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Mobile phone apps for family caregivers: A scoping review and qualitative content analysis

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Abstract

Background: The growth of mHealth apps has been exponential in recent years, but there is limited knowledge regarding the availability, functionality, and quality of apps to support family caregivers. Our objectives were to identify the apps currently available to support family caregivers and to analyze the app functions and evaluation claims.

Methods: This scoping review was conducted across the iOS, Android, and Windows Phone app stores in three steps: (1) electronic app search; (2) iterative inclusion and exclusion criteria development; (3) mixed-method analysis of app characteristics and evaluation claims.

Results: The search identified 1008 apps; 175 met our inclusion/exclusion criteria. Most apps offered either one (36%, 63/175) or two (41%, 71/175) specific functions, the most common of which were access to service and provider directories, providing patient-caring tips, and tools to facilitate daily activities associated with caring for a loved one. For fully two-thirds (67%, 118/175) of the identified apps, the functions serve to assist caregivers to support the care recipient as opposed to supporting the family caregivers themselves.

Conclusions: The findings of this review indicate that, while a wide range of family caregiver apps are now available across the mHealth landscape, most apps offer limited functionality. Therefore, there is a need for multi-functionality to avoid the inherent challenges that caregivers may experience when navigating and managing multiple apps to meet all their various needs. Moreover, as this specific niche continues to develop, greater attention should be devoted to supporting family caregivers' own personal care needs as caregiver burden is a pressing challenge.

Keywords

Family caregivers, family carers, mobile apps, smartphones, mHealth

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Background

Family caregivers include family, friends, and neighbors who provide social, psychological, and physical support and care for their loved ones, typically without financial compensation.[1] Recent estimates are that approximately 34 million American adults[2] and 8 million Canadians aged 15 and older are family caregivers.[3,4] On average, family caregivers provide 11 hours of care a week; when supporting those with conditions such as Alzheimer's disease or dementia, mental illness, or cancer, that number grows to over 100 hours per week.[1] Common assistance provided by family caregivers include: emotional and social support, transportation assistance, household chores (e.g. laundry, meal preparation), home and property

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maintenance, performing medical treatments, personal hygiene maintenance, and scheduling medical and personal appointments.[1] Most family caregivers have been involved in caregiving activities for at least a year or longer and often provide the majority of the patient care.[1,3,5]

Family caregivers face challenges balancing care for their loved one(s) with their existing personal and work duties, which may cause negative health effects both physically and psychologically.[1,2,6,7] Caregivers may experience fatigue, burnout, depression, anxiety, and sleep disturbances.[8–10] Sometimes, caregivers are not given a choice in taking on the responsibility of managing their loved one(s),[1] and with more hours of care, there is increased absenteeism from paid employment and reduced hours of work.[1,2,11] Caregiver burden and stress negatively affect both family caregivers and the care recipient(s). Negative effects may include higher anxiety and depression levels for caregivers and more frequent psychological (shouting, using harsh tones, swearing) or physical abuse (being withheld food, slapping, handling care recipient(s) in rough ways) experienced by the care recipient(s).[12,13] Caregivers also lack resources available to address their support needs and are often unaware of existing health and social supports for themselves.[7,13]

Mobile health applications (mHealth apps) may be one solution to help family caregivers care for their loved one(s) and themselves. mHealth, as defined by the World Health Organization (WHO) is: "medical and public health practice supported by mobile devices, such as mobile phones, patient monitoring devices, personal digital assistants, and other wireless devices."[14] In recent years, there has been a steady increase in the number of mHealth apps. In particular, the coronavirus disease (COVID-19) has accelerated development and adoption of technology in healthcare worldwide.[15–17] For example, in the time period of April to May 2020, 30 Apple Store and 28 Google Play COVID-19 related apps have been identified in the United States.[18] In addition, during COVID-19, the use of mHealth apps is enabling healthcare delivery while adhering to social distancing requirements.[19,20] Given the increase in smartphone use,[21] Internet access,[22] and family caregivers' expressed interests in adopting new technology,[23,24] mHealth apps could be an effective mechanism to support caregivers.

