Project Gem: A Teletherapy Platform to Connect Elderly with Family Caregivers

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Abstract

One of the most profound challenges that people face in old age is social isolation. Nearly half of elderly currently live alone or with just a spouse, and elderly who live alone are at increased risk for a number of serious behavioral and health problems including cognitive decline, depressive symptoms, reduced physical activity, and increased chronic disease morbidity. Family caregivers play an inimitably important role in supporting the socially isolated elderly in their families, but their ability to do so effectively is limited by geographic distance and lack of time, relevant resources, and information for caregiving. Additionally, the current SARS-CoV-2 pandemic has further isolated the elderly and placed a greater emotional burden on their families who live apart from them. To address the challenges of social isolation among elderly and empower the families who care for them, we have designed a new social technology platform, *Gem*, to enable family caregivers to provide companionship for the elderly in their families through reminiscence-based teletherapy. Our initial focus is on developing Gem for eldercare centers in Shanghai, where we conducted our field research in early 2020, and plan to expand to other cities in the US and abroad. By providing the infrastructure for families to interact with their elderly through meaningful and evidence-based activities, we plan to connect millions of socially disconnected elderly with their family caregivers around the world.

Keywords

Social inclusion; Elderly; Social Isolation; Family Caregiver; Teletherapy; Reminscence Therapy; Social Technology

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²Taylor is a true believer in cross-disciplinary research and collaboration. She has worked at Harvard's Wyss Institute designing textilebased, lower-extremity exosuits, and at NASA, re-designing intravehicular activity (IVA) apparel for astronauts on long-duration missions to Mars and engineering a cooling device for ballistic vests worn by NASA security personnel. At Harvard, Taylor hopes to continue cross-disciplinary problem-solving to further understand how to translate an idea into a product and improve people's lives.

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A. Background and Summary

Since 2015, my maternal grandmother and I have video called every Saturday evening on Wechat. She is 78 this year, and lives on her own in an apartment complex for elderly veterans in Hubei, China. My grandma is blessed with relative physical health, doing her own cooking and cleaning, but she can't walk around for too long before her knees start hurting. She spends a lot of time at home, where solitude mingles with loneliness. But since she knows how to use Wechat, we can spend an hour or two together in the same virtual space every week: to check in on each other; to see each other's faces; to commiserate about our respective difficulties in life, and try to laugh through them together.

One of the most profound challenges that people face in old age is social isolation. This issue is particularly marked in China, where the proportion of elderly is projected to rise from 12.4 percent of the total population in 2010 to 28 percent in 2040, the latter proportion representing <u>402 million elderly</u> (World Health Organization, 2015). Nearly half of these elderly currently live alone or with just a spouse, and elderly who live alone are at increased risk for a number of serious behavioral and health problems including cognitive decline, depressive symptoms, reduced physical activity, and increased chronic disease morbidity (Lei et al., 2015; Luo & Waite, 2014).

In the past few years, each of us on the team has spent a lot of time thinking about how to support elderly people who are socially disconnected. We sometimes feel futile about the limited face time each of us can have with our grandparents, but nevertheless feel a strong conviction that there are clever solutions to improving social connectedness and quality of life for the elderly vet unexplored. Based on fieldwork we did in January 2020 in Shanghai, we've realized that this sentiment is widely shared by children and grandchildren of socially isolated elderly across China. It is not that family members lack the desire to provide companionship for their parents and grandparents, but rather that they face a number of barriers that make it difficult to do so. One of the most difficult barriers is geographic distance. Due to the pull of higher education and the labor markets away from where their parents reside, adult children often cannot live close to their parents while pursuing their personal goals, and thus cannot easily care for them (Michielin & Mulder, 2007). The second is lack of relevant knowledge and support. Caregiving can be a thankless job, and it can exact a physical and emotional toll on family caregivers that is neither properly recognized nor supported by society (World Health Organization, 2020). Therefore, the most appropriate solution to alleviating the social isolation of elderly will not only provide meaningful connection to family caregivers irrespective of geographic distance, but also support and empower caregivers to provide the best possible care for their loved ones.

