

Chinese Immigrant Caregivers: Understanding Their Unmet Needs and the Co-Design of an mHealth App

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Article

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Abstract

Background. Immigrant caregivers support the aging population, yet their own needs are often neglected. Mobile technology-facilitated interventions can promote caregiver health by providing easy access to self-care materials.

Objective. This study employed a design thinking framework to examine Chinese immigrant caregivers' (CICs) unmet self-care needs and co-design an app for promoting self-care with CICs.

Methods. Nineteen semi-structured interviews were conducted in conceptual design and prototype co-design phases.

Findings. Participants reported unmet self-care needs influenced by psychological and social barriers, immigrant status, and caregiving tasks. They expressed the need to learn to keep healthy boundaries with the care recipient and respond to emergencies. Gaining knowledge was the main benefit that drew CICs' interest in using the self-care app. However, potential barriers to use included issues of curriculum design, technology anxiety, limited free time, and caregiving burdens.

Discussion. The co-design process appears to be beneficial in having participants voice both barriers and preferences.

Résumé

Context. Les aidants issus de l'immigration apportent du soutien à la population vieillissante, toutefois leurs propres besoins sont souvent négligés. Les interventions médiées par la technologie mobile peuvent promouvoir la santé des aidants en leur facilitant l'accès à de la documentation sur les autosoins.

Objectif. Cette étude a utilisé un cadre de réflexion conceptuelle pour examiner les besoins d'autosoins non satisfaits chez les aidants immigrés de Chine, et collaborer avec eux à la conception d'une application visant à promouvoir les autosoins dans cette population.

Méthodes. Dix-neuf entrevues semi-structurées ont été menées au cours des phases de conception du modèle et de conception collaborative du prototype.

Résultats. Les participants ont fait état de besoins d'autosoins non satisfaits, en citant l'influence de barrières psychologiques et sociales, du statut d'immigré et des tâches d'aidant. Ils ont exprimé le besoin d'apprendre à maintenir des limites saines avec le bénéficiaire des soins et à répondre aux situations d'urgence. L'acquisition de connaissances est le principal avantage qui a suscité l'intérêt des aidants immigrés de Chine à utiliser l'application d'autosoins. Cependant, les obstacles potentiels à l'utilisation de l'application sont la conception du programme, l'anxiété liée à la technologie, le manque de temps libre et le fardeau de la prestation de soins.

Discussion. Le processus de conception collaborative semble être bénéfique dans la mesure où les participants expriment à la fois les obstacles et les préférences.

Introduction

According to an estimate by the United Nations, the population of older adults will double by 2050 and triple by 2100 (United Nations, 2019). As the aging trend continues and accelerates, the growing demand for care services calls for a strong caregiver workforce (World Health

Organization, 2015). In the United States, first-generation Chinese immigrants are one of the largest groups of caregivers who serve older adults who do not speak English as their primary language, or at all (Rich & Hsiao, 2011). Chinese immigrant caregivers (CICs) assist many older adults to age in place (Kuzuya et al., 2011; Moon et al., 2018).

CICs tend to be middle-aged and older adults who are often challenged to take care of their own physical, psychological, and social well-being (Batalova & Zong, 2017; Miyawaki, 2015). Self-care can be a culturally foreign concept for first-generation CICs (Wu et al., 2020). Many CICs are unaware of the need for self-care or even feel unworthy of spending time and resources on caring for themselves (Sethi et al., 2018). Furthermore, fewer linguistically and culturally competent health education materials and services are available for this group due to language barriers and a lack of understanding of this underrepresented group's needs (Koehn et al., 2018; Lai & Suroid, 2008). CICs are less likely than non-Hispanic White caregivers to seek support (Pinquart & Sörensen, 2005). For example, few of them use social services for reducing caregiver burdens, such as respite care and transportation services (Miyawaki, 2015). More physical health impairments were reported in CICs than their non-Hispanic White counterparts (Pinquart & Sörensen, 2005). First-generation immigrant caregivers typically prefer interventions delivered in their native language (Semere et al., 2019). It is therefore critical to develop linguistically and culturally competent self-care interventions to enhance the health and well-being among diverse caregiver groups in North America, including CICs.

The California In-Home Supportive Services allows family members to serve as paid caregivers of older adults (Guerrero et al., 2020). Hence, family caregivers can be paid caregivers. In some cases, nonfamily members, such as close friends, could provide care to older individuals without receiving payment (unpaid). The distinction between family and nonfamily caregivers may not be as clear-cut for CICs. The distinction of family versus nonfamily could play a less significant role in CICs' experience than their shared cultural background and identities (Wu et al., 2020).

Therefore, instead of using the dichotomy of family versus nonfamily caregivers, the current study includes both paid and unpaid caregivers as they can share similar stressors as first-generation Chinese immigrants. Furthermore, paid CICs reported having a close relationship with the care receiver who resembles family relationships (Wu et al., 2020). Cultural beliefs and practice, such as Guanxi (relationships) and Renqing (favour), often motivate the paid caregivers to go beyond their job responsibilities and provide extra support (e.g., driving the care recipient to the airport during unpaid hours) (Wu et al., 2020).

