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Evaluating mobile Health technology use among cancer caregivers in the digital era

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Abstract

Introduction: Digital health technology-based interventions have the potential to support cancer caregivers in caregiving responsibilities and in managing their own health and well-being. The objective of this study was to examine the association between caregiving characteristics and different types of digital health technologies used in a national sample of caregivers of patients undergoing hematopoietic cell transplantation (HCT).

Methods: We conducted an online, cross-sectional survey of 948 HCT caregivers.

Results: Spousal caregivers comprised nearly one-third of respondents (27.1%) with a median age of 59 years (range: 18–80 years), compared with parents (32.9%: 38 years), adult children (28.9%: 38 years), and other (11.1%; e.g. friend, other family member: 36 years). Almost two-thirds (65.4%) of all respondents reported using an app for fitness or step counting and 41.3% reported using a smartwatch. However, spousal caregivers were the least likely group to use mobile apps (0.72; $P < 0.005$) or smartwatches (OR = 0.46; $P < 0.005$) compared with parent caregivers in models adjusted for demographics and coping style. Caregiving for six months or greater was associated with the use of fewer apps compared with caregiving for less than six months in adjusted models (OR = 0.80, $P < 0.005$). Caregivers of patients receiving an allogeneic transplant (i.e. non-self-donor) used more apps on average than caregivers of patients receiving an autologous transplant (i.e. self-donor) in adjusted models (OR = 1.36, $P < 0.005$).

Conclusion: Digital health technologies reflect promising avenues for supporting cancer caregivers. While digital technologies are becoming increasingly pervasive, older caregivers remain an underserved population. Future research should integrate older adult caregivers in the co-design and development activities of technology-driven caregiver support products.

Keywords

Hematopoietic cell transplantation, informal caregivers, digital health technology, mobile Health

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Introduction

Approximately 2.8 million Americans are providing unpaid, informal care to an adult with cancer.[1,2] With the growing number of cancer survivors and aging population, caregivers—including those who are aging themselves—represent a critical extension of our healthcare system.[3] Caregiving tasks are time- and labor-intensive, and they include multifaceted activities.[4] Unfortunately, these experiences often lead to significant physical, psychological, emotional, social, and financial challenges for caregivers.[5–7] Caregivers of patients undergoing allogeneic

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hematopoietic cell transplantation (HCT) represent an exemplar group of high-stress cancer caregiving. HCT caregivers must address the intense and persistent caregiving needs of some of the most critically ill patients with cancer—needs that continue throughout a prolonged hospital stay, followed by close outpatient follow-up over a period of many months.[8,9] Not surprisingly, the needs of cancer caregivers are complex, primarily driven by the patients' illness trajectories.[10–13] Yet, active and involved caregivers influence self-care and health outcomes of the patients they care for.[14] Thus, they serve a critical role in the current cancer care delivery systems.[15]

In recent years, digital health technology-based interventions have emerged as a novel platform to support informal caregivers in their caregiving responsibilities as well as in managing their own health and well-being.[16–18] However, current interventions have focused primarily on supporting caregivers in their role and responsibility as a caregiver. Interventions that address self-care as a means for caregivers to improve and maintain their own physical, mental, and spiritual health remain in formative stages.[19] For instance, mobile health (mHealth) and wearable sensors, which are increasingly being leveraged to support healthcare delivery, can help individuals monitor and manage their health and health behaviors. Furthermore, mHealth tools and data can be integrated with the electronic health record so that health information collected outside of healthcare visits can enhance healthcare supported by the electronic health record.[20]

Prior studies have documented demographic characteristics associated with using wearables and mHealth apps, such as age (younger), income (higher), education (college), sex (female), and race (White).[21–23] Indeed, in recent years, accessible, low-cost, and time-effective digital tools have gained traction in strengthening caregiver mental health for optimal caregiving.[24] They have been reported as particularly useful in those who experienced higher caregiving burden and distress due to caregiving tasks.[25] The use of mHealth is well-established in the setting of dementia caregiving.[26–28] However, there remains a gap in the literature on the use of wearables and mHealth applications among older caregivers of patients with cancer.[29] Thus, the current study drew upon our National Caregiver Health Survey of caregivers of HCT patients[30,31] to examine the association between caregiving characteristics, including care partner–recipient relationship, age, coping style, and different types of digital health technologies (i.e. health behavior-specific) used. Investigation into the use of different types of technologies could be important in determining their potential impact on caregivers and may also inform future digital health intervention design.