With backgrounds spanning the Harvard School of Public Health, Harvard Graduate School of Design, Harvard Paulson School of Engineering and Applied Sciences, and Harvard Medical School, we have designed a new social technology platform, *Gem*, to enable family caregivers to provide companionship for elderly through reminiscencebased teletherapy. The platform is currently being prototyped, and consists of an app and website which presents shared family photos, music, and other media in units called "Gems" to evoke precious memories and experiences that the elderly and larger family share. Gem's design draws from the well-established practice of reminiscence therapy, in which photos, favorite songs, and other treasured objects are used to help individuals recall their personal histories. This form of therapy has been repeatedly shown to improve quality of life, attitudes towards aging, and cognitive function in both cognitively normal and cognitively-impaired elderly (e.g. Lok et al., 2018; Siverova & Buzgova, 2019). In the current pandemic period, with elderly and other immunologically susceptible groups experiencing the brunt of quarantine restrictions, an intervention that connects socially isolated elderly to their families is urgently needed now more than ever before.

B. Gem Design

1. Overview

Leveraging concepts of reminiscence and cognitive behavioral therapy, we've created a web-based platform called Gem. Gem is a "learning by doing" digital activity for family caregivers to do either in-person or virtually with their aging loved ones. The Gem platform accomplishes its goal of connecting socially isolated elderly and their loved ones through four main ways: (1) upskilling and empowering caregivers with methods for interaction and care through reminiscence therapy techniques; (2) enabling communication among family caregivers and promoting active participation in caregiving by providing a shared platform; (3) helping the elderly care recipient strengthen their faculties through reflection and conversations between people and the elderly in their families.

Gem reminiscence therapy facilitates reflecting back on past memories and experiences with other people using tangible prompts such as photos and music to evoke memories and stimulate conversation (Woods et al., 2018). Multimedia that has traditionally been used for the reminiscence therapy includes photos, videos, music, and art (Imtiaz et al., 2018). The remote capability of our multimedia platform is particularly useful if family caregivers are living apart from the elderly care recipient, as well as for the rural populations whose access to eldercare resources are substantially limited.

The namesake of the platform is based on a unit of memory we call a "Gem," which is a multimedia creation centered on family photos narrated with audio recordings from loved ones. Gems can be built in real-time during an in-app video call between the elderly and their family member, and also added to over time by the elderly and any other users in the family unit. To build a Gem, the family caregiver will first upload family photos they'd like to discuss with their elderly to the platform. Once uploaded, the family caregiver can call the elderly person using the in-program video chat. Once they accept the call (potentially with the help of a nurse/aide or staff if they live in assisted living and need help), the caregiver can begin the activity session and flip through old photographs, audio clips that other family members have recorded in response to the photo, and ask different questions related to the photo that might help with recall and trigger meaningful conversations. Users will have the option to record and document their loved one's responses to photos and create "Gems," which can be shared with other family members, friends, and caretakers. Over time, these Gems will create a library documenting different photos throughout your loved one's life. This library doesn't just hold sentimental value, but can also help be an incredibly useful resource for elderly in assisted living by helping their nurses and care staff gain a much deeper understanding of the person they are caring for through bearing witness to precious parts of their lives, and hearing stories from them and their families.



Figure 1. Conceptual process of creating Gems.