A recent scoping review of apps for family caregivers of older adults identified 44 apps available on two commercial app stores (iTunes, Google Play).[23] While an important contribution to the literature, this review excluded those apps designed to support caregivers of patients with a specific health condition (such as diabetes or cancer), in addition to focusing exclusively on older adults. There have also been reviews exploring the mHealth apps for caregivers of people on specific diseases such as dementia,[25,26] stroke,[27] and cancer.[28] Our study builds and expands on these studies by performing a comprehensive scoping review of all caregiver apps for all disease states available across the three main commercial app stores (i.e. iTunes, Google Play, and Windows), including apps designed for specific health conditions and for caregivers of all ages, and extending the domains of analysis, beyond features and cost, to include domains reflecting the quality of apps and interoperability with other systems, both of which are important determinants of app adoption by clinical populations.[29]

The objectives of this scoping review are: (i) to identify the full range of mHealth apps for family caregivers currently available across three major commercial app stores (iTunes, Google Play, Windows Store); and (ii) to characterize the available apps through qualitative analyses of the app functions and evaluation claims. Following the methods section, the findings are organized to be aligned to these two objectives, first summarizing the apps found from the review, followed by a breakdown of the functionality of these apps. The discussion section outlines how these functions align to the different roles of caregivers, highlighting in particular "app gaps" that could be pursued by future developers in this space.

Methods

This scoping review was modeled after previous mHealth app scoping reviews with various disease-specific foci;[30,31] we then modified the design to fit our focus on family caregiver facing apps.

App search

On 23 May 2017, an initial electronic search using nine key words ("Caregiver(s)," "Family Caregiver(s)," "Informal Caregiver(s)," "Carer(s)," "Caregiving") on the official iOS (iTunes), Android (Google Play Store), and Windows Phone (Windows Store) app stores was conducted. No restrictions in terms of language, store sub-category, and the updated date of the app were imposed. App categories were not considered as one of the exclusion and inclusion criteria because category assignment is arbitrary [32–34] and the assigned categories do not necessarily reflect the app's true nature. A list of the identified apps was generated for each platform and duplicate apps were eliminated within each store. Finally, a master list combining the three store-specific lists was created and this list was used for initial screening.

Eligibility

After determining the initial total number of apps, we defined our inclusion and exclusion criteria iteratively (see Supplemental File 1). Because apps differ in their definition of family caregivers, each app's description was closely examined to determine whether it fit into our

study's definition of family caregivers outlined in the "Background" section. For apps with ambiguous or unclear descriptions, the app's website was consulted. If an app's purpose was still unclear, the three authors discussed as a group to reach a mutually agreed-upon decision. The flow diagram was modified iteratively throughout the app selection process.

Analyses of app characteristics, functions, and evaluation claims

Apps included for analysis were characterized in terms of cost associated with the app (purchase cost and/or in-app purchases), need for additional devices (e.g. Fitbit, iHealth, tablet, mobile phone device, voice assistant device), interoperability (platform, web-app availability, EMR/EHR integration), disease-specific focus (e.g. caring for patients with dementia), target caregiver age group, evaluation claims, and functions (see Supplemental File 2). App descriptions and web searches were used to collect necessary information on each app in July 2017. Afterwards, the information was abstracted into Microsoft Excel. Categories for functions and evaluation claims were identified through qualitative summative content analysis.[35]

Results

Our search resulted in findings that met our objectives of this scoping review, which were: (i) to identify the full range of mHealth apps for family caregivers and (ii) to characterize the functions and evaluation claims of the available apps. We summarize our findings in the paragraphs below.

Summary of search results

Figure 1 provides an overview of the general characteristics of the 175 apps included for analysis. In the initial search, 25% of the apps are from iTunes (255/1008 total number of app identified), 74% (743/1008 total number of app identified) from Google Play, and 1% (10/1008 total number of app identified) from Windows Store (these figures were generated before duplicates, e.g. apps available on multiple platforms, were accounted for). After applying the inclusion/exclusion criteria, 17% (175/1008) of the apps were included for analysis. The list of 175 apps identified are available in Supplemental File 3.

