Engaging Caregivers through mHealth to Support Chronic Care Patients

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ABSTRACT

As the U.S. population ages, the demand for long-term care services and support has increased, including those typically provided by informal caregivers. As a result of increased reliance on informal caregivers, caregiver burden is a growing concern, impacting the well-being of caregivers and patient outcomes. This paper explores the development, pilot, and evaluation of a caregiver engagement app designed to alleviate caregiver burden and enhance patient care in rural Michigan counties. Drawing on a multi-step approach, including key-informant interviews, empathy interviews, and

focus group discussions, caregiver needs were identified and incorporated into the app's design and interface. The app, genusConnect, provided caregivers with educational resources, care coordination tools, and communication features to support them and patient care. Pre-post intervention data indicated positive perceptions of the app's usability and efficacy in reducing caregiver burden and social isolation. Despite these promising findings, challenges remain in addressing financial support for caregivers and expanding the generalizability of the app to accommodate diverse caregiver populations and patient conditions. Future research should focus on addressing these limitations and further developing the app to better support caregivers and improve patient outcomes.

Keywords: Caregiver burden; informal caregivers; mHealth interventions; caregiver engagement; patient care coordination; aging population; long-term care; chronic care

INTRODUCTION

management

There has been much discussion on caregiver burden as caregivers become instrumental in caring for older patients with long-term care needs and other chronic care conditions (Keenan, 2023), and many health systems are attempting to address the health needs of caregivers while caring for patients after they are discharged from the hospital. As clinical and non-clinical care providers assume increasingly significant roles in patient care post-discharge and preventive care in the future (DeSalvo et al., 2016; Galea & Vaughan, 2021), it becomes crucial to redefine the role of caregivers. They are not merely supporters of patient care but pivotal healthcare workers providing comfort and resources to a growing aging population. As seniors live longer and rely on non-clinical care providers, it's crucial to find solutions that support caregivers. The rise of modern technology offers caregivers the chance to access online educational resources to understand their loved ones' diseases better and find available support resources. This opportunity is particularly relevant for younger caregivers who seek to utilize technology to meet the needs of their loved ones.

When patients' and their caregivers' goals align with those of their health-care team in reducing hospital readmissions and enhancing patient satisfaction, the question arises: How can you empower caregivers with knowledge and tools so they can effectively act as vital intermediaries in supporting patient needs?

Encouraging senior citizens' active engagement in healthcare policy-making enhances the provision of better services and the creation of responsive policies, which is critical for improving healthcare overall (Kolade et al., 2022). Caregivers can play

a crucial role in co-creating value with health systems at every stage of care management. This involvement includes activities such as participating in care-related tracking to enhance the effectiveness of policies aimed at improving health outcomes (Stefanoni et al., 2015). Just as deliberate citizen engagement can influence knowledge, attitudes, and promote active participation in policymaking (Carman et al., 2015), thereby strengthening government-citizen relationships (Abelson et al., 2010; Molster et al., 2013), actively engaging caregivers in healthcare planning for their loved ones should empower them in co-designing services utilized for patient care.

This dilemma leads to the first follow-up question: How can caregivers actively participate in the development of tools that enable them to serve as intermediaries, supporting the patients under their care?

Early research into how health systems from high-income countries have begun to educate and empower regional hospitals or other organizations in low-to middle-income countries with limited resources to design services for their patients has identified six different types of innovative services (Plum et al., 2020). These categories of innovations align with the WHO's building blocks of health systems (Indicators, 2010). These types of innovations can be adapted to educate and empower caregivers to support the patients they care for. The innovations utilized for healthcare organizations (on the left) and their potential adaptation for caregivers as intermediaries (on the right) are discussed in Table 1 below.

This leads to the second follow-up question: If caregivers are provided with a digital tool such as an app or portal, what innovative features should it include to help caregivers act as effective intermediaries in support the patients?

In this paper, we will discuss how a health system in Detroit, MI has embarked on the journey of engaging caregivers in designing the requirements for an app that supports the care of chronic care patients. We will then explore how caregiver feedback has been utilized to enhance the app's ability to serve their patients. The next section will delve into existing research on caregivers and underscore the significance of understanding their role in patient care. Following that, the third section will address the first question by outlining how the health system has collaborated with multiple stakeholders, including caregivers, to develop the initial version of the app. Moving forward, the fourth section will tackle the second question by examining how caregiver engagement with the app was evaluated to gain insights into its utilization and associated challenges. Finally, the fifth section will reflect on the feedback received and discuss how effective digital tool design and development can support caregivers and even educated and competent patient populations.

RESEARCH ON CAREGIVERS AND CAREGIVER BURDEN

Projections indicate that, by 2034, there will be more Americans aged 65 and older than children, marking the first time in U.S. history (Vespa et al., 2018). Demographic shifts toward an aging population in the United States present new challenges and an increased demand for long-term services and supports (LTSS). LTSS includes a broad spectrum of health-related, personal, and supportive services. These encompass aid with activities of daily living (ADLs; bathing, dressing, toileting, eating, etc.), instrumental activities of daily living (IADLs; cleaning, shopping, cooking, medication management), and health maintenance tasks (Harris-Kojetin et al., 2019).