Methods

We report findings from our National Caregiver Health Survey,[30,31] which is part of a larger, multi-phase project.[19,30,32–40] The survey was implemented by the Center for Survey Research at Indiana University (LY). An institutional review board reviewed this research and determined that it met the requirements for the protection of human subjects. The survey itself was developed through cognitive interviews of HCT caregivers using verbal probing and think-aloud approaches.[30]

Sampling frames

The sampling frames were email distribution lists from the National Bone Marrow Transplant Link (nbmtLINK) and Blood and Marrow Transplant Information Network (BMT InfoNet). Both are nonprofit organizations in the United States that serve transplant patients and caregivers. The nbmtLINK and BMT InfoNet advertised and provided access to the survey in their electronic newsletters to their email distribution lists, which include volunteers who opt in to the lists. In addition, we obtained survey responses by distributing a study brochure containing the survey URL and QR code at BMT InfoNet's *Celebrating a Second Chance at Life Survivorship Symposium* in May 2019. All members of the email lists were sampled, but there were other sources of potential error, such as nonresponse and measurement errors. Data were cleaned to eliminate duplicate responses.[31]

Data collection

This survey was administered online using Qualtrics software[41] between 2 May and 30 June 2019. Inclusion criteria included being an unpaid caregiver of an HCT recipient, 18 years of age or older, and able to complete the survey online in English. Respondents received a $20 Amazon gift card upon survey completion. The survey was approximately 16 min in duration.

Measures

Digital health technology use. The outcomes included three measures of the nature and extent of digital health technology use: use of a fitness tracker (yes/no), use of a smartwatch (yes/no), and total number of health apps used currently (ranging from 0 to 9). Fitness trackers and smartwatches both track physiological parameters, but smartwatches provide additional capabilities (email, call, and text). Engagement was defined as how often respondents used their wearable devices (e.g. often, sometimes, rarely, and never).

Caregiving characteristics. The six specific features of caregiving having potential association with digital health technology use were: caregiver relationship to care recipient (e.g. parent, adult child, spouse/partner, and another relative); whether the caregiver also supported others (yes vs.

no), care duration (less than six months vs. more than six months as this is a common time point of delineating acute from chronic care in the trajectory of HCT recovery),[42] care burden (hours per week: less than 20 vs. 20-40 vs. 40 or more); whether the caregiver lived with the care recipient (yes vs. no); and donor source (autologous vs. allogeneic).

Coping. We used a subset of 16 items from the 28-item Brief COPE, which assesses the self-reported frequency of use of 14 different coping strategies to deal with a particular situationally specific life event (in this case, self-care and caregiving for a person undergoing HCT), including self-distraction, active coping, denial, alcohol and drug use, use of emotional support, use of instrumental support, behavioral disengagement, venting, positive framing, planning the use of humor, acceptance, and religion.[31,43] We used exploratory factor analysis to reduce the 16 items into a smaller set of factors. Based upon a scree plot, we found that four factors were sufficient, with eigenvalues of 1.85, 1.52, 1.23, 0.83, and 34% of total variance explained. Based upon the individual factor loadings, we were able to categorize the four factors as four unique coping approaches: strategic, emotional, religious, and social support. The mean response to the component items in each factor served as the caregiver's mean frequency of use score for that factor. Note, the more frequently strategic, religious, and social support coping styles are used, the more adaptively functioning an individual is. In contrast, the more frequently emotional coping is used, the more disengaged an individual is from efforts to cope actively (i.e. less adaptive).

Caregiver demographics. We also incorporated eight caregiver demographics that have been identified in previous studies as being important characteristics associated with digital health technology use (age, sex, race, ethnicity, income, education, marital status, and employment status).

