to be offset by considerable curiosity and interest about the iPad expressed by

the care recipients as well as other family members. Journal entries noted that as the weeks progressed, care recipients recalled looking at the iPad and the pictures before, and often smiled when the iPad was brought out to use. Several appeared to enjoy the motion of pointing at images in the photos even if they did not recognize the person. The captions were very helpful in prompting memory and keeping focus.

Initially care recipients lost interest in the iPad if the caregiver stopped prompting or left the room. Towards the end of the trial two care recipients initiated using it on their own, requiring only occasional verbal interaction with the caregiver. Others did not initiate on their own even when the iPad was sitting out on the table. Caregivers expressed concerns that the iPad might be damaged inadvertently if left with the care recipient. Some wished for a more durable case and the ability to secure the iPad on a stand.

Only a few additional family members tried the app. Retirement home staff were intrigued but did not use it. It was not clear whether this was lack of time or lack of comfort with the technology. Three caregivers commented that it was rewarding for other family members to watch the care recipient interacting with the iPad.

During the debriefing interview participants offered a number of suggestions (Table 5) to make the app easier for them to use and provided ideas for how to promote it for other caregivers once it is ready for public use.

Table 5: Suggestions for Improvement and Promotion

Being free is a big feature	Promote on Facebook Newsfeed
One large page on the screen grabbed their attention the best	Promote the uniqueness of having three features, i.e. photos, videos and music, making it “One of a kind!”
Provide customized separate albums e.g. when the care recipient is restless, day program staff can play a video or audio of the caregiver to comfort the care recipient	Invite day program staff to include app in their regular program activities and show family members how to use it
Provide ability to customize the tagline “It’s a lovely day.”	Offer to train volunteers and students to use it with residents in retirement homes and day programs
Ability to customize the font size and template	Rather than a collage, have option to display one large photo on screen at a time

3.3 Effectiveness

Although there was variation in how the care recipients responded to the app as well as variation in each individual’s response over the 6 weeks, generally the experience with the app exceeded expectations as recorded by the caregivers in Table 5. When asked to indicate on a scale of 1 – 10, (with a ‘1’ being little or no expectation and ‘10’ being exceeding expectations) to what extent were expectations exceeded or not, the rating for the ‘interactive opportunities’ ranged from 5/10 to 10/10. One caregiver reported his

expectations were a zero before the trial, and that this rose to an 8 after the trial. He was surprised his wife was comfortable using the iPad since she is not familiar with computers.

The ratings on the same 10 point scale for ‘technical functioning’ of the app averaged 5/10. One caregiver noted that “if the technology things are fixed and capacity expanded to include YouTube videos, then Suvien will be the best available”. He added “Even without those fixes it is the best available.”

One caregiver described how her care recipient’s memory was “extended into a time frame or place beyond the specific photos on the screen.” He began to tell stories from the past that she had never heard during 8 years of caregiving. This occurred with daily use of the app throughout the trial period.

Another caregiver reported that “looking at the photos on the iPad triggered lots of stories about the past.” Although this did not happen with every care recipient it seemed that repetition of use of the app over the 6 weeks stimulated conversations for a longer time. Caregivers reported enjoyment in having a deeper connection and opportunity to engage in the ‘turn-taking/turn-making’ feature of conversation.

Another caregiver reported being exhausted after a “rough night and day” and “at her wit’s end trying to connect”. She was thrilled that Suvien “worked” by providing “some pre-bedtime, quiet interaction so the day did not end on a stressful stubborn note.”

No caregivers noted any improvements in performing activities of daily living such as grooming or sleep. One caregiver did record that sundowning behaviours did not happen on days when the app was used in the afternoon. Another caregiver observed the app was “effective to use as a distraction for restless behaviour.”

4. Discussion

This discussion focuses on the feedback presented by the data collected during the debriefing interviews and from reviewing the journals submitted at the end of the pilot. It is important to note that each person’s experience is unique. The changes that occur with dementia can strain relationships and in spite of challenges, each participant conveyed the desire to provide the care recipient with the best quality of life possible.

It has been noted earlier in this report and is worth repeating that the small sample size of this pilot is a limitation in being able to generalize the results. However, small studies can capture a number of specific observations that can be very useful in guiding future research. Small studies can also provide valuable product feedback.

The results from the 5 women and 2 men who completed the trial align with previous work showing that photos, music and videos can trigger memories and promote meaningful, positive conversations between caregivers and care recipients. All

caregivers were eager to participate in this pilot as they saw the potential for using an app like Suvien to enhance the quality of life for themselves and for other caregivers.