Table 1. Health Innovations Adapted for Caregiver Engagement

1) Service delivery innovations	
Train medical institutions and local communities so they can improve preventive and secondary medical care delivery	Train caregivers on preventive and other care related monitoring of patients by recognizing their context (e.g., chronic care, Alzheimer's, living alone)
2) Workforce development innovations	
Train clinicians with research skills to better collect, analyze, and diffuse data and care practices	Train caregivers by improving their knowledge on tracking patient conditions and what to look for in symptoms that may need more clinical attention
3) Health information innovations	
Educate care providers on how to leverage technologies for data collection and analysis	Support caregivers with technologies that track patient conditions and analyze their statues
4) Product innovations	
Identify vaccines, devices, technologies, etc. to facilitate healthcare delivery	Develop tools to help caregivers support patients on medication administration, and reduce patient stress and anxiety
5) Health financing innovations	
Focus on health care institutions' ability to sustain care delivery through payment and reimbursements	Educate and support caregivers on where and how to seek financial resources to care for patients and caregivers
6) Policy innovations	
Develop rules, regulations, policies, and operational standards to ensure quality of care	Help caregivers develop time and resource management skills, so they can recruit family members and friends and assign roles to deliver prompt care to their patients

It is estimated that up to 75% of LTSS is provided informally (unpaid) by friends and family members at a recipient's home, while the other fourth comprises professional (paid) services at a home or institutional setting such as nursing homes (Medicine, 2008; Thomas & Applebaum, 2015). A survey of caregiver burden found it is common for informal caregivers to experience emotional stress (72%), miss an important meeting or event (67%), and balance work, family, and caregiving responsibilities (65%) (Keenan, 2023). As a result, the spare time of informal caregivers is reduced. Even with available relaxation time, many informal caregivers often choose not to unwind. Instead, they tend to hide and suppress their negative emotions (Ferrell et al., 2018; Mishra et al., 2018).

Caregiver stress has been recognized as a significant risk factor for nursing home placement and caregiver morbidity and mortality (Aneshensel et al., 1993; Chen et al., 2020; Fredman et al., 2010; Schulz & Beach, 1999; Spillman & Long, 2009). Over time, caregiver burden is correlated with an increased frequency in the use of health services and medications (Chessick et al., 2009; Haley et al., 1987; O'Reilly et al., 1996). Despite the negative effects faced by caregivers, support and training for the group is minimal (Thomas & Applebaum, 2015).

As demographics shift and healthcare worker shortages increase, it is critical to develop efficient and scalable tools to address caregiver burden and improve the delivery of care, increase social interaction, address daily needs of care, coordinate key medical, social, and behavioral needs, and coordinate logistics for care recipients (Hussain et al., 2012; Juraschek et al., 2012; Zhang et al., 2020). Mobile health (mHealth) interventions have been widely advocated as a strategy to self-manage chronic conditions for patients and their families (Istepanian et al., 2007; Kay et al., 2011; Logan, 2013; Steinhubl et al., 2013; Stowell et al., 2018). mHealth applications (apps) have been shown to help with chronic disease management, medication compliance, addressing care in rural communities, and improving health outcomes (West, 2012).

Several studies suggest mHealth interventions effectively address mental health issues, enhance access to care and quality of life, and reduce caregiver burden for individuals with chronic diseases and their informal caregivers (Gallagher-Thompson et al., 2010; Gately et al., 2019; McKechnie et al., 2014; Núñez-Naveira et al., 2016; Sherifali et al., 2018). However, when examining studies concentrating on cancer patients and their informal caregivers, Li et al.

(2022) found that mHealth interventions enhance the quality of life for caregivers and alleviate depression, but they do not demonstrate a statistically significant impact on reducing caregiver burden.

The next section will delve into how a health system has engaged caregivers, alongside other stakeholders, in designing the requirements for developing an app to support informal caregivers in a rural region of Michigan.

CAREGIVER ENGAGEMENT IN DESIGNING REQUIREMENTS FOR AN MHEALTH TOOL

The project to develop a caregiver engagement app, as an mHealth tool, was sponsored by the Michigan Health Endowment Fund through the Healthy Aging Grant. Although the project period was extended due to delays caused by the pandemic, it was successfully completed by the end of December 2022. This initiative entailed a 2-year implementation grant, preceded by a 2-year planning grant, and aimed to serve caregivers in Laneway, Jackson, and Hillsdale counties.