Statistical methods

All continuous measures were summarized with a sample mean and sample standard deviation, while all categorical measures were summarized with the proportion of the sample in each category. We also tabulated the percentage of missing values for each measure. Of the 948 respondents, 719 (76%) had complete data, and the percentage of missing values ranged from 0% to 9% for each variable in our data. Before any analyses were done, we used multiple imputation with chained equations[44] to impute the missing values for each respondent; all analysis results are based upon 10 imputed datasets. We individually assessed the (unadjusted) association of each caregiving factor with the probability of using a fitness tracker and the probability of using a smartwatch with logistic regression and with the mean number of apps with Poisson regression. We then incorporated all seven caregiver demographics and four coping style measures into the regression models to produce an adjusted association of each caregiving factor with each measure of digital health technology use. In all models, statistical significance was defined as a p-value <0.005 to account for multiple comparisons and limit false-positive findings. All analyses were done in the statistical software R (version 4.0.4).

Results

Caregiver demographics

The mean age of the survey respondents ($n = 948$) was 43.92 years (range 18–89 years, SD = 13.02) (Table 1). A majority (65.4%) identified as female, married (86.8%), and employed (78.4%). Over three-quarters were White (78.7%) and non-Hispanic (82.6%), and most reported at least a college education (70.1%) and an annual household income >US$50,000 (65.7%).

Caregiving characteristics

About one-third of caregivers were parents of their recipients (32.8%). The rest were adult children (28.9%), spouses/partners (27.1%), or another relative, such as a cousin or friend (11.0%). Spousal caregivers were the oldest group of caregivers, with a median age of 59 years (range: 18–80 years), compared with parents (median age: 38 years), adult children (median age: 38 years), and another relative (median age: 36 years). Most caregivers supported another relative (68%) and resided in the same household as their care recipient (82.9%) with about one-quarter (24%) spending >40 h per week caregiving. Just over half (52.8%) reported caregiving for more than six months. Most respondents (84.8%) were caregivers to allogeneic HCT patients. See Table 1 for a summary of caregiver demographics and caregiving characteristics.

Coping characteristics

The mean self-reported measure of strategies used for coping or regulating cognitions in response to stressors is presented in Supplemental Table 1. Of the four coping strategies emerging from our factor analysis, the mean score for emotional coping was the lowest (mean = 2.5, SD = 0.7), with lower scores being more adaptive (i.e. lower scores reflect greater engagement with efforts to cope actively). The mean score for strategic coping was highest (mean = 3.2, SD = 0.4), with higher scores being more adaptive (i.e. higher scores reflect more active and engaged coping strategies in dealing with self-care).

Table 1. Caregiver demographics and caregiving characteristics.

Demographic	Category	*N* (%)
Age	≤40 years	479 (50.5)
	>40 years	465 (49.1)
	Not reported	4 (0.4)
Sex	Male	324 (34.2)
	Female	620 (65.4)
	Not reported	4 (0.4)
Income	≤$50,000	249 (26.3)
	$50,001–$99,999	373 (39.3)
	≥$100,000	250 (26.4)
	Not reported	76 (8)
White race	Yes	746 (78.7)
	No[a]	194 (20.5)
	Not reported	8 (0.8)
Hispanic ethnicity	Yes	158 (16.7)
	No	783 (82.6)
	Not reported	7 (0.7)
Currently married	Yes	823 (86.8)
	No	120 (12.7)
	Not reported	5 (0.5)
Employed	Yes	743 (78.4)
	No	197 (20.8)

(continued)

Table 1. Continued.

Demographic	Category	*N* (%)
	Not reported	8 (0.8)
Education attained	Some college or less	280 (29.5)
	College degree or more	665 (70.1)
	Not reported	3 (0.3)
Characteristic		
Caregiver relation to the recipient	Parent	311 (32.8)
	Adult child	274 (28.9)
	Spouse	257 (27.1)
	Other relation	104 (11.0)
	Not reported	2 (0.2)
Transplant type	Allogeneic	804(84.8)
	Autologous	130 (13.7)
	Not reported	14 (1.5)
Caring for others	Yes	644 (67.9)
	No	301 (31.8)
	Not reported	3 (0.3)
Care duration	≤6 months	443 (46.7)
	>6 months	501 (52.8)
	Not reported	4 (0.4)
Weekly burden	≤20 h/week	343 (36.2)
	20–40 h/week	376 (39.7)
	>40 h/week	224 (23.6)

(continued)

Table 1. Continued.

Demographic	Category	*N* (%)
	Not reported	5 (0.5)
Lives with recipient	Yes	786 (82.9)
	No	156 (16.5)
	Not reported	6 (0.6)

[a]White: 746; African American: 91; Asian: 62; Native Hawaiian or Pacific Islander: 27; American Indian or Alaska Native: 24; Other: 3.