Caregiver Self-Management Program (CSMP) is an intervention that seeks to raise awareness of and facilitate CICs' self-care with a curriculum based on the body–mind–spiritual (BMS) model (Wang et al., 2021). BMS is a holistic health approach that was developed from Chinese culture. It emphasizes the interaction and integration of physical health, mental health, and spiritual well-being. The content was developed with a sequential approach with evidence mapping, needs assessments with community-based organizations, and focus groups with CICs (Chi et al., 2020). For physical health, the CSMP included content on diet and water intake, chronic condition management, medication management, exercise, and sleep. For mental health, the program introduced problem-solving therapy, the caregiver's role and personal boundaries, societal-cultural factors that could affect the caregiver and care recipient's interactions, caregiver

support, and hospice care. For the spirituality domain, mindfulness and breathing exercises were discussed, and participants were asked to keep gratitude journals to reflect on their daily activities. The BMS exercise ties the body, mind, and spirit aspects of the training together. The CSMP intervention program was further evaluated, and feedback was received from 22 CICs (mean age 60.5, 77.3% female, 72.7% paid caregivers) (Wang et al., 2021).

The feasibility of the 4-week in-person CSMP program was pilot-tested with CICs in Los Angeles, California (Chi et al., 2020; Wang et al., 2021). During the in-person training period, conflicting schedules, needs of care recipients, and transportation barriers prevented many potential participants from attending and completing the curriculum (Chi et al., 2020). Delivering interventions through mobile health (mHealth) tools could make them accessible to more caregivers and reduce the barriers of transportation and scheduling (Ploeg et al., 2018; Sherifali et al., 2018). Nonetheless, to the best of our knowledge, no mHealth tools have been developed to facilitate self-care in first-generation CICs.

Developing mHealth tools to deliver self-care interventions is a complex process that calls for a design thinking framework and co-design engagement. The design thinking framework involves empathizing with the users' needs, defining the issues to be addressed, ideating, prototyping the tool, and putting it to test (Chen et al., 2020; von Thienen et al., 2018). Empathizing is the process in which app designers and developers put themselves into the user's perspectives and understand their needs (von Thienen et al., 2018). Defining is the process of abstracting and operationalizing the issues that need to be addressed (von Thienen et al., 2018). Furthermore, in the ideating step, the development team translates the problems and unmet needs into app functionalities and design. Lastly, in the prototype phase, the mobile app is developed and tested (von Thienen et al., 2018).

Co-design goes beyond empathizing with users and speculating on their needs. Co-design engages many stakeholders, such as software engineers, researchers, consumers, community coordinators, or health care providers. Traditionally, only health experts and technology experts were engaged. Researchers have increasingly recognized the importance of engaging potential consumers as early as possible in the mHealth tools design process (Bate & Robert, 2006; Kildea et al., 2019; Rathnayake et al., 2021).

Guided by the design thinking framework, the current study engaged CICs to participate in a co-designed development of a mobile app to deliver the CSMP intervention. This study employed a qualitative approach to examine the current unmet self-care needs of potential users (i.e., going beyond empathize and define). Qualitative methods are suited for this inquiry as it engaged the co-designers to freely express their attitudes, opinions, and provide in-depth feedback to the app design. As part of the co-design process, the feasibility and acceptability of the CSMP intervention with mobile technology were assessed. This article reports two phases of co-designing the CSMP mobile app with CICs: the conceptual design phase and the prototype design phase.

In each of the co-design phases, the research questions (RQs) to be answered are:

1. The conceptual design phase RQ1: What are CICs' unmet self-care needs?
2. The prototype design phase RQ2: To what extent would delivering the CSMP intervention with a mobile app be feasible?

Feasibility is evaluated by identifying facilitators and barriers to the CICs' use of the CSMP mobile app.

Few previous studies had utilized a co-design approach with CICs. The current study adds to the scientific knowledge on the unmet self-care needs of CICs and empirical evidence of applying a design thinking framework with this population.

Methods

Study design

The research team conducted semi-structured interviews with co-designer participants in the conceptual design phase to understand Chinese caregivers' unmet self-care needs and inform potential users of the proposed design of app features. With feedback collected in the conceptual design stage, a prototype of the CSMP app was developed and shown to the participants in the prototype design phase. The prototype design phase focused on examining acceptability and feasibility. Individual semi-structured interviews were conducted to assess the feasibility of using the CSMP app to promote caregivers' health, and to collect general feedback on desirable features of the proposed app design. The study design and procedures (UP-18-00192) were approved by the University of Southern California Internal Review Board.

Description of the CSMP curriculum

The CSMP intervention is guided by the BMS framework (Chan *et al.*, 2002; Lee *et al.*, 2018). There are four modules addressing four aspects of knowledge and skills related to self-care: (a) the role and stress of caregivers; (b) diet, exercise, and healthy sleep; (c) medication management and problem-solving skills; and (d) support system and health maintenance (Wang *et al.*, 2021). The participants were encouraged to complete self-care 'homework', such as excising with instructional videos, and keep a gratitude diary. Details of the curriculum has been documented else (Liu *et al.*, 2020; Wang *et al.*, 2021).

Participants

Participants were recruited from the greater Los Angeles, California. Conceptual design participants were purposefully sampled from the in-person intervention group participants of the previous pilot study of the CSMP in-person intervention (Chi *et al.*, 2020). These former participants had an experience with the CSMP curriculum design. The pre-exposure to the CSMP curriculum prepared the caregivers to be key informants for co-designing the app. Because of the existing rapport between the research team and participants developed during the in-person intervention study, all seven invited participants agreed to continue.