Key partners involved in the project include Henry Ford Health Global Health Initiative, which wrote, developed, implemented, and evaluated the project, and Henry Ford Allegiance, based in Jackson, where the principal investigator was located. Nora Health, an organization that collaborated with the Henry Ford Health Global Health Initiative in India during the planning phase of the grant, was also a crucial partner. The project was piloted on the Genus Connect platform, and the Region 2 Agency on Aging (R2AAA) served as the source of all caregivers involved. The project was guided by a three-step approach:

- 1. Conduct process and informative research.
- 2. Design and implement the genusConnect app.
- 3. Develop a pilot program and evaluate the effectiveness of the app.

CONDUCT PROCESS AND INFORMATIVE RESEARCH

Key-informant interviews (KII) were conducted by researchers of the study at clinical and community sites. Guiding questions addressed areas such as: provided services, population needs, influencing and limiting factors, current assets, additional necessary resources, and opportunities for improvement. Clinical staff were asked additional questions about readmissions, hospital discharge, and staff capacity. All interviews were recorded and transcribed. The data was then coded with shorthand labels to describe their context. Once codes were developed,

patterns were identified among them and lumped together into broader themes. KIIs suggested social isolation and emotional suppression were key contributing factors to poor outcomes for caregivers.

In addition to KIIs, empathy interviews were conducted by two community partners. These interviews consisted of the following instructions: 1) follow a caregiver for a day to understand what they are going through; 2) interview the caregiver in their own home or place in which they are most comfortable; 3) follow the caregiver to 1–2 appointments; 4) go into the interview with an idea of what you'd like to find out, but do not use a specific template. Empathy interviews highlighted the need for better communication and identified gaps in care that resulted in avoidable hospital admissions.

Focus group discussions (FGD) were composed of seven participants between 50–77 years—five of the participants identified as former or current informal caregivers. An FGD guide was developed and focused on the following three main areas: patient hospital discharge experience, caregiver experience and acceptability of technology, and services and resources. Participants shared their sentiments about the length of the hospital admission, the setting of the discharge process, and the resources needed to promote healthy and independent living.

Design and Implementation of the genusConnect App

The identification of caregiver needs phase of the trial yielded themes that were incorporated into the genusConnect app. By providing patients and their families with the resources and tools they need to make informed decisions about their health, the genus platform can increase a caregiver's perceived susceptibility and severity of a problem with patients, increase their perceived behavioral control, increase their autonomy, competence, and relatedness, and involve them in the decision-making process. The genus platform includes several services such as "genusTiles", "genusCoach", and "genusConnect" that can be used to provide patients and their families with the information and resources they need to make informed decisions about their health, and involve them in the decision-making process and tailor care to meet their unique needs and preferences.

"genus Tiles" provides caregivers and their families with accurate and relevant information about the patient's condition and treatment options, which can

help improve their understanding of the need for adherence to recommended guidelines. "genusCoach" facilitates interactive remote conversations between case managers and caregivers, which can provide additional opportunities for education and engagement. "genusConnect" provides caregivers and their families with a care app that can be used to access educational resources, schedule appointments, and communicate with care teams and community partners, which can help to ensure continuity of care. For example, caregivers can use "genusConnect" to communicate with their care team, schedule appointments, and access educational resources, while "genusCoach" can be used to facilitate interactive remote conversations and provide real-time conversation analytics. Community partners such as care coordination centers, primary care providers, and other healthcare providers can access the genus platform through an SDK to integrate it into their own applications or platforms.

Specific examples of caregiver engagements on behalf of patients

Understanding of the caregiver's perspective:

 By using feedback from caregivers and their families, caregivers can gain a better understanding of their perspectives, beliefs, attitudes, and motivations

Supporting the importance of education:

 By providing caregivers and patients with accurate and relevant information, healthcare providers can help improve their understanding of their condition and treatment options and increase their adherence to recommended guidelines.

Engagement of caregivers and their families:

By involving caregivers and patients as well as their families, healthcare
providers can improve communication and coordination of care, which
can lead to better outcomes.

Promoting the importance of self-efficacy:

By providing caregivers and patients with the information and resources
necessary for making informed decisions, healthcare providers can enhance
their self-efficacy. This, in turn, can boost their propensity to engage in
supporting both their own health and that of the patients under their care.

Facilitating the continuity of care:

By providing caregivers and patients consistent care across different stages
of care, the app can help ensure that patients receive appropriate and
timely care.

By looking at the six innovation services discussed in Table 1, the app attempts to address five of the six innovations (patient monitoring. education/ training to gather knowledge of the patient conditions, using digital tools to monitor patient conditions, administer medications, and communicate with caregivers, and use time-management and care-related administration with friends and family members). It does not explicitly provide any assistance on financial resources caregivers may need.

The next section will discuss the third step: design of the pilot program and evaluation of the app's efficacy.

EVALUATION OF THE CAREGIVER APP

The evaluation of the app aimed to assess how well its design, based on an understanding of caregivers' needs, met their expectations. Two hypotheses were formulated:

- Primary hypothesis: Between baseline and six months, informal caregivers in the study would report a decrease in caregiver burden associated with patient care.
- Secondary hypothesis: Informal caregivers would report a decrease in the social isolation they experience while caring for patients from baseline to six months.