Digital health technology use

Almost half (45%) of respondents used an iPhone, while 53% used an Android or Windows phone. The remaining 2% used another type of cell phone. About two-thirds (65.4%) of respondents reported using an app for fitness or step counting, and 41.3% reported using a smartwatch. The average number of apps used was 3.3 (range 0–9).

Associations between caregiving characteristics and digital health technology use

Fitness tracker. In unadjusted models, caregivers who were adult children of their care recipient were significantly more likely to use a fitness tracker compared with caregivers who were parents of their care recipient (OR = 5.80, $p < 0.005$) (Table 2). Those caregiving for six months or greater were significantly less likely than those caregiving for less than six months to use a fitness tracker (OR = 0.40, $p < 0.005$). Donor source also emerged as an important variable with caregivers of patients undergoing allogeneic transplant more likely to use a fitness tracker than caregivers of patients undergoing autologous transplant (OR = 2.02, $p < 0.005$). After adjusting for demographic and coping characteristics, the caregiver relationship remained associated with the use of a fitness tracker with adult children who were caregivers (OR = 5.82, $p < 0.005$), and caregivers of another relative (OR = 2.51, $p < 0.005$) being significantly more likely to use a fitness tracker than caregivers of a child.

Smartwatch. Unadjusted (OR = 0.28, $p < 0.005$) and adjusted (OR = 0.46, $p < 0.005$) models showed that spousal caregivers were significantly less likely to use a smartwatch compared with caregivers who were parents of their care recipient (Table 3). Caregivers caring for others were also more likely than those not caring for others to use a smartwatch in both unadjusted (OR = 2.29, $p < 0.005$) and adjusted (OR = 1.79, $p < 0.005$) models. Similar to findings associated with the use of a fitness tracker, caregivers of patients undergoing allogeneic transplant were more likely to use a smartwatch, in both unadjusted (OR = 4.63, $p < 0.005$) and adjusted (OR = 3.05, $p < 0.005$) models.

Number of health apps. Multiple caregiving characteristics were associated with the mean number of apps in both unadjusted and adjusted models (Table 4). On average, caregivers who were children of their recipient used more apps than caregivers who were parents of their recipient in both unadjusted (OR = 1.23, $p < 0.005$) and adjusted (OR = 1.28, $p < 0.005$) models. Caregivers of patients receiving an allogeneic transplant also used more apps on average than caregivers of patients receiving an autologous transplant, in both unadjusted (OR = 1.89, $p < 0.005$) and adjusted (OR = 1.36, $p < 0.005$) models. Additionally, caregiving for six months or greater was associated with the use of fewer apps compared with caregiving for less than six months in both unadjusted (OR = 0.66, $p < 0.005$) and adjusted (OR = 0.80, $p < 0.005$) models.

Discussion

In this study, we analyzed responses from 948 caregivers of our National Caregiver Health Survey to assess the relationship between caregiver characteristics and the use of three types of digital health: fitness trackers, smartwatches, and mobile apps. Prior studies have examined the use of fitness trackers, smartwatches, and various mobile apps among other populations, including the general United States public, caregivers of children with cancer, older adults with dementia, and caregivers of older adults.[21,45–48] However, to our knowledge, these variables (e.g. fitness trackers, smartwatches, number of apps) have not been explored in the context of caregivers of patients undergoing HCT. With the rapid insurgence of telehealth, propelled by the current COVID-19 pandemic, having a

Table 2. Unadjusted and adjusted associations of caregiving characteristics with the use of a fitness tracker.[a]