For the prototype design phase, 12 CICs were recruited, including the seven caregivers who participated in the conceptual design phase and five additional caregivers who did not know the CSMP intervention content. Such a hybrid sample design was intended to have the seven conceptual designers to provide experience-based perspectives, and the five newly recruited caregivers to offer fresh ideas for the app design. The five new participants were recruited from the CSMP in-person intervention comparison group. The conceptual design participants were predominantly female paid caregivers. To gain a more comprehensive perspective, the research team purposefully sampled more male and unpaid caregivers in the

prototype design stage. In total, 19 interviews were conducted, including 7 in the conceptual design phase and 12 in the prototype design phase.

Procedures

All interviews were conducted in Mandarin. The participants were assured that the data collected would be confidential. After obtaining informed consent, all interviews were voice-recorded.

Conceptual design phase

An interview protocol was developed by the research team to guide the semi-structured conceptual design interviews. All interviews were conducted in a private meeting room in a senior housing community where the conversations could not be overheard. Two interviewers, a graduate-level research assistant (K.Y.) and a senior scientist (S.W.), attended each interview session. Neither knew the participants ahead of time, one interviewer mainly asked questions, and the other took notes. Participants were referred as 'co-designers' and were informed that their feedback was essential for constructing the proposed app. The participants were first asked to share their previous experience using mobile technology. Then, the participants described any scenarios in which he/she would like to find self-care knowledge and external caregiving help. Potential functions of the CSMP app, including learning the CSMP curriculum, content searching, video coaching, in-app messaging, and tracking health behaviours, were discussed with caregiver participants. Caregiver co-designers communicated what app functions they would like to see. Each interview took about 2 hours and participants received a \$150 gift card upon completing the conceptual design sessions. Data collection for the co-design phase took place from March to April 2018.

Prototype design phase

The research co-designers created an app prototype incorporating the conceptual co-designers' feedback balanced with the researchers' expertise on self-care and mobile app design experience. The CSMP app prototype was structured similarly to the in-person intervention, including four-course modules and 'homework' activities. The first prototype session showed the participants what the actual app's interfaces would look like. However, the users could not use the app on their phones in the prototype design phase.

Each subsequent prototype design session included two parts: an hour-long individual app prototype testing session and an hour-long post-testing semi-structured interview. The interviewers were graduate-level research assistants. In the app testing session, during the first 30 minutes, the participant was asked to navigate the app independently, and two interviewers observed and took notes without interrupting the participant. In the next 30 minutes, the participant was instructed to use various functions of the app. In the interview session following the app testing, the participants were asked to express their opinions about the app and provide suggestions for app design improvement. Upon completing each activity (i.e., app testing and the interview), each participant was compensated with a \$75 gift card for their time and input. The prototype design phase was from April to June 2019.

Data analysis

All interview recordings were transcribed verbatim, and interviewer field notes were also included in the analysis. Two trained

independent coders conducted thematic content analysis with the 19 transcripts using QSR International's NVivo 12 software. All of the design phase transcripts were coded by two coders (K.Y. and H.J.). For the conceptual design phase, the coding process was inductive, and themes and subthemes emerged from participants' narratives. Two coders met weekly to discuss and resolve differences in coding. The codes were organized to address the research objectives of better identifying CICs' unmet self-care needs to co-design the CSMP app.

For the prototype design phase interviews, the coding was both deductive and inductive. Initial codes were generated from the interview guide. Two coders (K.Y. and H.J.) read through the transcripts to identify novel codes that were not included in the interview guide. K.Y. and H.J. independently coded half of the transcripts ($n = 6$). The extent of overlap among coders was determined considering the uniformity of the transcripts (Potter & Levine-Donnerstein, 1999). The codes were compared, and disagreements were resolved in the research team's weekly meetings. Upon reaching an agreement, the codes of each independent coder were reconciled. The NVivo's built-in coding comparison function was used to calculate the inter-coder kappa. After about 4 weeks of training and code comparison, K.Y. and H.J. reached an overall interrater reliability (Cohen's kappa) of 0.82, suggesting good consistency between coders, they continued to code the other half of the transcripts on their own. The coders continued to regularly discuss any quotations that could not be categorized into existing codes. Themes and subthemes were generated from condensing and summarizing the codes. The transcripts were analysed in Chinese. After the themes were finalized, the authors translated example quotations into English. Participants' sex, age, payment status (paid/unpaid), and whether they had previous experience with the in-person CSMP were provided for the selected quotations. The findings were sent to the participants for confirmation and additional comments, if any (Birt et al., 2016). The entire research team reviewed results and came to consensus on any ambiguous points.

Results

Sample characteristics

Table 1 presents sample characteristics by study phases. The age of the 12 co-designers ranged from 50 to 90 years. All the conceptual designers were female, about 57 per cent had above high school level of education. Most of the conceptual co-designers were caregivers who were paid for their work. Only one participant had lived in the United States for less than 10 years. Among the five newly recruited prototype co-designers, one was male. Out of the total 12 participants who attended prototype design sessions, about half of the caregivers were unpaid caregivers. On average, newly recruited prototype co-designers were older, had higher levels of education, and lived in the United States for a longer period than caregivers who participated in both conceptual and prototype design phases.

RQ1: What are the unmet self-care needs of CICs?

Most of participants' unmet self-care needs emerged in the conceptual design phase. The CIC reports led to three subthemes under the theme of barriers to self-care: psychological barriers, challenges faced by immigrants, and work-related restrictions. Besides barriers, CICs also described their wishes for app functions that could be helpful for them.