Two outcome measures were utilized: the Lubben Social Network Scale (LSNS) (Lubben, 1988), a validated tool for measuring subjective caregiver burden, and the Caregiver Burden Scale, a self-report measure. The evaluation employed a pilot pre-post intervention trial to determine the effectiveness of the genusConnect app among informal caregivers. Baseline data included 16 informal caregivers, while three- and six-month post-intervention data included 9 participants.

The inclusion criteria for the study were as follows: 1) taking care of a person aged 60 and older who is diagnosed with chronic obstructive pulmonary disease (COPD), congestive heart failure (CHF) or urinary tract infection (UTI)-related sepsis; 2) living in Lenawee, Jackson, or Hillsdale counties; 3) signing the

informed consent form to participate in the study. Exclusion criteria included caregivers of patients with a diagnosis of dementia. Participants were identified through sites at R2AAA and Henry Ford Jackson Hospital.

Procedure

After caregivers indicated their willingness to participate, they were provided with both written and verbal details, accompanied by a consent document. Upon obtaining the signed informed consent form, participants were given the pre-intervention survey by telephone, which collected demographics, caregiver responsibilities, assessed social isolation through the LSNS, and assessed caregiver burden through the Caregiver Burden Scale.

After attending an app training session, participants were provided with a link to download the genusConnect app onto their mobile devices (Smartphone or Tablet). They were instructed to explore topics and experiment with different features of the app. Consistent with the design of other mHealth interventions, the evaluation period spanned three months, followed by a subsequent six-month follow-up (Gallagher-Thompson et al., 2010).

Participants completed two post-intervention surveys, which assessed caregiver burden, after three and six months of testing by telephone. Participants received a \$50.00 gift card after completing each survey and if they elected to participate in the FGD, equating to a maximum of \$250.00 per participant. All personal data underwent anonymization through the assignment of a unique PIN number. The codified information was securely stored in a database under the supervision of the project leaders in each respective location.

Approval for the study protocol was obtained from the Henry Ford Health Institutional Review Board (IRB) Office. Prior to the commencement of data collection, all participants were given comprehensive information about the study and signed the informed consent form.

Results

Tables 2 and 3 provide demographic information and an assessment of the app. At baseline, 75% (12) of participants were female and the mean age was 52.6 years. The relationship between the caregiver and the individual for whom they

provided care was: child (13.3%; 2), sibling (6.75%; 1), spouse/partner (6.7%; 1), other relative (13.3%; 2), friend (26.7%; 4), and hired caregiver (33.3%; 5). Demographics of the person receiving care at baseline include 43.8% (7/16) female and a mean age of 68.4 years. Most of the participants were females and were on average 48.05 to 58.66 years old, which is in accordance with the general characteristic of informal caregivers (Caregiving, 2020; Sharma et al., 2016). Though we were unable to calculate a significant difference, due to a small sample size, we did observe that the social isolation and burden scores decreased from baseline to post-intervention.

Table 2. Demographics

Caregiver		Baseline	3-Months Post	6-Months Post
Gender	Female	75.0% (12)	100% (9)	100% (9)
	Male	25.0% (4)	0	0
Age		52.6 (SD 14.1) Range (26 to 79)	45.4 (SD 12.6) Range (26 to 66)	45.4 (SD 12.6) Range (26 to 66)
Ethnicity*	White	No data	100% (8)	88.9% (8)
	African American	No data	0	11.1% (1)
Education	Grad HS/GED	25.0% (4)	22.2% (2)	22.2% (2)
	Some college	50.0% (8)	55.6% (5)	55.6% (5)
	Bachelor's degree	12.5% (2)	22.2% (2)	22.2% (2)
	Post-graduate	12.5% (2)	0	0
Employment**	Full time	56.3% (9)	66.7% (6)	44.4% (4)
	Part time	25.0% (4)	22.2% (2)	33.3% (3)
	Unemployed	6.3% (1)	0	0
	Retired	12.5% (2)	11.1% (1)	11.1% (1)
Relationship***	Child	13.3% (2)	25.0% (2)	25.0% (2)
	Sibling	6.7% (1)	0	0
	Spouse-Partner	6.7% (1)	0	0
	Other relative	13.3% (2)	12.5% (1)	12.5% (1)
	Friend	26.7% (4)	25.0% (2)	25.0% (2)
	Hired caregiver	33.3% (5)	37.5% (3)	37.5% (3)

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Older Adult				
Gender	Female	43.8% (7)	44.5% (4)	44.5% (4)
	Male	56.2% (9)	55.5% (5)	55.5% (5)
Age		68.4 (SD 6.6) Range (59 to 82)	66.9 (SD 4.9) Range (62 to 78)	66.9 (SD 4.9) Range (62 to 78)
Ethnicity	White	No data	100% (9)	100% (9)