Caregiving characteristic	Unadjusted		Adjusted for demographics and coping	
	Odds Ratio	95% CI	Odds Ratio	95% CI
Caregiver relationship to the recipient				
Parent	Ref	Ref	Ref	Ref
Adult child	**5.80**	**[3.89, 8.66]**	**5.82**	**[3.62, 9.36]**
Spouse	0.82	[0.59, 1.15]	0.86	[0.57, 1.30]
Other	1.66	[1.05, 2.62]	2.51	[1.49, 4.21]
Care for others				
No	Ref		Ref	
Yes	1.41	[1.07, 1.87]	0.96	(0.67, 1.38)
Care duration				
Less than six months	Ref		Ref	
Six months or greater	**0.40**	**(0.30, 0.52)**	**0.46**	**(0.32, 0.66)**
Care burden				
Less than 20 h/week	Ref		Ref	
20-40 h/week	**1.79**	**(1.32, 2.42)**	1.41	(1.01, 1.98)
40 or more hours/week	0.93	(0.66, 1.30)	0.93	(0.62, 1.39)
Caregiver lives with the care recipient				
No	Ref		Ref	
Yes	0.84	(0.59, 1.20)	0.73	(0.49, 1.08)
Donor type[b]				
Autologous	Ref		Ref	
Allogeneic	**2.02**	**(1.39, 2.95)**	1.41	(0.91, 2.17)

[a]Boldface indicates $p < 0.005$.
[b]Autologous = self-donation of hematopoietic stem cells (HSCs); Allogeneic = donation of HSCs by a donor other than self (e.g. sibling, relative, and unrelated donor).

better understanding of digital health technology use is important for future study design.[21,45,48,49]

Herein, two caregiver characteristics emerged in the use of digital health technology: (i) caregiver relationship with care recipient and (ii) care burden (i.e. duration of caregiving and allogeneic vs. autologous transplant type). Compared with parents caregiving for their children as the referent group, spousal caregivers were the least likely group to use a fitness tracker, smartwatch, or mobile apps. Given that spousal caregivers were the oldest group of caregivers in our sample, our findings suggest a need for more technology training for older caregivers, including best practices for integrating health behavior-specific technology use into their daily activities, routines, and even

Table 3. Associations of caregiving characteristics with the use of smartwatch.[a]

Caregiving characteristics	Unadjusted		Adjusted for demographics and coping	
	Odds Ratio	95% CI	Odds Ratio	95% CI
Caregiver relationship to the recipient				
Parent	Ref	Ref	Ref	Ref
Adult child	1.16	(0.83, 1.60)	1.14	(0.75, 1.73)
Spouse/partner	**0.28**	**(0.19, 0.42)**	**0.46**	**(0.29, 0.72)**
Other	1.06	(0.67, 1.67)	1.10	(0.66, 1.83)
Care for others				
No	Ref			
Yes	**2.29**	**(1.70, 3.08)**	**1.79**	**(1.2, 2.67)**
Care duration				
Less than six months	Ref			
Six months or greater	**0.58**	**(0.44, 0.76)**	0.70	(0.48, 1.00)
Care burden				
Less than 20 h/week	Ref		Ref	
20-40 h/week	0.91	(0.68, 1.23)	0.87	(0.62, 1.22)
40 or more hours/week	0.61	(0.43, 0.86)	0.80	(0.52, 1.25)
Caregiver lives with the care recipient				
No	Ref		Ref	
Yes	1.07	(0.75, 1.52)	1.25	(0.84, 1.86)
Donor type[b]				
Autologous	Ref		Ref	
Allogeneic	**4.63**	**(2.72, 7.88)**	**3.05**	**(1.70, 5.47)**

[a]Boldface indicates $p < 0.005$.
[b]Autologous = self-donation of hematopoietic stem cells (HSCs); Allogeneic = donation of HSCs by a donor other than self (e.g. sibling, relative, and unrelated donor).

caregiving responsibilities. Notably, spousal caregivers are generally more likely to be sole caregivers (i.e. without support from other caregivers), so it is important to ensure that such a technology is not an additional demand or burden.[50]

Our data suggest relatively high adoption of digital health technology (e.g. fitness trackers, smartwatches, and mobile apps) among HCT caregivers in this national sample. Caregiver use of smartwatches in our sample (41%) was high compared with wearable device use among the general adult public, as reported in other studies (20%–30%).[21,51–53] Considerable literature has established that the length of time caregiving influences caregiver burden or strain and impacts caregivers' capacity

Table 4. Unadjusted and adjusted associations of caregiving characteristics with a mean number of apps.[a]