Table 1. Sample characteristics of conceptual and prototype design participants*

Variables	Conceptual design ($n = 7$)	Prototype design ($n = 12$)
	n (%)	n (%)
Age**		
<60	1 (14.3)	1 (8.3)
60–69	4 (57.1)	4 (33.3)
70–79	2 (28.6)	3 (25.0)
≥80	0 (0.0)	4 (33.3)
Sex – female	7 (100.0)	11 (91.7)
Education		
High school or less	3 (42.9)	5 (41.7)
Above high school	4 (57.1)	7 (58.3)
Payment status		
Paid	5 (71.4)	6 (50)
Unpaid	2 (28.6)	6 (50)
Years residing in the US		
<10	1 (14.3)	2 (16.7)
10–20	4 (57.1)	4 (33.3)
>20	2 (28.6)	6 (50.0)

*The two phases have overlaps of participants. All seven conceptual designers participated in the prototype design phase. The other five prototype design participants were naïve with respect to the CSMP app design concepts.

**Age ranged from 50 to 90 years.

Theme 1: Barriers for conducting self-care

Subtheme 1: Psychological and social barriers

CIC participants described psychological and social barriers, including lack of caregiving boundaries, reluctance to ask for help, and ignoring their own emotional needs. For instance, one caregiver participant described a care recipient who considered her a 'servant'.

Paid caregiver participants indicated it was difficult to keep boundaries between their work and personal relationships with the care recipients. As a result, they often took on extra work under the pressure of social desirability. For example, one participant gave the care recipient free rides to the airport, not only because she hoped to maintain a good relationship with the care recipient but also because she worried the care recipient had no one else to seek assistance from if she said no. The blurred boundary of the caregiver–care recipient relationship could be a barrier for caregivers to conduct self-care.

Our jobs are meant to assist older adults to live lives with dignity. However, some people treat us like servants. (62, female, paid caregiver, participated in the in-person CSMP)

When the caregivers themselves needed help, some participants said they did not want others to know about their issues. It seemed like a 'bad idea' for them to show weaknesses.

Many Chinese people are restrained. It seems almost like a bad idea to let others know about things that happened to you. (72, female, unpaid caregiver, participated in the in-person CSMP)

CICs hesitate to trouble other people. Despite experiencing many of the reported stressors, Chinese caregivers said they were likely to ignore their emotional feelings. They reserved negative emotions to themselves and were unlikely to seek professional help.

Chinese people tend not to take psychological self-care seriously. I thought taking care of others was my job, and I take care of my family too. It is my duty. I ignored my own feelings and emotions. (74, female, paid caregiver, participated in the in-person CSMP)

Subtheme 2: Challenges faced by immigrants

Language barriers and unfamiliarity with the welfare system not only prevented participants from access to the services from which they could benefit, but also led to a tendency of losing existing supports as a result of confusion in communication. These barriers add extra difficulties for self-care. For example, one participant's health care plan was suspended due to miscommunication caused by language barriers.

Sometimes I tell people that I am 'blind,' 'crippled,' and 'deaf.' Because I don't drive, I am 'crippled.' I cannot read in English or understand English in daily conversations, so I am 'blind' and 'deaf.' Language barrier is a huge problem for me. (68, female, paid caregiver, participated in the in-person CSMP)

A lot of unfamiliar things to deal with. For example, my Medicare plan was stopped because I needed to pay a fee. I asked a staff at the Social Security Administration. Someone told me I don't have to pay for the fee because I will be eligible for Medicaid. I don't need to pay the out-of-pocket as long as I have Medicaid. So, I did not pay the fee and lost the Medicare plan. (68, female, paid caregiver, participated in the in-person CSMP)

Subtheme 3: Work-related restrictions

Many participants worked with more than one older adult care recipient. Working long hours left them with minimal time for self-care. Furthermore, caregivers described themselves as independent contractors. Without a managing party to monitor and advocate for their benefits, some caregivers did not get to take off public holidays. One participant expressed frustration in not having another person to substitute for their job even when they did not feel well.

Eleven hours on Mondays, Wednesdays, and Fridays... Eight hours on Tuesdays, Thursdays, and Saturdays. ... So, I treasure the only day off very much. People asked me to do more cleaning work on Sunday. I said no. I cannot take more work. (63, female, paid caregiver, participated in the in-person CSMP)

We don't have sick leaves. In fact, we don't even get to take public holidays off. (63, female, paid caregiver, participated in the in-person CSMP)

Theme 2: Preferences for app functions

Subtheme 1: Provide training for both caregivers and care recipients

In the conceptual design phase, the participants communicated their desired app functions. One participant commented on the importance of mutual understanding between caregivers and care recipients. Therefore, she wished the older adults who receive care

could have education on the boundaries between a caregiver and a care recipient.

Could you please inform the care recipients of how (the caregivers) care for them? They might need to learn too. (63, female, paid caregiver, participated in the in-person CSMP)

Subtheme 2: Responding to emergencies

Another participant conveyed the need to learn about responding to emergencies because she had panicked during an urgent incident. This was a suggestion for adding more intervention content about responding to emergencies.

It is practical to learn about handling emergencies. It is useful. (74, female, unpaid caregiver, participated in the in-person CSMP)

Subtheme 3: Engaging design

One unpaid caregiver participant expressed their wishes of an app design to be engaging and fun.

Short movie clips could be attractive. It would be even better if (the app) having stories. (72, female, unpaid caregiver, participated in the in-person CSMP)

RQ2: Feasibility of delivering the CSMP intervention with mobile apps

Theme 1: Facilitators for using the CSMP app – gaining knowledge

Gaining knowledge was the main benefit that drew CICs' interests in using the CSMP App. Many caregiver participants stated that the content itself was the most attractive element of the CSMP App.

