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Faculty of Behavioural, Management and Social Sciences

Mobile applications

for informal caregivers: a systematic review of

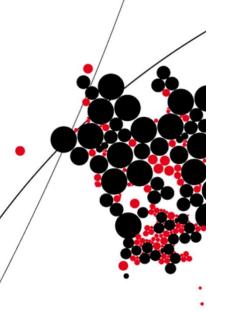
existing mobile applications

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Abstract

Worldwide, there are many informal caregivers who care for someone without any financial reward. As a result, they may experience stress and negative feelings. They have to manage their own life together with the life of the person they care for. To support informal caregivers in these challenging situations, many different face-to-face and web-based interventions have been developed. However, these interventions have some disadvantages such as their limited accessibility, as they may be dependent on personal appointments or the availability of a computer. Furthermore, they might be time-consuming. Mobile health (mHealth) could be a possible solution to these problems. It can be integrated in the informal caregivers' everyday lives, which means access to an intervention at any time. This study aims to examine which mobile applications for informal caregivers exist at the moment, what their content is, and what kind of mHealth features are incorporated in these mobile applications.

A systematic review in Apple's App Store was conducted with the Dutch and English search terms "caregiver", "mantelzorger", "informal caregiver", "mantelzoger", and "informal care". All mobile applications were analyzed in a systematic way with two extraction sheets. One was about the content of the mobile applications related to caregiving tasks, such as information, facilities to improve contact to health professionals, practical tools, and related to informal caregivers' well-being, namely peer support, psychological exercises, recreation and practical tools. The other extraction sheet was related to mHealth related features, namely multimodal presentation of content, interactivity, integrated in daily life, use of other hardware and use of related software. All mobile applications were rated with these extraction sheets by one rater.

The results showed that mobile applications for this target group are scarce (N=35). Most of the content related features refer to practical tools related to caregiving tasks such as creating a care team (17%), and information on certain topics such as medical information (22%). Referring to mHealth related features, it appeared that the most used modal presentation is text-based (48%). Besides, the results showed that the mobile applications studied are relatively new (not older than six years old) and do not have any ratings in Apple's App Store.

This study emphasized the limited availability of mobile applications for informal caregivers; people, who could benefit from supportive tools not only about how to provide and organize care but also how to increase their own well-being. Significantly, the existing mobile applications were not fully making use of the potential of mHealth. Further research is needed to examine which features are interesting and effective to incorporate in mobile applications for informal caregivers.

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1. Introduction

By 2050, 22 per cent of all people around the world will be 60 years of age or older, which is around one quarter of the world's population (Wadd & Galvani, 2014). Worldwide, many people will be affected by this demographic change (O'connell, Chin, Cunningham, & Lawlor, 2003). As the number of elderly people with chronic diseases will increase, health-related costs will also increase. The responsibility for care is shifting from healthcare providers to patients and their families (Kajaks, Longfield, Orozco, Holyoke, & Dutta, 2015). Patients are staying at home instead of in hospitals. Family members and friends who provide care for someone with specific health problems, chronic diseases or other disabilities without any salary or financial compensation are called informal caregivers (Walker, Pratt, & Eddy, 1995; through Guay et al., 2017). In the Netherlands, almost 15% of the population, 18.1% of the nation's women and 11.7% of its men (Sociaal en Cultureel Planbureau, 2015), are giving care to a family member or friend for an average of eleven hours each week (Centraal Bureau voor Statistiek, 2016).

According to Guay et al. (2017), informal caregivers do not only care for their loved ones, but also carry out different tasks. For example, they provide emotional support, take responsibilities for the household and children, and manage the care receivers' diseases by scheduling appointments or administering medication (Stenberg, Ruland & Miaskowski, 2010). There are some informal caregivers who may find the different tasks and responsibilities as a positive experience and associate being an informal caregiver with positive aspects, such as the special and intimate relationship with the patient that has developed due to the level of care given over a (long) period of time (Cohen, Colantonio, & Vernich, 2002). But there are also informal caregivers who experience all kind of burdens, which can have a negative influence on the their physical, emotional and social well-being leading to depression, anxiety, and high levels of stress (Zarit, Todd, & Zarit, 1986; through Guay et al., 2017; Adelman, Tmanova, Delgado, Dion, & Lachs, 2014). For example, partners of cancer patients often experience negative aspects such as feelings of sadness, fatigue or sleeping problems (Stenberg, Ruland, & Miaskowski, 2010). Furthermore, they may experience difficulties with accepting the illness and dealing with it. Moreover, they may feel like they have a duty of care and must be there to support their loved one at all times (De Klerk, de Boer, Plaisier, Schyns, & Kooiker, 2015). Some partners even forget to care for themselves including taking care of their own needs, wishes, and free time. This can lead to emotional and physical exhaustion and a so called "emotional roller-coaster" with feelings of fear, guilt, helplessness and frustration (Stenberg, Ruland & Miaskowski, 2010). Besides, informal caregivers who are taking care of someone with physical disabilities or difficulties have higher risks of low back pain and back injury due to the physical care that they are providing (Kajaks et al., 2015).