All who completed the pilot were diligent in documenting their experiences with the app. Those who did not complete the trial faced unexpected personal and/or technical issues that prevented full engagement and participation. All who participated conveyed that the app was helpful in prompting interactions in spite of any technical problems they experienced. Several pointed out that being able to upload photos, videos and music made Suvien superior to a photo album, and to other apps that only allow one media format.

As dementia progresses there are fewer opportunities for shared activities. Use of the app provided a structured way to connect that did not require a lot of effort from the caregiver. It seemed that regular active engagement with the care recipient and the repetitive structured interactions using the content in the app improved the relevance of the communication, extended the length of the conversation in some cases, and had an overall positive impact by improving mood. For one care recipient who was sad in the weeks following the death of her dog, the family reported that “her mood brightened” when she saw the iPad and the pictures. A number of comments about how experiences with the app exceeded expectations were triggered by an emotional re-connection with the care recipient.

5. Conclusions / Recommendations

In partnership with the Alzheimer Society of Ontario and the Ontario Brain Institute, the Centre for Elder Research conducted a 6-week pilot study to evaluate the impact, usability and effectiveness of a new tablet-based app called Suvien on the caregiving process for those caring for an individual with dementia.

Although the small numbers in this trial do not allow for any statistical analyses, the results are very encouraging in suggesting how an easy-to-use app can provide a positive interaction with the person with dementia. Even if the exchange, prompted by the images or music on a tablet, is simply a distraction, it served to ease the strain of caregiving as it often shifted the mood away from a negative encounter. Over the 6 weeks of the trial there were many examples of enjoyable interactions that, even if brief, gave an opportunity for the participants to connect with the person and not just the dementia. The association between use of the app and mood warrants further study.

This trial demonstrated how a tablet with personalized images, music and videos was used to facilitate conversation and positive interactions with individuals who have dementia. Although there are similar apps on the market, Suvien is currently the only app (to our knowledge) that can be loaded with photos, music and videos. This can offer greater diversity, interest and enjoyment. As the use of apps and tablets continues to grow, it is expected that discomfort with technology and hence hesitation in using the app will diminish.

Given the growing numbers of people with dementia there is clearly a need for more research-based interventions regarding effective approaches to interact with individuals with dementia. The flexibility and portability of the iPad makes it an ideal platform for personalized multi-media content to stimulate conversations with people with dementia. Future studies could explore the impact of regular use of the app over an extended time. Towards the end of this pilot two care recipients picked up the iPad on their own and began to use the app.

Although this study did not measure the stage of dementia it could be assumed that the care recipients were at least in the moderate stage. A research study with people in the early stages to determine how use of the app is impacted as the disease progresses and whether use of the app might slow the disease progression is warranted.

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Appendix A Flyer sent to participants

*An invitation for
caregivers of older adults with dementia
to participate in a study on the
effectiveness of a new tablet-
based application*



WHEN

Orientation session
with Suvien team
5:00 - 6:30 p.m.
Tuesday, March 3, 2015.

WHERE

Orientation session will be held at the
Sheridan Centre for Elder Research
1430 Trafalgar Road, Oakville
Participants will work from home
over the six-week study period.

REGISTRATION DEADLINE FRIDAY, FEBRUARY 24

If you have any questions,
or to register please contact:
Paulina Camino at
905.845.9430 x 8617 or email at
paulina.camino@sheridancollege.ca

The Centre for Elder Research is conducting a six-week study to evaluate the impact, usability and effectiveness of a new tablet-based app called Suvien.

Suvien has been designed for people with dementia and their caregivers to facilitate meaningful conversations. The user can share memories by simply touching a familiar photo to read a caption about it, playing their music, or watching a favourite movie or TV show.

We invite the caregivers participating in the study to personalize the app and use it over the course of their regular caregiving duties as much as possible over a six-week period. At the end of the six weeks, caregivers will be asked to evaluate the app and suggest ways it could be made more useful for them.

An iPad will be provided for use to each participant during the study along with ongoing technical support.

This study has been approved by Sheridan's Research Ethics Board. Participants in this study cannot have participated in a previous Centre for Elder Research study in the last six months.



facebook.com/serclab



twitter.com/sheridanelder



serclab.wordpress.com

Appendix B
Letter of information



Letter of Information
Suvien App Trial

Please read this information form carefully. If you have any questions, please ask a researcher before signing the consent form.

You have been invited to participate in a project to explore the ways that a new tablet-based app could support the caregiving process for those caring for an individual with dementia. This project is supervised by Pat Spadafora, Director of the Sheridan Centre for Elder Research, and Lia Tsotsos, Principal Researcher at the Centre; Susan Pratten, a Sheridan faculty member, is also involved as an associate researcher. This research is being conducted in partnership with the Alzheimer Society of Ontario and the Ontario Brain Institute.