People can be empowered by knowledge. I will definitely be happy to use the App. An hour is no problem. I will find time to learn. Why? It is helpful for me, for others, and even for the next generation. (81, male, unpaid caregiver, new to CSMP content)

The content is valuable for both caregivers and care recipients. I need to manage my own health before I can take care of the patient. A caregiver is not competent without health care/dietary knowledge. I can find useful information with the CSMP App and search for more practical knowledge. (68, female, paid caregiver, participated in the in-person CSMP)

Theme 2: Barriers for using the CSMP app

Subtheme 1: Time restrictions and sense of burden

However, some participants said they did not have time to use the app, which could be because the current curriculum design is not attractive to them. The participants said 'not everyone is a good student', suggesting that she viewed the intervention as a course. Another participant expressed similar feelings and commented the course like format could become a burden to her, like extra work.

I don't have a lot of time, and personally speaking, not everyone is a 'good student.' (68, female, paid caregiver, participated in the in-person CSMP)

Honestly, I don't want to have one more responsibility. Studying is good. However, if this (CSMP app) is like coursework, I think it is a little burdensome to me. (82, female, unpaid caregiver, new to CSMP content)

Subtheme 2: Technical issues

Not all caregiver participants were tech-savvy. Technical issues could become a barrier to using the CSMP app for those who were not comfortable with using technology.

It is not that I am not interested. First of all, I have technical questions. If I cannot open the app, I cannot stick to the training. Secondly, learning on the app is not an urgent matter, which could be delayed if I chose not to ask for help immediately. (68, female, paid caregiver, participated in the in-person CSMP)

Theme 3: Fit between the person and the technology

One participant commented on the 'fit' between the app design and the users' educational background and openness to learn new knowledge. The fit between the person and the app design could affect the acceptability and intention to use the CSMP app.

I like it, but I am not sure if this is for everyone.... It could depend on one's educational background and if he/she likes to learn new things. Some people don't like to be bothered to learn. (83, female, unpaid caregiver, new to CSMP content)

In sum, the CICs identified three types of barriers to conducting self-care, which included psychological and social barriers, challenges faced by immigrants, and work-related restrictions. They recommended providing education to the dyad of caregivers and care recipients, adding educational materials on reacting to emergencies, and making the app design engaging with movie clips and stories. Learning about self-care is the driving motivator for the CICs to use the CSMP app. Nonetheless, they suggested that constrained time and unfamiliarity with technology can prevent them from adopting this tool. The fit between technology and person was critical for developing an effective intervention.

Discussion

In this study, CICs engaged in the co-design of a mobile app developed from a design thinking framework for their self-care. Participants communicated their unmet self-care needs mainly in two aspects: barriers for self-care and preferences for the CSMP intervention content and app functions. The three aspects of self-care barriers correspond with the three facets of CICs' identities: first, the participants grew up with and were deeply influenced by Chinese culture; second, as immigrants, they struggled to adapt to the social environment in the United States; and third, providing personal care to older adults set restrictions to their self-care opportunities.

CICs reported psychosocial barriers for self-care, including lack of boundaries, reluctance to ask for help, and low awareness of the necessity of self-care, especially caring for one's emotional well-being. Chinese culture emphasizes respecting seniors (Filial piety) and prioritizing interpersonal relationships (Guanxi) over personal feelings, which makes it difficult for caregivers to say no to older adult care recipients (Guo et al., 2019; Lin et al., 2015). Various considerations, such as affection, traditions, and meeting interpersonal expectations, motivate CICs to be filial (Hsueh et al., 2008). However, the sense of filial piety could change depending on the caregivers' level of acculturation. Discrepancies in the filial expectations between the caregiver and the care recipient have been reported to be associated with poor psychological outcomes for

the caregivers (Guo et al., 2019; Liu et al., 2019). For the employed caregivers, filial piety and Guanxi made it difficult for them to keep professional boundaries (Chen & Chen, 2012). For unpaid caregivers, self-sacrifice inclinations could add to caregivers' burden. A systematic review has shown that culturally tailored interventions are more effective in promoting self-management among Chinese immigrants in the United States (Huang & Garcia, 2020). These culturally specific stressors need to be featured in self-care interventions for first-generation CICs.

Seeking help is not easy for many caregivers; yet, it can be especially challenging for immigrant caregivers who are not familiar with the social service and welfare systems in the United States (Haralambous et al., 2014). A study in Canada reported barriers for Chinese immigrants to access social services, including language barriers, long waiting lists, complicated procedures for accessing services, and discomfort in asking for help (Lai & Surood, 2008). The current study with U.S.-based CICs echoes with the existing literature: the participants work long hours without work-related benefits. Caregivers who had no access to supportive and educational services and fewer respite hours report worse psychological outcomes (Campioni & Zebrak, 2020). Lacking boundaries compounded with reluctance to ask for help tends to result in a high level of psychological distress (Wong, 2007). Mental health and psychological well-being, as culturally 'foreign' concepts for Chinese communities, are unlikely to be considered and addressed (Masuda & Boone, 2011; Wynaden et al., 2005). The findings of the study contribute to the knowledge on the influence of the intertwined cultural, immigration-related, and occupational factors on self-care behaviours of the population.