Summary of general app characteristics

The majority of the included apps are free both at the time of download (90%, 18/175) and within an app (69%, 121/175). Sixty-six percent (116/175) of the apps do not require additional device(s) and most apps were not disease specific (65%, 113/175) and did not have a specific target carer age group (98%, 172/175) (see Table 1). In terms of interoperability, 65% (113/175) of the apps are available on both Android and iOS platforms, 43% (76/175) of the apps have web-app availability, and 4% (7/175) of the apps have EMR/EHR integration.

Summary of app functions

Overall, two-thirds (67%; 118/175) of the identified family caregiver apps provide only patient-focused functions; that is, functions that are designed to assist the caregiver to support the care recipient (see Table 1). By contrast, only one-third (33%; 57/175) of the identified apps provide functions designed to assist family caregivers with supporting themselves. Approximately one-quarter (26%; 46/175) of the apps contained both types of functions.

Typical patient-focused functions included booking services through the app, private/individual business directories, tips/articles to care for patient, care coordination with patient's circle of care, live video monitoring, writing/tracking symptoms or diary, and medication reminders. Family caregiver focused functions included self-care tips/resources specific for family caregivers, coaching services from professionally trained providers, and a forum for sharing concerns with other family caregivers with similar experiences for emotional and social support.

Within an app, there is usually one (36%; 63/175) or two (41%; 71/175) functions that the user (family caregiver) could use simultaneously. As can be seen in Figure 2, the most common function available is the Education/Resources/Patient Support Tools function (84/341 total functions). Table 2 summarizes the analysis of apps containing solely family caregiver focus functions ($n = 11$) or in combination with patient focus functions ($n = 46$). The most common type of family caregiver focus function is for self-care (60% for apps containing solely family caregiver focus functions, 70% for apps containing a combination of family caregiver and patient focus functions).

Summary of evaluation claims

Table 3 summarizes the types of evaluation claims found in the app descriptions and/or websites. Only 26% (45/175) of the apps have evaluation claims which vary in the way they are expressed in their app description and/or their website. Apps mentioning the involvement of health care professionals/experts and external organizations/associations in the development of the app (38/45 apps with evaluation claims, 84%) commonly have phrases such as "Developed by and "Worked with [...]." There are fewer apps with evaluation claims which incorporate "evidence-based"/"research-based" phrases (4/45 apps with evaluation claims, 9%) or mention that a research study is being or has