^{*1} missing at 3-months post-intervention

Table 3. Caregiver Responsibilities

		Baseline	3-Months Post	6-months Post
Number of hours/week provide care		30.0 (SD 39.2) Range (4 to 168~)	19.7 (SD 12.2) Range (6 to 40)	15.4 (SD 12.8) Range (1 to 40)
Number of other caregivers		1.2 (SD 1.7) Range (0 to 6)	1.2 (SD 0.4) Range (1 to 2)	(SD 1.2) Range (0 to 3)
Activities provide for person you care for	Take to medical appointments	62.5% (10)	44.4% (4)	44.4% (4)
	Grocery shopping	81.3% (13)	77.8% (7)	77.8% (7)
	Pick up prescriptions	68.8% (11)	77.8% (7)	66.7% (6)
	Cook means	87.5% (14)	77.8% (7)	77.8% (7)
	Clean house	93.8% (15)	88.9% (8)	88.9% (8)
	Provide general transportation	56.3% (9)	55.6% (5)	55.6% (5)
	Laundry	75.0% (12)	66.7% (6)	66.7% (6)
~168 hours – 24 hours/day				

Participants reported an increase in positive perceptions of the educational materials provided by the app. They also indicated an improvement in ease of use, including user interface and design, and expressed a higher likelihood

^{**1} missing at 6-months post-intervention

^{***1} missing at 3-months and 6-months post-intervention

of recommending the app to other caregivers. Tables 4 and 5 present data on app utilization and how participants found it beneficial in reducing their social isolation.

Table 4. Caregiver Burden with Mean Scores by Item and Total Scale (Scoring:1 [not at all] to 4 [often] - possible range 21 to 84)

	Baseline	3-Month Post	6-Month Post
1. Do you feel tired and worn out?	2.7 (1.0)	2.4 (1.1)	1.8 (1.0)
2. Do you feel lonely and isolated because of your caregiver responsibilities?	1.7 (1.0)	1.0 (0)	1.2 (0.7)
3. Do you think you have too much responsibility because of your caregiver responsibilities?	2.4 (1.4)	1.2 (0.7)	1.3 (0.5)
4. Do you feel as if you would like to run away from the entire situation you find yourself in?	2.0 (1.1)	1.1 (0.3)	1.2 (0.7)
5. Do you find yourself facing practical problems as a caregiver that you think are difficult to solve?	1.9 (0.9)	1.1 (0.3)	1.3 (0.7)
6. Do you ever feel offended and angry with the person you care for?	1.8 (0.9)	1.3 (0.5)	1.7 (1.0)
7. Do you think your own health has suffered because of your caregiving responsibilities?	1.9 (1.3)	1.9 (1.4)	1.3 (0.7)
8. Has your social life with family and friends decreased because of your caregiving responsibilities?	2.3 (1.2)	1.8 (1.2)	1.8 (1.2)
9. Does the physical environment make it difficult for you to provide care?	1.7 (0.9)	1.2 (0.7)	1.6 (0.9)
10. Do you feel tied down by your caregiving responsibilities?	2.1 (1.0)	1.4 (0.9)	1.3 (0.7)
11. Do you feel embarrassed by the behavior exhibited by the person you care for?	1.9 (1.1)	1.1 (0.3)	1.4 (0.9)
12. Has being a caregiver prevented you from doing what you had planned to do in this phase of your life?	2.2 (1.3)	1.0 (0)	1.4 (0.9)

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Table 4. Continued.

13. Do you find it physically trying to do your caregiving responsibilities?	1.8 (1.0)	1.9 (1.2)	1.8 (1.0)
14. Do you think you spend so much time on your caregiving responsibilities that the time for yourself is insufficient?	1.9 (1.0)	1.3 (0.7)	1.3 (0.7)
15. Do you worry that you are not taking care of the person in the proper way?	1.9 (1.1)	1.1 (0.3)	1.4 (0.9)
3.16 Are you sometimes ashamed of the person's behavior?	1.9 (1.2)	1.1 (0.3)	(missing)
16. Is there anything in the neighborhood where you provide care that makes it difficult to undertake your responsibilities?	1.3 (0.4)	1.0 (0)	1.2 (0.4)
17. Have you experienced economic/money problems because of your caregiving responsibilities?	1.9 (1.1)	1.3 (0.7)	1.8 (1.1)
18. Do you find it stressful to undertake your caregiving responsibilities?	2.4 (1.3)	1.1 (0.3)	1.7 (1.0)
19. Do you feel that life has treated you unfairly?	1.9 (1.1)	1.0 (0)	1.2 (0.7)
20. Did you expect your life would be different than it is at your age?	2.1 (1.1)	1.6 (0.9)	1.3 (1.0)
21. Do you avoid inviting family and friends to the house of the person you care for?	1.7 (1.1)	1.0 (0)	1.4 (1.0)
OVERALL CAREGIVER BURDEN SCALE SCORES	**39.9 (14.5) Range 22 to 68	27.0 (5.8) Range 20 to 38	30.2 (10.3) Range 21 to 48
**overall baseline only includes respondents who took the 3-month and 6-month post.			