PURPOSE OF THE STUDY

The specific purpose of this study is to evaluate the impact, usability and effectiveness of a new tablet-based app called Suvien on the caregiving process for those caring for an individual with dementia. Caregivers will be invited to personalize the app and use it over the course of their regular caregiving duties as much as possible over a 6-week period. The app is designed to facilitate meaningful conversation with individuals living with dementia, and caregivers will be asked to evaluate the app and suggest ways that it could be made more useful for them. The results from this trial will be used by the Suvien team to improve the app for a broader public launch.

CONFIDENTIALITY

Any information that is obtained in connection with this study will remain confidential. You will never be identifiable based on your data. Your personal data and notes will be associated with a code, which will be stored in a file with only your age and gender. Your consent form and any forms filled out by you will be stored in a secure location that will be accessible by key only to Pat Spadafora, the Director of the Centre for Elder Research, and Lia Tsotsos, Principal Researcher.

PROCEDURE

Suvien is an app that can display personalized multi-media content and can be used to facilitate conversation with an individual who has dementia. Since the content is personalized, as part of this study you will be asked to provide photos, videos and/or pieces of music that could be uploaded to the app; these media items will also require captions to identify them and provide conversation prompts. In a presentation with the Suvien team, you will learn how to upload the content to the app and configure it to suit your needs. The Suvien team will be able to provide support for this process throughout the study, and your photos and videos will remain completely private at all times.

Once you have set up the Suvien app with your personalized content, you will be asked to complete a few brief surveys about your current experience as a caregiver and how you use technology to support your role. This should take less than half an hour. You will then take the Suvien app home on an Apple iPad that will be loaned to you for the duration of the study. (If you have your own tablet, you are welcome to use that instead.)

For the next 6 weeks you will be invited to use the Suvien app as much as possible with your loved one, aiming for at least a 2-3 times per week. The program itself can track or log usage details, such as when you launch the app,

how many times you click on an image, and how long you use it. These will be collected automatically, but you will be asked to keep a log of any notable incidents (both positive and negative) that occur while you are using the app. Notable incidents could include errors or problems with app, limitations that you notice over the course of use, suggestions for functionality you would like to have, examples of the impact the app had on your interactions with your loved one, or examples of the impact the app had on you in your role as a caregiver.

When the 6 weeks are done, you will be invited back to the Centre to return the tablet and submit your log. At this time, you will be asked to once again complete some brief surveys and participate in a short debriefing meeting (either one on one with a member of the research team, or in a focus group, the choice is yours) about your experience over the past 6 weeks. This process will take less than an hour.

After the study is concluded, if you are interested in continuing to use the Suvien app, your profile will be maintained in the system and you can use any personally-owned tablet to continue using it. If you do not wish to continue using Suvien, your personal content will be permanently deleted from the Suvien database.

POTENTIAL RISKS AND DISCOMFORTS

There is the possibility that you may feel uncomfortable answering some of the questions relating to your role and experience as a caregiver, or the nature of the interactions you have with your loved one. You are not required to answer any question if you feel uncomfortable doing so. You may also withdraw from the research project and discontinue use of the app at any time.

POTENTIAL BENEFITS

All participants will have the opportunity to contribute to the improved design of an app that is intended to support the caregiving process. This has the potential to help you in the future or other caregivers who are also dealing with the challenges of supporting someone with dementia. As a result of this work the Alzheimer Society of Ontario will have a better understanding of how technology-based tools can support caregivers.

Participation and Withdrawal

Your participation in this project is voluntary. You are under no pressure to participate in the project, and if you choose to participate you are free to stop at any time, with no penalty to yourself. You may also exercise the option of removing your data from the study.

If you have any questions or concerns about the research, please feel free to contact:

Lia Tsotsos, Principal Researcher, Sheridan Centre for Elder Research
905-845-9430, ext. 2407; lia.tsotsos@sheridancollege.ca

Rights of Research Participants

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study. This study has been reviewed and received ethics clearance through the Sheridan Research Ethics Board (SREB). If you have questions regarding your rights as a research participant, contact:

Dr. Kirsten Madsen, Chair, Sheridan Research Ethics Board
905-845-9430, ext. 2795; kirsten.madsen2@sheridancollege.ca
1430 Trafalgar Road, Oakville, Ontario L6H 2L1

Sheridan

Appendix C
Consent



Consent Form

SIGNATURE OF PARTICIPANT

I understand the information provided for the **Suvien App Trial** study as described herein. My questions have been answered to my satisfaction, and I agree to participate in this study. I have been given a copy of this form.