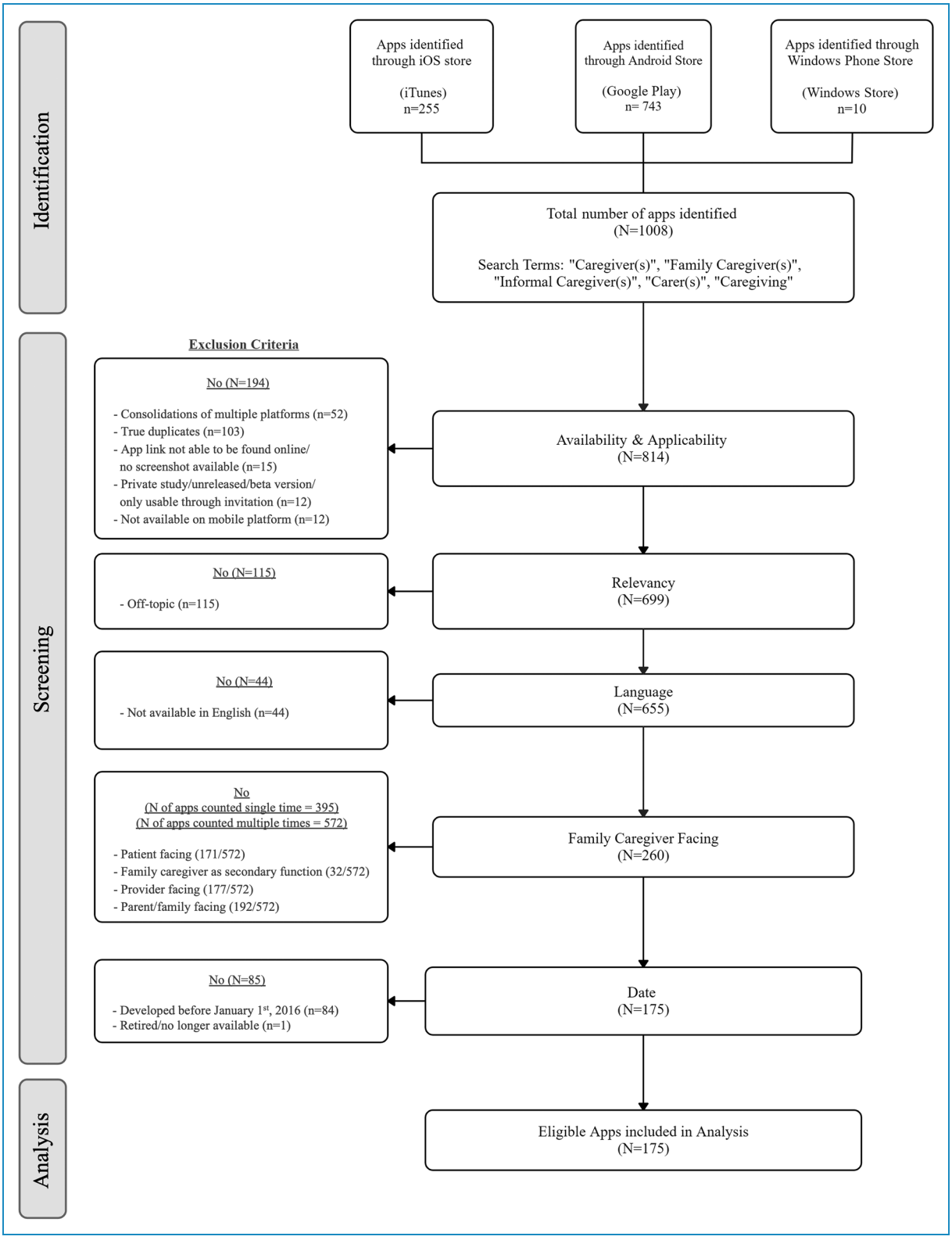

Figure 1. Flow diagram of overall app screening process.

Table 1. Summary of general app characteristics.

Cost for app	Free	90% (157/175)
	Paid (range: $0.99–134.99 USD)	10% (18/175)
Additional cost within app	Purchase within app	7% (12/175)
	Subscription/ Session fee	10% (18/175)
	Upgrade to paid functions/ Subscriptions	14% (24/175)
	None	69% (121/175)
Need for additional devices	Existing device available in the market	22% (39/175)
	App-specific device	10% (17/175)
	Either existing device/ app-specific device	2% (3/175)
	None	66% (116/175)
Disease-specific	Yes	35% (62/175)
	No	65% (113/175)
Target caregiver age group	General	98% (172/175)
	Young	2% (3/175)
Focus	Patient focus	67% (118/175)
	Family caregiver focus	6% (11/175)
	Combined focus	26% (46/175)
Number of functions per app	1 Function	36% (63/175)
	2 Functions	41% (71/175)
	3 Functions	17% (29/175)
	4 Functions	5% (9/175)
	5 Functions	2% (3/175)
Interoperability		
• **Platform**	Android & iOS	65% (113/175)
	Android	18% (32/175)
	iOS	14% (25/175)
	Android & iOS & Windows	2% (3/175)
	Windows	1% (1/175)
	Android & Windows	1% (1/175)
	iOS & Windows	0% (0/175)
• **Web-app availability**	Yes	43% (76/175)
	No	42% (73/175)
	N/A	15% (26/175)
• **EMR (electronic medical record)/EHR (electronic health record) integration**	Yes	4% (7/175)
	No	96% (168/175)
Evaluation claims	Yes	26% (45/175)
	No	74% (130/175)

already been conducted (3/45 apps with evaluation claims, 6%).