During weekly coaching calls, caregivers requested various resources in addition to technology support. These included meal delivery services such as Meals on Wheels, respite care for adults such as adult day care, reliable transportation options, accessibility accommodations, home repairs, and assistance with end-of-life planning such as creating a will document. Participants reported an increase in positive perceptions of the educational materials provided by the app,

as well as an improvement in ease of use, including user interface and design. Additionally, they expressed a higher likelihood of recommending the app to other caregivers.

Table 5. Social Isolation Mean Scores for Relatives and Friends (Scoring: 0=none, 1=1, 2=2, 3=3 or 4, 4=5 to 8, 5=more than 9 – possible range for each section 0 to 15)

	Baseline	3-Month Post	6-Month Post
4.1 How many relatives do you see or hear from at least once a month?	3.4 (1.3)	3.2 (1.8)	2.8 (1.5)
4.2 How many relatives do you feel at ease with that you can talk about private matters?	2.4 (1.4)	2.6 (1.5)	2.9 (1.7)
4.3 How many relatives do you feel close to such that you could call on them for help?	2.5 (1.2)	2.8 (1.5)	3.0 (1.3)
OVERALL SOCIAL ISOLATION SCORE FOR RELATIVES	9.7 (3.6) Range 4 to 14	8.6 (4.1) Range 0 to 15	8.7 (3.6) Range 5 to 15
4.4 How many friends do you see or hear from at least once a month?	2.8 (1.7)	2.7 (1.7)	2.2 (1.7)
4.5 How many friends do you feel at ease with that you can talk about private matters?	2.1 (1.3)	2.3 (1.7)	2.2 (1.7)
4.6 How many friends do you feel close to such that you could call on them for help?	2.1 (1.7)	2.6 (1.7)	2.0 (1.7)
OVERALL SOCIAL ISOLATION SCORE FOR FRIENDS	6.6 (4.7) Range 0 to 15	7.6 (5.1) Range 0 to 15	6.4 (5.1) Range 0 to 15

^{**}overall baseline only includes the 9 participants who took the 3-month and 6-month post survey

CONCLUSION AND FUTURE RESEARCH DIRECTIONS

To enhance the health outcomes of patients receiving care from informal caregivers, this paper offers a blueprint for a mHealth intervention that directly targets the complex needs of caregivers. In addition to improving patient care coordination, the mobile app offers caregivers several tools designed to combat

caregiver stress and isolation. This was achieved by integrating caregiver feedback and emphasizing user-friendly and user-oriented design elements. The app's features include details on patient care, condition monitoring, the ability to schedule assistance for patients' needs, and the ability to communicate virtually with patients and healthcare professionals when necessary. While the results suggest promising outcomes, several considerations and avenues for future research warrant discussion.

The positive feedback regarding the app's usability and effectiveness in reducing social isolation and burden scores highlights the significance of customized digital solutions for caregivers' changing requirements. Interventions like mHealth will be needed to support patient care and allow informal caregivers access to mental health resources that address stress and loneliness as the number of caregivers increases. The ability of the app to facilitate care coordination, provide educational resources, and foster communication between caregivers, patients, and healthcare providers demonstrates a promising approach to empowering informal caregivers as important intermediaries in patient care. Moreover, the increase we observed in positive perceptions about the app suggests mHealth interventions have the potential to further improve caregiver well-being and the quality of care provided to patients.

However, challenges remain when addressing financial support for unpaid caregivers and broadening the app's functionality to cover a variety of caregiver groups and patient situations. While the app helps reduce caregiver hardship through a variety of tools, such as providing information and communication tools, it does not specifically provide caregivers with information about how they could address the financial burdens that come with caregiving obligations. It is important to address the lack of tools and features that target this part of the caregiver load, such as financial aid programs or tools for handling caregiving-related costs, in future iterations of the app.

Another limitation of the study that is important to discuss is the fact that the majority of participants were solo caregivers. This raises concerns regarding the app's generalizability and efficacy for caregivers working in other caregiving contexts. More research is needed to understand how the app can be modified to enhance the user experience for solo caregivers and effectively meet the varied needs of caregivers who care for patients with medical conditions other than those studied, even though the app was designed to support the general caregiver

population. Furthermore, it's critical to assess how the app can support caregivers with varying degrees of technological literacy to guarantee that everyone can benefit equally from it.

To fully empower caregivers as intermediaries in patient care, several steps can be taken:

- 1. Conduct additional testing upfront by further canvassing the community and identifying their needs before implementation.
- 2. Test multiple mobile apps with similar capabilities and select the one shown to be most effective.
- Target a network of caregivers in a community or through community groups, utilizing texting as an alternative to phone calls to connect with future caregivers.
- 4. Provide additional training assistance, especially for caregivers with lower levels of technology literacy.
- 5. Identify additional resources to support caregivers and alleviate their financial burden as they seek alternatives to reduce the cost of care.