2. Product Demonstration of Gem Creation

To illustrate how *Gem* creation works, a step-by-step example excerpted from our prototype begins on the right. This is a photo of one of our families (William's): from left to right are his aunt, great-aunt, and grandmother in an apartment in Hubei, China, in the year 1997. This screen is what his grandmother would see while she is using the platform. The title, location, and time period that the photo is from is shown in the upper left corner in light blue text. The creation process begins by tagging the people in the photo (*Step 1*: Tagging). This can be done by the elderly person themselves, or interactively over an in-app video call with a family member (an option that exists for each step of Gem creation). After tagging, the elderly user is given the option to narrate the photo with their memories and recollections of the event in the photo (Step 2: Recording). In her voice recording on this photo, for instance, my grandmother shared that this is a Lunar New Year celebration in her apartment in Cheliangchang, a neighborhood in Wuhan where railroad workers lived. She recounted that my grandfather had worked in an iron-smelting factory there for several years during the Cultural Revolution period, and it was in this apartment that they raised me in my early childhood. Once the user is done recording, their recollections are saved onto the photo, and they can then choose to share this newly created Gem with other family members (Step 3: Sharing).



Step 1: Tagging



Step 2: Recording (continued on next page)



Step 2: Recording, continued

Xingxing, Mom has shared a Gem with you



Step 3: Sharing

The above screen is what a family member would see when the elderly user shares a Gem. The user can see the photo, read the place and time, listen to their loved one's recorded recollections, and, most importantly, leave audio recordings and comments of their own. For instance, my aunt and my mother can also record their memories of the photo, and together our recordings would constitute a vocal "memory box" for my grandma. After multiple audio channels are filled for each *Gem* on the platform, it will fulfill three critical needs: (1) to enable family members who cannot easily visit to provide a sense of presence and companionship for the elderly in their families; (2) to provide a form of reminiscence therapy that can preserve cognitive function and memory for elderly who are living alone; and (3) to foster meaningful conversations and strengthen the relationships between people and the elderly in their families, even if they are

spatially separated. Addressing these needs is not only important in the context of China's rapidly increasing elderly population, but is also highly relevant to the enormous body of people around the world who have elderly parents and grandparents living on their own. In the current pandemic period, where elderly are experiencing the brunt of quarantine requirements, our mission to connect socially isolated elderly with their family caregivers is more urgent than ever before. In the long term, the UN projects that the number of people aged over 65 will double between 2019 and 2050 to 1.5 billion people, and the need for innovative social technologies to connect elderly with their families will remain paramount. With the support of the Geneva Challenge 2020, we will be able to both create the beta version of our Gem platform and pilot it at eldercare facilities in Shanghai and other cities to test its efficacy. We are hopeful and eager to realize this mission as soon as possible.



"Mature" Gem with audio recollections from many family members



Library of Gems that can be viewed, added to, and played back by the elderly and other family users. Future iterations will integrate music and other media into the creation process.

C. Gem Testing

1. Problem Statement and Project Scope

During our field research trip to Shanghai in Winter 2019-2020, we visited nursing homes, senior citizen universities, and eldercare facilities and conducted interviews with elderly, care recipients, and caregivers. Following the in-depth interviews, we found that elderly in assisted living needed more help transitioning mentally, physically, and socially. Elderly also expressed anxiety about the aging process, loneliness, and reluctance to burden their adult children with their concerns. On the other side, we found that family caregivers face a number of challenges to caring for their elderly, including geographic distance, lack of time, and lack of appropriate eldercare resources and information.

We chose Shanghai as a pilot metropolitan city for our project since the city has a high senior population and is actively exploring ways to address the aging population. Working in Shanghai also enabled us to conduct preliminary field research with the support of Fudan University in China. We were able to visit Shanghai from December 20, 2019 to January 15, 2020, to collect initial data and conduct qualitative studies to deeper understand the context of eldercare there and investigate potential user needs. After finalizing the fully functioning prototype, we aim to conduct a field-testing and impact measurement in China, US, and other countries.

2. Hypothesis

Our hypothesis is that Chinese elderly who regularly use *Gem* will show improved mood, quality of life, and cognitive function at the end of an eight-week testing period compared to those who do not.

3. Specific Aims

Our aims are broadly divided between design and testing phases. We are currently in the design phase, and have already created wireframe prototypes in Adobe XD and Figma (*Figure 2*).