Due to the quickly evolved landscape of mHealth apps since our initial search, the authors conducted a short, targeted search of recently published mHealth apps using the same nine keywords ("Caregiver(s)," "Family Caregiver(s)," "Informal Caregiver(s)," "Carer(s)," "Caregiving") in the iOS, Android, and Windows Phone app stores. We restricted the search to 1 year (24 November 2020 to 24 November 2021) and identified 14 unique apps in total that had not been identified in the initial search. Similar to our findings, the majority of the functions in these 14 apps were patient focused. In particular, most apps offered monitoring/alerts (5/14 apps) and patient case management functions (5/14 apps). Other

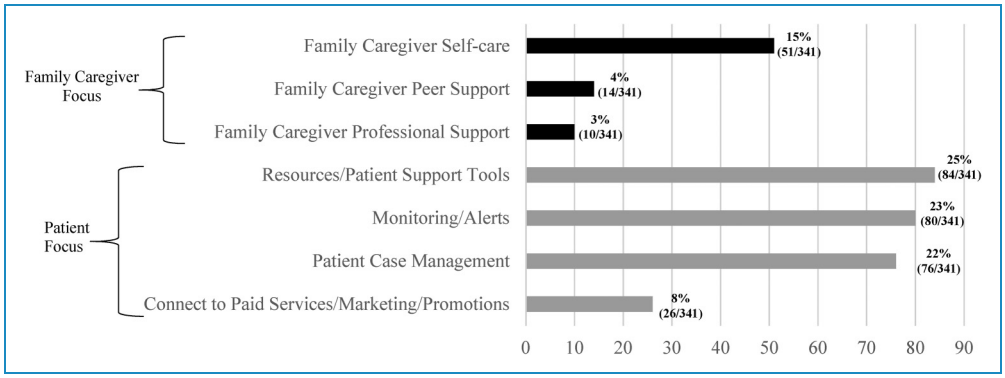

Figure 2. Analysis of app functions.

Table 2. Analysis of apps containing family caregiver focus functions.

Apps containing only family caregiver focus functions	Family caregiver self-care	Peer support	Professional support
N = 11 apps Total number of functions = 15	60% (9/15)	33% (5/15)	7% (1/15)
Apps containing both family caregiver focus functions and patient focus functions	Family caregiver self-care	Peer support	Professional support
N = 46 apps Total number of functions = 60	70% (42/60)	15% (9/60)	15% (9/60)

functions provided by the newly identified apps included resources/patient support tools, family caregiver professional support, and family caregiver peer support. The list of the identified apps in this updated search are available in Supplemental File 4.

Discussion

Principal findings

The key findings of this scoping review are that a variety of mHealth apps are currently available to support family caregivers, but that critical gaps remain to be filled. The following sections describe three critical "app gaps" identified through this scoping review and offers recommendations on where future development and evaluation should go in the caregiver app space.

App gap #1: Insufficient caregiver support functions. Overall, disproportionately more of the identified family caregiver apps were designed to assist caregivers with supporting patients as compared to assisting caregivers to support themselves. Of those apps that do aim to provide support for caregivers, functions typically focus on self-care support such as meditation guides, reading articles/anecdotes, and monitoring their own health independently. There are few apps available for caregivers to request peer and professional assistance. Even amongst apps that provide peer and professional assistance to caregivers, not all them (e.g. *Young Onset Dementia, Oxleas Dementia, OC Senior Resources*) provide active, interactive support (e.g. social health network, phone/video chat/message communication). Instead, they mostly provide service directories for family caregivers to register for peer support group events.