Overall, the genus Connect app's development and assessment represent a noteworthy addition to the fields of mHealth interventions, patient care coordination, and caregiver support. More research is needed to understand how the app might be modified to better suit solo caregivers and to understand how well it works to assist patients with a range of medical issues not included in the study. Our study presents a viable way to lessen caregiver strain and enhance patient outcomes by including caregivers as important stakeholders in the design and evaluation phases. To better meet the changing requirements of patients and caregivers in a variety of caring scenarios, more research is necessary to address these issues and improve the app. Through ongoing research and collaboration, we can continue to advance the field of caregiver support in the realm of mHealth and enhance the quality of care provided to patients across the care continuum.

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REFERENCES

- Abelson, J., Montesanti, S., Li, K., Gauvin, F.-P., & Martin, E. (2010). Effective strategies for interactive public engagement in the development of healthcare policies and programs. Canadian Health Services Research Foundation Ottawa.
- Aneshensel, C. S., Pearlin, L. I., & Schuler, R. H. (1993). Stress, role captivity, and the cessation of caregiving. *Journal of health and social behavior*, 54–70.
- Caregiving, N. A. f. (2020). Caregiving in the US. AARP; Bethesda, MD: The National Alliance for Caregiving.
- Carman, K. L., Mallery, C., Maurer, M., Wang, G., Garfinkel, S., Yang, M., Gilmore, D., Windham, A., Ginsburg, M., & Sofaer, S. (2015). Effectiveness of public deliberation methods for gathering input on issues in healthcare: Results from a randomized trial. *Social Science & Medicine*, 133, 11–20.
- Chen, C., Thunell, J., & Zissimopoulos, J. (2020). Changes in physical and mental health of Black, Hispanic, and White caregivers and non-caregivers associated with onset of spousal dementia. *Alzheimer's & Dementia: Translational Research & Clinical Interventions*, 6(1), e12082.
- Chessick, C. A., Perlick, D. A., Miklowitz, D. J., Dickinson, L. M., Allen, M. H., Morris, C. D., Gonzalez, J. M., Marangell, L. B., Cosgrove, V., & Ostacher, M. (2009). Suicidal ideation and depressive symptoms among bipolar patients as predictors of the health and well-being of caregivers. *Bipolar disorders*, 11(8), 876–884.
- DeSalvo, K. B., O'Carroll, P. W., Koo, D., Auerbach, J. M., & Monroe, J. A. (2016). Public health 3.0: time for an upgrade. *American journal of public health*, 106(4), 621.
- Ferrell, B. R., Kravitz, K., Borneman, T., & Friedmann, E. T. (2018). Family Caregivers: A qualitative study to better understand the quality-of-life concerns and needs of this population. *Clinical journal of oncology nursing*, 22(3).
- Fredman, L., Cauley, J. A., Hochberg, M., Ensrud, K. E., Doros, G., & Fractures, S. o. O. (2010). Mortality associated with caregiving, general stress, and caregiving-related stress in elderly women: Results of caregiver-study of osteoporotic fractures. *Journal of the American Geriatrics Society*, 58(5), 937–943.
- Galea, S., & Vaughan, R. (2021). Embedding prevention at the heart of the US health conversation. In (Vol. 111, pp. 17–19): American Public Health Association.
- Gallagher-Thompson, D., Wang, P.-C., Liu, W., Cheung, V., Peng, R., China, D., & Thompson, L. W. (2010). Effectiveness of a psychoeducational skill training DVD program to reduce stress in Chinese American dementia caregivers: results of a preliminary study. *Aging & mental health*, 14(3), 263–273.
- Gately, M. E., Trudeau, S. A., & Moo, L. R. (2019). In-home video telehealth for dementia management: Implications for rehabilitation. *Current geriatrics reports*, 8, 239–249.
- Haley, W. E., Levine, E. G., Brown, S. L., Berry, J. W., & Hughes, G. H. (1987). Psychological, social, and health consequences of caring for a relative with senile dementia. *Journal of the American Geriatrics Society*, 35(5), 405–411.
- Harris-Kojetin, L. D., Sengupta, M., Lendon, J. P., Rome, V., Valverde, R., & Caffrey, C. (2019). Long-term care providers and services users in the United States, 2015–2016.