Besides the many-faceted self-care barriers, CIC participants articulated preferred intervention content and mHealth app functions. Caregivers who were less appreciated by the care recipients were more likely to report unmet needs (Campioni & Zebrak, 2020). Many participants suggested that it is important yet challenging to communicate with the care recipients. Hence, they wished there could be an intervention program to increase care recipients' awareness of the quality of their relationships with the caregivers. Communication with care recipients is part of the CSMP curriculum. However, the current intervention is focused on promoting caregivers' health. Training care recipients is out of the scope of the current program, but it is worth considering to adopt a dyadic approach in future interventions with this population. In our study sample, family caregivers tended to be older themselves. The tasks of caregiving, especially responding to emergencies, can be stressful. They can feel more helpless because they are not familiar with the health care systems in the United States and have language barriers. Many of the participants expressed the need to learn how to handle emergencies. Given this unmet need expressed in the conceptual design phase, the research team developed a list of emergency resources and translated them into Chinese to be included in the CSMP app prototype.

Many caregiver participants have already been using mobile phones, which laid the foundation for delivering the CSMP intervention via the co-designed app. Participants had various opinions towards adopting the CSMP app to learn about self-care. While some participants considered the content to be beneficial, which motivated them to use the CSMP app, other participants expressed potential technical issues as a barrier, time as a boundary, and burdens as a concern. Participants mentioned the 'fit' between the intervention and the propensity of the user. In this study, older CICs reported more concern about the potential burden of using the CSMP app than younger participants. The senior technology

acceptance model states that older adults often perceive less technology self-efficacy and more anxiety than their younger counterparts, which could affect their acceptance of technology (Chen & Chan, 2014). Facilitating conditions for Internet use among Chinese older adults include increased access and availability, technical support, and reducing the cost (Pan & Jordan-Marsh, 2010). In order to encourage older Chinese caregivers to adopt mHealth tools for self-care, merely providing access to the CSMP app might not be enough. Offering technical and interpersonal support might help to reduce technology anxiety and promote self-efficacy.

Previous research studying caregivers' unmet needs have focused on challenges and barriers. However, the positive side, that is, what support the caregivers wish to have, has been less understood. The design thinking guided co-design approach includes the caregiver in the early stages of app design and encourages the caregiver participants to voice their needs. Participants wished the curriculum and app could be more fun and engaging, for example, by including short movie clips and using a story-telling approach. The research team plan to revise the delivery of the CSMP intervention to include more multimedia content and add interactive features to the CSMP app in the future research stage.

Very few behavioural health intervention programs have been designed and culturally tailored for CICs. With the continued trend of population aging and the increasing Chinese immigrant population, it is of both clinical and policy importance to study the unmet needs of this group. The current study is one of the first empirical research that adopted a co-design approach to qualitatively understand the CICs' unmet needs, design an mHealth tool, and the efficacy of the intervention to be tested in future randomized clinical trials. Furthermore, the intervention has the potential to be adapted to serve immigrant caregivers from other Asian countries. The BMS model has been shown to be culturally competent for other Eastern Asian cultures. The CSMP program could be developed to be an evidence-based practice for addressing caregiver burden and promoting self-care.

Some limitations should be noted in interpreting and applying findings in this study. First, unpaid caregivers were underrepresented in this sample in the conceptual design phase. The study sample was overrepresented by paid female caregivers. The findings could be biased towards this group. Second, the findings in this study might not be generalizable to CICs outside metropolitan areas in the United States, where the supportive services available to caregivers could be very different. Third, the heterogeneity between paid and unpaid caregivers, plus having a small convenient sample, might introduce bias to our study findings. The assessment of CICs' needs and mHealth feasibility testing need to be replicated with more CIC study participants with thoughtful sampling methods. CICs are active globally, supporting the older adult population aging in place. Future research could explore and examine the unmet self-care needs of CICs within diverse societal contexts. More culturally competent mobile technology intervention tools need to be developed to support this group to manage physical health and psychological well-being. The interviews were conducted over 5 years ago. The self-care needs of CICs can evolve over time, especially considering the changes brought by the COVID-19 pandemic. Future studies could consider re-evaluating caregivers' needs with more recent data.

In conclusion, the current study employed a co-design approach to emphasize with CICs' lived experience, define the unmet self-care needs, ideate and prototype the CSMP app, and tested the feasibility (i.e., barriers and facilitators) for CICs to adopt the tool.

Many caregivers have already adopted mobile technology and could envision learning with the CSMP app daily, which indicates some feasibility for delivering the intervention using the co-designed app. Designing the app to be engaging and fun appears necessary for attracting a broader spectrum of users from the targeted population. CICs, including paid and unpaid caregivers, are a diverse group with distinctive unmet self-care needs and various preferences for mHealth tools. The co-design process appears to be beneficial in having participants voice both barriers and preferences. Researchers who aspire to develop self-care mHealth interventions for CICs might consider adopting a design thinking guided co-design approach.