This gap is critical because family caregivers stress the importance of managing their own physical and psychological well-being.[36] One of the main unmet needs for family caregivers is to receive additional professional help and peer support to obtain advice, emotional support and learn about stress and coping strategies.[2,37] Family caregivers prefer a combination of in-person services and static self-care information to access support services.[38–42] Caregivers do not want to solely rely on online learning materials or forums. Apps providing social network (*e.g. Javoo Connect*), for instance, allow caregivers to connect with other undergoing similar personal experiences which helps bring positive outcomes in their quality of life.[43–44]

Providing further in-person peer support group involvement and professional assistance will be beneficial for caregivers who have difficulty seeking mental and physical health support due to negative societal views, lack of self-confidence, or the inability to recognize the need to seek help.[7] Since caregivers are responsible for increasing levels of care of their loved one, they are often too occupied to reflect on their own health. Caregivers also express feeling invisible when health care teams forget to include them when coordinating their loved one's care.[7]

Table 3. Analysis of types of evaluation claims.

Types of evaluation claims	$N = 45$ Apps with evaluation claims	Example of evaluation claims	
		App name	Claim
Mentioning the involvement of health care professionals/experts/researchers or external organizations/associations in the development of the app	38/45 (84%)	Young Onset Dementia (YOD)	"We work closely with GP's and Clinicians in order to create mobile apps that improve healthcare and awareness."
		MedOClock FREE Pill Reminder	"Our Partners: Griffe, Golden Home Care, Foundation Maison Gilles-Carle, SOS Sitter"
Incorporating "evidence-based"/ "research-based" phrases	4/45 (9%)	Mindoula	"The service is an affordable, *evidence-based* alternative to the traditional behavioral health case management approach."
		Endeavor 3: Phone	"Endeavor 3 is the only *research-based* scheduling system available [...]"
Mentioning that research study is being or already conducted	3/45 (6%)	Wildflowers Caregivers	"Wildflowers *User Studies Have Begun*- University Of Toronto User Study-Studies are now underway with Dr Norman Farb of the University of Toronto [...]"
		CareGeneral	"We commissioned Mather Lifeways Institute on Aging to conduct a *feasibility study* of our platform."

Supportive and positive interactions with their health care professionals and peers undergoing similar experiences can greatly assist with these challenges. By providing an environment for family caregivers to comfortably and safely share how they are feeling and coping with their stress,[7,45] family caregivers will feel less isolated, will more easily navigate health services from their peers' personal experiences,[45–46] and will gain practical tips and advice to manage their challenges.[45,47]

App gap #2: Insufficient support of the caregiver role. A variety of functions are provided through the currently available apps. The most common function offered is *Education/Resources/Patient Support Tools*, which provides access to service and provider directories, patient-caring tips, and patient supporting tools to facilitate daily activities. This function corresponds to caregivers' primary use of technology.[23,37,46–47] The *Education/Resources/Patient Support Tools* function assists with family caregiver's expressed difficulties in figuring out where to initially search for information and the lack of support received from non-medical staff.[23,37–38,48–49] With the necessary articles, tips, and directories to desired services within the apps, family caregivers can save time when searching and easily obtain answers and information in caregiver-friendly terms.[23,38]

However, education and information support tools only represent one of the activities of caregiving. A web-based survey conducted by Zulman et al. (2013) demonstrated that technology-using out-of-home caregivers were interested in multiple health information technology functions, including communicating with their loved ones' health care professionals and accessing their loved ones' medical test results online.[24] Our analysis revealed, however, 77% (135/175) of the apps only had one (37%, 64/175) or two (41%, 71/175) functions. Caregivers have already expressed concerns with the time it takes to engage in technology,[23,24] which is a problem exacerbated by the fact that apps only address one or two of their needs at a time. These difficulties could contribute to family caregivers' preference to use the Internet to seek information instead of mobile apps.[31]

App gap #3: Sparse evaluation claims. Few of the apps identified in this review present evaluation claims regarding quality and effectiveness. The quality and trustworthiness of the information available is a major technology barrier faced by caregivers.[50] In the literature, caregivers often compare various sources of information to acquire necessary information.[38–41,51–52] For this study, a broad, general criterion was used for evaluation claims and included apps that mentioned or suggested that the app is

evidence based from their app descriptions or websites. Twenty-six percent (45/175) of the apps claimed to have been evaluated; however, as noted in our findings, the range of evaluation claims varied Therefore, it is challenging for family caregivers and their providers to find or recommend mobile apps containing accurate and up-to-date information.[53]