- Hussain, A., Rivers, P. A., Glover, S. H., & Fottler, M. D. (2012). Strategies for dealing with future shortages in the nursing workforce: a review. *Health Services Management Research*, 25(1), 41–47.
- Indicators, A. (2010). Monitoring the building blocks of health systems. *Geneva, Switzerland:* WHO Document Production Services.
- Istepanian, R., Laxminarayan, S., & Pattichis, C. S. (2007). *M-health: Emerging mobile health systems*. Springer Science & Business Media.
- Juraschek, S. P., Zhang, X., Ranganathan, V., & Lin, V. W. (2012). United States registered nurse workforce report card and shortage forecast. *American Journal of Medical Quality*, 27(3), 241–249.
- Kay, M., Santos, J., & Takane, M. (2011). mHealth: New horizons for health through mobile technologies. *World Health Organization*, 64(7), 66–71.
- Keenan, T. A. (2023). U.S. Voters' Views on Support for Family Caregivers. AARP Research. https://doi.org/10.26419/res.00616.001
- Kolade, O., Porat-Dahlerbruch, J., van Achterberg, T., & Ellen, M. (2022). Strategies for engaging senior citizens and their informal caregivers in health policy development: a scoping review protocol. *Bmj Open*, 12(10), e064505.
- Li, Y., Li, J., Zhang, Y., Ding, Y., & Hu, X. (2022). The effectiveness of e-Health interventions on caregiver burden, depression, and quality of life in informal caregivers of patients with cancer: A systematic review and meta-analysis of randomized controlled trials. *International journal of nursing studies*, 127, 104179.
- Logan, A. G. (2013). Transforming hypertension management using mobile health technology for telemonitoring and self-care support. *Canadian Journal of Cardiology*, 29(5), 579–585.
- Lubben, J. E. (1988). Assessing social networks among elderly populations. *Family and community health*, 11(3), 42–52.
- McKechnie, V., Barker, C., & Stott, J. (2014). Effectiveness of computer-mediated interventions for informal carers of people with dementia—a systematic review. *International Psychogeriatrics*, 26(10), 1619–1637.
- Medicine, I. (2008). Retooling for an aging America: building the health care workforce. In: The National Academies Press Washington, DC.
- Mishra, S. I., Brakey, H. R., Kano, M., Nedjat-Haiem, F. R., & Sussman, A. L. (2018). Health related quality of life during cancer treatment: Perspectives of young adult (23–39 years) cancer survivors and primary informal caregivers. *European Journal of Oncology Nursing*, 32, 48–54.
- Molster, C., Potts, A., McNamara, B., Youngs, L., Maxwell, S., Dawkins, H., & O'Leary, P. (2013). Informing public health policy through deliberative public engagement: perceived impact on participants and citizen–government relations. *Genetic testing and molecular biomarkers*, 17(9), 713–718.
- Núñez-Naveira, L., Alonso-Búa, B., de Labra, C., Gregersen, R., Maibom, K., Mojs, E., Krawczyk-Wasielewska, A., & Millán-Calenti, J. C. (2016). UnderstAID, an ICT platform to help informal caregivers of people with dementia: a pilot randomized controlled study. BioMed research international, 2016.

- O'Reilly, F., Finnan, F., Allwright, S., Smith, G. D., & Ben-Shlomo, Y. (1996). The effects of caring for a spouse with Parkinson's disease on social, psychological and physical well-being. *British Journal of General Practice*, 46(410), 507–512.
- Plum, A., Tanniru, M., & Khuntia, J. (2020). An innovation platform for diffusing public health practices across a global network. *Health Policy and Technology*, 9(2), 225–234.
- Schulz, R., & Beach, S. R. (1999). Caregiving as a risk factor for mortality: the Caregiver Health Effects Study. *Jama*, 282(23), 2215–2219.
- Sharma, N., Chakrabarti, S., & Grover, S. (2016). Gender differences in caregiving among family-caregivers of people with mental illnesses. *World journal of psychiatry*, 6(1), 7.
- 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), e10668.
- Spillman, B. C., & Long, S. K. (2009). Does high caregiver stress predict nursing home entry? INQUIRY: The Journal of Health Care Organization, Provision, and Financing, 46(2), 140–161.
- Stefanoni, S., Williamson, C., & Asia, E. (2015). Review of Good Practice in National Policies and Laws on Ageing. *HelpAge International Asia, Pacific Regional Devel-opment Centre (HAI)*.
- Steinhubl, S. R., Muse, E. D., & Topol, E. J. (2013). Can mobile health technologies transform health care? *Jama*, 310(22), 2395–2396.
- Stowell, E., Lyson, M. C., Saksono, H., Wurth, R. C., Jimison, H., Pavel, M., & Parker, A. G. (2018). Designing and evaluating mHealth interventions for vulnerable populations: A systematic review. Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems,
- Thomas, K. S., & Applebaum, R. (2015). Long-term services and supports (LTSS): A growing challenge for an aging America. *Public Policy & Aging Report*, 25(2), 56–62.
- Vespa, J., Armstrong, D. M., & Medina, L. (2018). *Demographic turning points for the United States: Population projections for 2020 to 2060.* US Department of Commerce, Economics and Statistics Administration, US. . . .
- West, D. (2012). How mobile devices are transforming healthcare. *Issues in technology innovation*, 18(1), 1–11.
- Zhang, X., Lin, D., Pforsich, H., & Lin, V. W. (2020). Physician workforce in the United States of America: forecasting nationwide shortages. *Human resources for health*, 18(1), 1–9.

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