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References

- Batalova, J., & Zong, J. (2017). *Chinese immigrants in the United States*. <https://www.migrationpolicy.org/article/chinese-immigrants-united-states>.
- Bate, P., & Robert, G. (2006). Experience-based design: From redesigning the system around the patient to co-designing services with the patient. *Quality and Safety in Health Care*, 15(5), 307–310. <https://doi.org/10.1136/qshc.2005.016527>
- Birt, L., Scott, S., Cavers, D., Campbell, C., & Walter, F. (2016). Member checking: A tool to enhance trustworthiness or merely a nod to validation? *Qualitative Health Research*, 26(13), 1802–1811. <https://doi.org/10.1177/1049732316654870>
- Campione, J. R., & Zebrak, K. A. (2020). Predictors of unmet need among informal caregivers. *Journals of Gerontology: Series B*, 75, 2181–2192. <https://doi.org/10.1093/geronb/gbz165>
- Chan, C., Ying Ho, P. S., & Chow, E. (2002). A body–mind–spirit model in health. *Social Work in Health Care*, 34(3–4), 261–282. https://doi.org/10.1300/J010v34n03_02
- Chen, E., Leos, C., Kowitt, S. D., & Moracco, K. E. (2020). Enhancing community-based participatory research through human-centered design strategies. *Health Promotion Practice*, 21(1), 37–48. <https://doi.org/10.1177/1524839919850557>
- Chen, K., & Chan, A. H. S. (2014). Gerontechnology acceptance by elderly Hong Kong Chinese: A senior technology acceptance model (STAM). *Ergonomics*, 57(5), 635–652. <https://doi.org/10.1080/00140139.2014.895855>
- Chen, X.-P., & Chen, C. C. (2012). Chinese Guanxi: The good, the bad and the controversial. In *Handbook of Chinese organizational behavior: Integrating theory, research and practice* (pp. 415–435). Edward Elgar Publishing. <https://doi.org/10.4337/9780857933409.00030>
- Chi, I., Liu, M., & Wang, S. (2020). Developing the Asian Pacific Islander caregiver train-the-trainer program in the United States. *Journal of Ethnic & Cultural Diversity in Social Work*, 29(6), 490–507. <https://doi.org/10.1080/15313204.2018.1656906>
- Guerrero, L. R., Eldridge, C., & Tan, Z. S. (2020). Competency-based training for in-home supportive services providers of consumers with ADRD. *Gerontology & Geriatrics Education*, 41(1), 121–132. <https://doi.org/10.1080/02701960.2019.1658579>
- Guo, M., Kim, S., & Dong, X. (2019). Sense of filial obligation and caregiving burdens among Chinese immigrants in the United States. *Journal of the American Geriatrics Society*, 67(S3), S564–S570. <https://doi.org/10.1111/jgs.15735>