Clinicians also do not have the time to search online for the specific app to check for the accuracy of information presented during their consultation.[54] Apps would mention that its development involved professionals, experts, partners, organizations, association, or that the development process was otherwise evidence-based. However, apps did not present any supporting studies or made it difficult for users to find them on their websites or their app descriptions. Therefore, although the results reveal 26% (45/175) of the apps have evaluation claims, it is unlikely that all of these apps have undergone rigorous evaluations. Caregivers want to be well-informed, but current information on apps is insufficient to meet this need.[38]

Limitations

Apps were not downloaded to analyze function and characteristics due to resource constraints. Therefore, they may not truly reflect their functions, or we may have missed out on some functions or evaluation claims that were not explicitly mentioned in the app description and/or website. Also, because apps are continuously being updated, deleted, and added, some features of the apps (names, descriptions, functions, etc.) may have changed since our initial search in May 2017.

Future directions

Apps aiming to support family caregivers should incorporate more functions that are specifically designed to help the family caregiver as opposed to the care recipient, especially in terms of connecting caregivers to professional or peer support. Future development of apps should ensure user-centered co-design with family caregivers to accurately capture and fully address family caregivers' needs,[55–56,57] while improving meaningfulness and usability of apps.[58] This may be best achieved throughout the app development process by having an iterative design process collaborating with multidisciplinary teams and having focus group discussions or interviews with target groups.[55,59] App development companies can also actively participate or even sponsor symposia and conferences related to family caregivers to get a better idea of the challenges the users or family caregivers are going through and develop apps that meets their specific goals. Conducting systematic evaluations, usability and feasibility testing can further ensure high levels of quality and the users' needs are being met.[57–58]

App developers should recognize and accommodate the various caregiver age groups, such as the young caregiver population, when developing apps. A recent estimate is that approximately 17% of caregivers are between the ages of 15 and 24.[1] Young caregivers are less exposed to the health care system and they are less likely to be familiar with existing support services available to caregivers.[7] They are also at higher risk of vulnerability and lack of recognition as a caregiver due to their younger age and experience.[7] With the majority of young caregivers having access to smartphones nowadays,[60] mHealth apps will allow for easy access to necessary services or information.

Finally, future work could seek to categorize caregiver apps along the lines of caregiver roles and activities. This categorization could help caregivers more quickly identify apps to serve their needs. Categorization could also help to advance future synthesis studies exploring the role of mHealth technologies in supporting caregivers. Working together with diverse caregiver groups across different ages, languages, and ethnic and racial backgrounds could help to develop such a categorization that would advance meaningful of use mHealth apps for caregivers.

Conclusions

This scoping review provides a detailed depiction of the mHealth apps that assist and support family caregivers. Our results indicate that most family caregiver facing apps are largely designed to assist caregivers to support their loved ones rather than to support the family caregivers themselves. An important limitation is how most apps only serve to support one or two activities of caregiver, which can result in a need for multiple apps to support various activities, potentially serving to increase caregiver burden. Furthermore, many apps lack a substantive evaluation which could further exacerbate challenges when caregivers are deciding on which apps may be of most benefit. The next generation of evidence-based mHealth apps could be improved by addressing technology barriers that family caregivers face such as limited access, cost, trustworthiness of information available, and unfamiliarity with programs or websites that provided support.[23,24,50] These study findings can be used to inform the future development of caregiver apps to better meet these needs, in particular. Ideally future apps would be co-designed with family caregivers, and specifically targeted at caregivers who are most at risk of caregiver burnout such as those caring for patients with complex needs patients or end-of-life patients.[61] Through co-design, apps may have a greater opportunity to meet the diverse needs of family caregivers, and as such, help to reduce overall caregiver burden.

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