Figure 2. Wireframe prototype in Figma

Specific Aims: Design Phase

Specific Aim I. *Create a MVP (minimum viable product) by September 2020.* Working prototypes have already been created on Adobe XD and Figma, and we are discussing with developers to codify the app and website.

Specific Aim II. *Improve the MVP and create beta platform for testing phase by mid-October 2020.* Since the platform is still in development, there is high potential that we will expand its functionality over the next two months. For instance, our group has discussed incorporating additional interactive elements that would enable the elderly to make recordings to reinforce what they would like to remember about themselves: for instance, foods they like to eat, their fashion sense, their hobbies, and so on. Such elements would not only help elderly preserve their concept of self, but also provide a valuable resource for caregivers and eldercare centers.

Specific Aims: Testing Phase

Specific Aim III. *Distribute the platform to an eldercare facility in Shanghai.* Through our collaborators at Fudan University and Jiangsu Industrial Technology Research Institute (JITRI), we have working relationships with multiple eldercare facilities in Shanghai like Qinheyuan. Our student collaborators at these institutions can help us distribute the platform to elderly, their families, and their caretakers at Qinheyuan or a

similar facility, and train them on how to use it. We would also love to expand to testing in other cities, particularly with the support of the Geneva Challenge.

Specific Aim IV. *Evaluate the efficacy of using Gem on mood, quality of life, and cognitive function over an eight-week period.* The same collaborators aforementioned, in cooperation with caregivers at the facility we select, will help administer tests at baseline and at the end of eight weeks. Specific methodology is described below.

4. Methods

The testing phase will apply widely used and validated metrics to assess mood, quality of life, and cognitive function at baseline and eight weeks. Mood will be assessed by trained facility caretakers using the Patient Health Questionnaire Mood Scale (PHQ-9; Martin et al., 2006); quality of life will be assessed using the Quality of Life Scale (QOLS) described by Burckhardt & Anderson, 2003; and cognitive function will be assessed using the Mini-Mental State Examination (MMSE; NIH, 2006). All assessments are readily available in Chinese, and will be performed at baseline and eight weeks post-intervention. An additional project-specific survey assessing perception of the Gem platform, usage, and constructive feedback will also be administered at the completion of the pilot. Caregivers and our collaborators at Fudan and JITRI will help elderly and their families populate the apps with photos and other media. The patient population to test will consist of ten elderly with normal cognitive function and ten elderly with mild cognitive impairment (MCI) as designated by their medical records, and twenty age- and cognitive status-matched controls.

Trends in the proxy measures of mood, quality of life, and cognitive function described above will be compared within cognitive status groups between those who received the photobook and those who didn't using a two-sample t-test. Regression analysis will be performed on usage as a predictor of each of these metrics. All statistical analysis will be done in Python.

5. Preliminary Testing

Members of the Gem team and our networks have tested the Gem interface and platform with the elderly in our families to great effect and feedback. Below is a screenshot of a session that one of our team members, Taylor, had with her grandmother, who lives apart from her. Her grandmother ended up wanting to continue the Gem creation activity for three times longer than they originally planned (45 minutes), and by the end of the session, her grandmother's mood was greatly improved. Our initial testing has strongly suggested that the Gem platform is well received by elderly, and the "boxes of

memories" generated in the creation process are invaluable to them in times of solitude. As elderly and their families are separated more than ever during the current pandemic, we hope to reconnect them in this memory arena.



Figure 3. One of our team members, Taylor, recounting memories on the *Gem* interface with her grandmother.

D. Timeline

As mentioned previously, working prototypes have already been created on Adobe XD and Figma, and the immediate next step is to codify the app and website into a version we can use for beta testing.

September 2020: create MVP for beta testing Mid-October: create final beta version for testing phase Late-October: distribute platform to collaborators at Fudan/JITRI in Shanghai to test at eldercare centers; potentially test in other cities in the US and abroad Oct-Dec: pilot testing phase Dec-Jan 2021: data analysis and write-up; prepare for public release

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