- Haralambous, B., Dow, B., Tinney, J., Lin, X., & Blackberry, I. (2014). Help seeking in older Asian people with dementia in Melbourne: Using the cultural exchange model to explore barriers and enablers. *Journal of Cross-Cultural Gerontology*, *29*(1), 69–86. <https://doi.org/10.1007/s10823-014-9222-0>
- Hsueh, K.-H., Hu, J., & Clarke-Ekong, S. (2008). Acculturation in filial practices among U.S. Chinese caregivers. *Qualitative Health Research*, *18*(6), 775–785. <https://doi.org/10.1177/1049732308318923>
- Huang, Y.-C., & Garcia, A. A. (2020). Culturally-tailored interventions for chronic disease self-management among Chinese Americans: A systematic review. *Ethnicity & Health*, *25*(3), 465–484. <https://doi.org/10.1080/13557858.2018.1432752>
- Kildea, J., Battista, J., Cabral, B., Hendren, L., Herrera, D., Hijal, T., & Joseph, A. (2019). Design and development of a person-centered patient portal using participatory stakeholder co-design. *Journal of Medical Internet Research*, *21*(2), Article e11371. <https://doi.org/10.2196/11371>
- Koehn, S., Baumbusch, J., Reid, R. C., & Li, N. K. M. (2018). 'It's like chicken talking to ducks' and other challenges to families of Chinese immigrant older adults in long-term residential care. *Journal of Family Nursing*, *24*(2), 156–183. <https://doi.org/10.1177/1074840718774068>
- Kuzuya, M., Hasegawa, J., Hirakawa, Y., Enoki, H., Izawa, S., Hirose, T., & Iguchi, A. (2011). Impact of informal care levels on discontinuation of living at home in community-dwelling dependent elderly using various community-based services. *Archives of Gerontology and Geriatrics*, *52*(2), 127–132. <https://doi.org/10.1016/j.archger.2010.02.016>
- Lai, D. W. L., & Suroid, S. (2008). Service barriers of Chinese family caregivers in Canada. *Journal of Gerontological Social Work*, *51*(3–4), 315–336. <https://doi.org/10.1080/01634370802039650>
- Lee, M. Y., Chan, C. C. H. Y., Chan, C. L. W., Leung, P. P. Y., & Ng, S.-M. (2018). *Integrative body–mind–spirit social work: An empirically based approach to assessment and treatment*. Oxford University Press.
- Lin, X., Bryant, C., Boldeiro, J., & Dow, B. (2015). Older Chinese immigrants' relationships with their children: A literature review from a solidarity–conflict perspective. *Gerontologist*, *55*(6), 990–1005. <https://doi.org/10.1093/geront/gnu004>
- Liu, J., Wu, B., & Dong, X. (2019). Psychological well-being of Chinese immigrant adult-child caregivers: How do filial expectation, self-rated filial performance, and filial discrepancy matter? *Aging & Mental Health*, *24*, 489–496. <https://doi.org/10.1080/13607863.2018.1544210>
- Liu, M., Jiang, T., Yu, K., Wu, S., Jordan-Marsh, M., & Chi, I. (2020). Care Me Too, a mobile app for engaging Chinese immigrant caregivers in self-care: Qualitative usability study. *JMIR Formative Research*, *4*(12), Article e20325. <https://doi.org/10.2196/20325>
- Masuda, A., & Boone, M. S. (2011). Mental health stigma, self-concealment, and help-seeking attitudes among Asian American and European American college students with no help-seeking experience. *International Journal for the Advancement of Counselling*, *33*(4), 266–279. <https://doi.org/10.1007/s10447-011-9129-1>
- Miyawaki, C. E. (2015). A review of ethnicity, culture, and acculturation among Asian caregivers of older adults (2000–2012). *SAGE Open*, *5*(1). <https://doi.org/10.1177/2158244014566365>
- Moon, H., Rote, S., & Haley, W. E. (2018). Factors that contribute to remaining in the community among older adults. *Aging & Mental Health*, *22*(11), 1502–1509. <https://doi.org/10.1080/13607863.2017.1363869>
- Pan, S., & Jordan-Marsh, M. (2010). Internet use intention and adoption among Chinese older adults: From the expanded technology acceptance model perspective. *Computers in Human Behavior*, *26*(5), 1111–1119. <https://doi.org/10.1016/j.chb.2010.03.015>
- Pinquart, M., & Sörensen, S. (2005). Ethnic differences in stressors, resources, and psychological outcomes of family caregiving: A meta-analysis. *Gerontologist*, *45*(1), 90–106. <https://doi.org/10.1093/geront/45.1.90>
- Ploeg, J., Ali, M. U., Markle-Reid, M., Valaitis, R., Bartholomew, A., Fitzpatrick-Lewis, D., McAiney, C., & Sherifali, D. (2018). Caregiver-focused, web-based interventions: Systematic review and meta-analysis (Part 2). *Journal of Medical Internet Research*, *20*(10), Article e11247. <https://doi.org/10.2196/11247>
- Potter, W. J., & Levine-Donnerstein, D. (1999). Rethinking validity and reliability in content analysis. *Journal of Applied Communication Research*, *27*(3), 258–284. <https://doi.org/10.1080/00909889909365539>
- Rathnayake, S., Moyle, W., Jones, C., & Calleja, P. (2021). Co-design of an mHealth application for family caregivers of people with dementia to address functional disability care needs. *Informatics for Health and Social Care*, *46*(1), 1–17. <https://doi.org/10.1080/17538157.2020.1793347>
- Rich, A., & Hsiao, K. (2011). *Improving language access to keep California's older adults at home: An examination of the in-home supportive services program*. National Senior Citizens Law Center. <http://nslcarchives.org/index.php/ihss-improving-language-access/#.XITMmZNcGhc>
- Semere, W., Nápoles, A. M., Gregorich, S., Livaudais-Toman, J., & Karliner, L. (2019). Caregiving for older adults with limited English proficiency: Transitioning from hospital to home. *Journal of General Internal Medicine*, *34*(9), 1744–1750. <https://doi.org/10.1007/s11606-019-05119-y>
- Sethi, B., Williams, A., Desjardins, E., Zhu, H., & Shen, E. (2018). Family conflict and future concerns: Opportunities for social workers to better support Chinese immigrant caregiver employees. *Journal of Gerontological Social Work*, *61*(4), 375–392. <https://doi.org/10.1080/01634372.2017.1419395>
- Sherifali, D., Ali, M. U., Ploeg, J., Markle-Reid, M., Valaitis, R., Bartholomew, A., Fitzpatrick-Lewis, D., & McAiney, C. (2018). Impact of Internet-based interventions on caregiver mental health: Systematic review and meta-analysis. *Journal of Medical Internet Research*, *20*(7), Article e10668. <https://doi.org/10.2196/10668>
- United Nations. (2019). *World population prospects 2019: Highlights*. United Nations, Department of Economic and Social Affairs, Population Division. <https://www.un.org/development/desa/publications/world-population-prospects-2019-highlights.html>
- von Thienen, J. P. A., Clancey, W. J., Corazza, G. E., & Meinel, C. (2018). Theoretical foundations of design thinking. In H. Plattner, C. Meinel, & L. Leifer (Eds.), *Design thinking research: Making distinctions: Collaboration versus cooperation* (pp. 13–40). Springer International Publishing. https://doi.org/10.1007/978-3-319-60967-6_2
- Wang, Y., Liu, M., & Chi, I. (2021). An evaluation of self-care and caregiving training curriculum content for Chinese immigrant caregivers: A participatory design approach. *Journal of Applied Gerontology*, *40*, 1818–1827. <https://doi.org/10.1177/0733464820987920>
- Wong, D. (2007). Crucial individuals in the help-seeking pathway of Chinese caregivers of relatives with early psychosis in Hong Kong. *Social Work*, *52*(2), 127–135. <https://doi.org/10.1093/sw/52.2.127>
- World Health Organization. (2015). *World report on ageing and health*. World Health Organization. <https://www.who.int/ageing/events/world-report-2015-launch/en/>
- Wu, J., Liu, M., Ouyang, Y., & Chi, I. (2020). Beyond just giving care: Exploring the role of culture in Chinese American personal care aides' work. *Journal of Cross-Cultural Gerontology*, *35*(3), 255–272. <https://doi.org/10.1007/s10823-020-09404-w>
- Wynaden, D., Chapman, R., Orb, A., McGowan, S., Zeeman, Z., & Yeak, S. (2005). Factors that influence Asian communities' access to mental health care. *International Journal of Mental Health Nursing*, *14*(2), 88–95. <https://doi.org/10.1111/j.1440-0979.2005.00364.x>