Name of Participant

Age

Gender

Signature of Participant

Date

SIGNATURE OF INVESTIGATOR

In my judgment, the participant is voluntarily and knowingly giving informed consent and possesses the legal capacity to give informed consent to participate in this research study.

Name of Investigator

Signature of Investigator

Date

Sheridan

Appendix D Suvien user guide



You Will Need:


- ✓ Computer and iPad with internet access
- ✓ Photos, songs, videos that would be of interest to the person with dementia in your care

Preparing Suvien on your computer




To register for Suvien and manage content, please use your **computer**, not your iPad

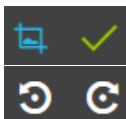
1. Visit <http://test.suvien.com>
2. Click 'Register' on the Sign-In page. Complete the registration form with **your** name and other information.

Adding a Profile

3. Now that **you** have a User ID and Password, click  to add the profile of a person with dementia in your care.
4. Complete the form with **their** information.
5. Click the 'Choose File' button to select a Profile picture for the person with dementia.

Managing Content (adding Photos, Video, Songs)

6. To add photos, click . Follow the prompts. Click 'Continue'.
7. To add videos, click . Follow the prompts. Click 'Continue'.
8. To add songs, click . Follow the prompts. Click 'Continue'.
9. By default, all content has the caption 'Photo', however you can type in a caption for each photo or song.
10. If you wish, you can click a specific photo and use the tools shown below to edit the photo.




to crop the photo, focusing on the part of the photo you like best

to rotate the photo counter-clockwise or clockwise

Inviting Family Members

11. If you wish, you can invite family members to share in Suvien. They will be able to manage content for the person with dementia in your care, and will also be able to launch the Suvien app. Click 'Invite Others' in the menu bar.
12. Type in the email address of the family member and click 'Send Email' to invite them to Register for Suvien.

Launching Suvien on your iPad

13. Touch the Suvien TEST app from your iPad home screen. This will launch the Suvien application.
14. You may notice a brief black screen that says '*Loading Hydrated Application*'. This is normal. If you have options presented, touch '*Update & restart now*'. This is how we will update the application for you.
15. If you have any problems with Suvien, double-click your iPad button  , touch the Suvien app page, and swipe your finger upwards to close the app. This way, you will get the latest updates the next time you start Suvien.

Appendix E
Survey (pre-measures)



“Suvien: Impact, usability and effectiveness”

Thank you for agreeing to participate in this 6 week pilot study to evaluate the impact, usability and effectiveness of a new personalized tablet based application called Suvien.

In order to better understand our findings, we would appreciate it if you would provide the following personal information about yourself and the person for whom you are providing care. We will also ask some questions about your use of technology.

You may choose to not answer any of these questions for any reason, and can stop going through this questionnaire at any time. There are three parts to the survey.

PART A

1) Your gender is:

- Male
- Female

2) The person you provide care to is:

- Male
- Female

3) What is your year of birth? 19 __ __

4) What is the birth year of the person for whom you provide care? : 19__ __

5) What is your relationship with the person for whom you provide care?

- Spouse/Common-law partner
- Adult child (specify whether son or daughter) _____
- Sibling
- Friend
- Other (please specify) _____

6) What is the residence of the person for whom you provide care?

- In their own home (including apartment/condo)
- With you in your home (including apartment/condo)

- Easily attainable
- Enhance quality of life
- Ease of use
- Other: _____

4) Are there any reasons why you choose to not use technology to support your caregiving, or you find technology is not helpful to your situation?

5) Why were you interested in this trial study?

6) How do you intend to use the Suvien app?

7) What outcomes do you expect from this trial?

Thank you for completing this survey.

Appendix G Positive and Negative Affect Schedule (PANAS)

Positive and Negative Affect Schedule

This scale consists of a number of words that describe different feelings and emotions. Read each item and then mark in the appropriate answer in the space next to that word. Indicate to what extent on a typical day you experience these feelings and emotions.

Use the following scale to record your answers:

1	2	3	4	5
very slightly or not at all	a little	moderately	quite a bit	extremely
..... interested	 hostile	 inspired
..... distressed	 enthusiastic	 nervous
..... excited	 proud determined
..... upset	 irritable	 attentive
..... strong	 alert	 jittery
..... guilty	 ashamed	 active
..... scared			 afraid

Watson, D., Clark, L. A. & Tellegen, A. (1988). Development and validation of brief measures of positive and negative affect: The PANAS scales. *Journal of Personality and Social Psychology*, 54, 1063-70.