Caregiving characteristic	Unadjusted		Adjusted for demographics and coping	
	Mean ratio	95% CI	Mean ratio	95% CI
Caregiver relationship to the recipient				
Parent	Ref	Ref	Ref	Ref
Adult child	**1.23**	**(1.13, 1.34)**	**1.28**	**(1.15, 1.42)**
Spouse/partner	**0.56**	**(0.50, 0.63)**	**0.72**	**(0.63, 0.83)**
Other	1.05	(0.93, 1.18)	**1.21**	**(1.07, 1.37)**
Care for others				
No	Ref			
Yes	**1.63**	**(1.49, 1.79)**	**1.29**	**(1.16, 1.44)**
Care duration				
Less than six months	Ref			
Six months or greater	**0.66**	**(0.61, 0.71)**	**0.80**	**(0.73, 0.88)**
Care burden				
Less than 20 h/week	Ref		Ref	
20–40 h/week	**1.14**	**(1.05, 1.24)**	1.11	(1.02, 1.21)
40 or more hours/week	**0.81**	**(0.73, 0.91)**	0.98	(0.87, 1.11)
Caregiver lives with the care recipient				
No	Ref		Ref	
Yes	0.95	(0.87, 1.05)	0.97	(0.88, 1.07)
Donor type[b]				
Autologous	Ref		Ref	
Allogeneic	**1.89**	**(1.60, 2.23)**	**1.36**	**(1.15, 1.60)**

[a]Boldface indicates $p < 0.005$.
[b]Autologous = self-donation of hematopoietic stem cells (HSCs); Allogeneic = donation of HSCs by a donor other than self (e.g. sibling, relative, and unrelated donor).

to care for their own health (self-care).[54–56] It is possible that these technologies enable caregivers to monitor and support their own health and well-being in an accessible way. Given that almost all participants in our sample own a smartphone, providers and health systems could leverage digital health technologies to reach caregivers in unprecedented ways. Nonetheless, older patients and caregivers face unique barriers to adopting health behavior-specific technologies—including issues with perception, cognition, mood, and physical functioning.[57–59] As such, supporting older caregivers may require different strategies or approaches to engage them.

Findings from this study also provide us with a greater understanding of the needs of HCT caregivers who are

experiencing a greater burden associated with their responsibilities (i.e. differential circumstances based on caregiver type—spouse, parent vs. adult child) and with their care recipient's needs (i.e. allogeneic vs. autologous transplant). Our respondents were mainly caregivers of allogeneic HCT patients (85%) who generally face a more difficult transplant recovery due to the physiological and immunological challenges of using donor stem cells (e.g. graft-versus-host disease and infectious disease complications). Given our findings that caregivers of allogeneic HCT patients were more likely to use mHealth technologies than their autologous counterparts, our study suggests that digital health technology may play a role in supporting caregivers who face a high caregiver burden. Future research should examine the circumstances under which caregivers use different types of digital health technologies, the frequency and duration of this use, and caregiver outcomes such as their ability to meet their own lifestyle goals while supporting a care recipient.[60]

Our study has several limitations. First, our study was conducted at a cross-sectional time point in each of the caregivers' transplant journeys. Thus, findings may not be generalizable across all caregivers of patients undergoing HCT. Second, while we included survey items that quantified the number and type of digital apps, data on how caregivers are using such technology (i.e. engagement with apps and functions) were not obtained. These questions are currently being explored as a follow-on from the study herein. Third, we recruited from the email distribution lists of two well-known transplant organizations, so our sample may not be completely representative of the overall HCT caregiver population (i.e. caregivers who are not part of these networks). Additionally, our study may reflect selection bias, whereby caregivers with high digital literacy and high rates of health behavior-specific technology use may have been more likely to participate in an online survey than caregivers with low digital literacy and technology use. Further, respondents may have been able to participate in the study because of the low burden associated with their caregiving responsibilities. The sample was also highly educated, relatively affluent, and mostly White. To address efforts of health equity, future research should investigate the use of digital health technologies among caregivers from historically underserved groups, including those who are elderly, of lower literacy levels, of racial minorities, and of lower socioeconomic status.

Conclusion

The findings herein suggest that consumer digital health technologies, such as fitness trackers, smartwatches, and mobile apps, maybe promising avenues for supporting caregivers of patients undergoing HCT. Not surprisingly, older spousal caregivers reported significantly reduced adoption of these health behavior-specific technologies compared with younger caregivers. Thus, to overcome these challenges, integrating older caregivers into co-design and development practices will be essential, so that their experiences lead to user-centered products that impact not only the health of the recipient they care for, but their own health and well-being.

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