Appendix H
Journal prompts



Suvien: Impact, usability and effectiveness

Thank you for agreeing to participate in this 6 week pilot study to evaluate the impact, usability and effectiveness of a new personalized tablet based application called Suvien.

In order to better understand our findings, we would appreciate it if you would keep a journal over the course of the 6 weeks. By logging notable events, impressions and outcomes related to your use of the app, you will help us better understand its impact and effectiveness.

If possible, please write a journal entry each time you use the Suvien app (at the very least), but you are welcome to write as much as you would like! Here are some ideas to get you started, but feel free to go beyond these ideas to discuss the things that interest you over the course of this project!

How did you use the app? What was the outcome?

What motivated you to use the app today?

Was the interaction you had today positive? Why or why not?

Have you learned any new strategies for engaging the person you provide care for?

Do you have suggestions for the Suvien developers to improve the app?

Did you notice any changes in their behaviour after using the app?

Did you notice any changes in their activities of daily living after using the app (for example, feeding, toileting, grooming, walking, transferring, etc.)?

Over the course of the project, have you noticed any changes in terms of mood, emotional expression or engagement with the person you provide care for?

Over the course of the project, have you noticed any changes in their sleep patterns?

Are others using the app to support their interactions with the person you provide care for?

Appendix I Sample of post-measures script

Debriefing for Caregiver Participants Sheridan Centre for Elder Research

SCRIPT for Individual Interview

Introductions: *"Hello and welcome! My name is"*

Thank you so much for taking the time to come today and take part in this feedback session. It is very important to the project that we have this opportunity to listen to your experiences and observations about using Suvien over the past 6 weeks. We appreciate your willingness to try the app and to keep a journal of your experiences.

Explain the Purpose:

I will be asking a number of set questions about your experiences. We want to hear highlights of your use of the app, both positive and negative, and any suggestions you may have for the project team. There are no right or wrong answers. In today's discussion feel free to refer to your journal to recall examples.

Explain the Format:

Before we begin, I want to ask you if it is all right with you if Ritu take notes during the discussion. We do not want to rely on memory alone and will refer to these notes to assist with analyzing the data from all the participants. Again, I want to stress that all the information provided is confidential and no identifying data will be included in the project report.

This discussion will last about 30 - 45 minutes. About 10 minutes before the end I will notify you that we are coming to an end. This will give you a chance to share any final comments that you have not had a chance to express, or to ask any questions.

Again we want to thank you for participating.

We know that conversations and connections with people living with dementia can be challenging and that communication is often unpredictable. Each person's response is unique and an individual's ability to benefit depends on many factors. I want to assure you that we have no expectations about your use of the app and what that may mean.

Here is the first question:

Question #1: First, can you describe how the app was used? Were there any patterns?

- regarding when and why you used it,
- who initiated its use,
- did the person with dementia initiate use?
- did other family members or caregivers make use of it, etc.

Question #2: Thinking back to your use of Suvien recall any positive or rewarding experiences that you associate with using the app. If you recall some, can you please describe the most rewarding experience?

Follow-up question: [if needed] Do you want to give another example?

Sheridan Centre for Elder Research

Suvien Report

Question #3 Thinking back to your use of Suvien recall any negative or disappointing experiences that you associate with using the app. If you recall some, can you please describe the most disappointing experience?

Follow-up question: [if needed] Do you want to give another example?

Question #4: Thinking back to your use of Suvien, were there any surprising experiences, either positive or negative? If yes, can you please describe?

Question #5: What do you like the most, if anything, about using the Suvien app?

Follow-up question: [if needed] Is there anything you would like to add?

Question #6: What do you not like, if anything, about using the app?

Follow-up question: [if needed] Is there anything you would like to add?

We are over half way completed. There are 4 more questions.

Question #7: As a caregiver would you recommend this app to other caregivers of family members living with dementia? Why or why not?

Question #8: What advice about promoting the app to caregivers would you give the Suvien developers?

Question #9: Do you have specific suggestions for improving the user experience that have not been mentioned? (i.e. what needs fixing before it goes to market?)

And here is the last question:

Question #10: "If you were to rate your experience with using Suvien on a scale of 1 – 10 with a 10 being it exceeded your expectations and a 1 being it was less than what you expected, where would you place your overall experience?"

Introduce Closure: (10 minutes before end)

We are moving into the end of our discussion. Do you have any questions or additional comments?

Recorder: give a brief summary of the main points.

Do you want to add or clarify any of the points?

Thank you again for participating.