Informal caregivers have various needs while caring for their loved ones which can be divided into being related to caregiving tasks and being related to the informal caregivers' own well-being. Occasionally, informal caregivers might not know enough about how to give proper care or how to be empathetic to the patients' needs in the way that is required. This is mainly due to the fact that they have not been given professional training on how to correctly care for a person with a certain chronic disease such as cancer or diabetes. Also, they might not know how to behave in their challenging situation (Sermeus, 2016). Therefore, informal caregivers need information on these topics (Docherty et al., 2008; Sobnath et al., 2017). Further, informal caregivers should be in contact with health professionals, such as general practitioners, oncologists, nurses or psychologists, to be up to date about the development of the disease and to receive (medical) support from a health professional who has a different perspective than the informal caregiver (Feeney et al., 2001). For the informal caregivers it these professionals should be easy to reach. Therefore, there is a need of facilities to improve the contact with these professionals. Occasionally, informal caregivers also experience some difficulties with the planning of tasks and general management of their loved one (caregiving related tasks) (Osse, Vernooij-Dassen, Schadé, & Grol, 2006). In this situation, they could make use of practical tools to help them with provide and organize care for the loved one such as creating a sufficient schedule including all important and caregiving related appointments (Osse et al., 2006; Sermeus, 2016; Syrowatka, Krömker, Meguerditchian, & Tamblyn, 2016).

On the other hand, there are several needs regarding the informal caregivers' own well-being separated from the act of giving care to the loved one. It is more about the informal caregivers themselves. They may experience the need to share their experience about personal feelings or to talk to people who are in the same situation to feel some support (Sermeus, 2016). This can be done by being in contact with other informal caregivers, such as peer support. It is also possible to share information on social media or meet others in this way (Middelweerd et al., 2015). As already mentioned, some informal caregivers experience high levels of distress and difficulties coping with their emotions. In line with that, in studies, informal caregivers have indicated the need for information or exercises that can help them with these aspects. Psychological exercises, such as mindfulness-based or relaxation exercises, may be helpful for them (Whitebird et al., 2012). Also, self-compassion, prayers or goal-setting can work as psychological exercises for informal caregivers to decrease stress levels (Neff, Hsieh, & Dejitterat, 2005). Informal caregivers might also lack time for themselves and are often

consumed with feelings of responsibility and guilt when they do find some free time (Stenberg, Ruland & Miaskowski, 2010). This can be reduced by providing informal caregivers more personal recreation and free time, away from caring for their loved one (Cantor, 1983; Liu & Yu, 2017). There are also practical tools related to themselves, such as recording own health records. To summarize, the following main categories play a crucial role for informal caregivers. First, related to caregiving tasks which are *information*, *facilitaties to improve the contact with health professionals* and *related practical tools*. Second, main categories related to informal caregivers' own well-being which are *peer support*, *psychological exercises*, *recreation*, and *related practical tools*.

Several interventions have been developed to support informal caregivers in these domains, with the aim of supporting them in their daily life, reducing their burdens and maintaining their own health (Guay et al., 2017). There are many face-to-face interventions, but informal caregivers do not always have the time to meet with health professionals due to their caregiving tasks or other responsibilities. Also, some web-based interventions exist, such as "Hold on, for each other", which support the partners of cancer patients (Köhle, Drossaert, Schreurs, Hagedoorn, Verdonck-de Leeuw, & Bohlmeijer, 2015) or the psychoeducational intervention "Diapason" for informal caregivers of patients with Alzheimers (Cristancho-Lacroix, Wrobel, Cantegreil-Kallen, Dub, Rouquette, & Rigaud, 2015). But some of the web-based interventions lack certain features, such as the availability of resources "on the go", which means dependence on a computer for the informal caregivers.

A solution to this problem may lie in the possibilities mobile health (mHealth) could offer. According to Roberts et al. (2016), informal caregivers' preferences for communication is using a mobile application to text, such as a message from their children reminding them to take their medication or other treatment. They would also use mobile applications for monitoring and tracking purposes, such as medication intake (Roberts et al., 2016). mHealth is not only more affordable than face-to-face and web-based interventions, but also more accessible for informal caregivers (Chiarini, Ray, Akter, Masella, & Ganz, 2013). According to Silva, Rodrigues, De la Torre Díez, López-Coronado and Saleem (2015), mHealth can have major improvement on patients' life. This is because of the possibility to connect to a smartphone anywhere anytime. It is a "right-on-the-spot" opportunity. mHealth delivers healthcare services overcoming geographical, temporal and even organizational barriers. Also, the size of a smartphone plays a crucial role because it fits into hands and pockets, so informal caregivers can carry their smartphones at all times (Miller, 2012). Mobile applications also include certain features that other do not have. These features are the possibility to connect with other devices (Miller,

2012), GPS (Schoeppe et al., 2017), visual output and input of pictures or videos (Miller, 2012), audio output and input (Miller, 2012), haptic and motor features (Miller, 2012), sending awards and rewards (Schoeppe et al., 2017), push notifications (Schoeppe et al., 2017), reminder/alarm (Liu, & Yu, 2017; Schoeppe et al., 2017), uploading and downloading files (Liu & Yu, 2017), calendar (Liu & Yu, 2017), feedback (Syrowatka et al., 2016), making a personal account and offline usability. While dealing with mHealth, negative aspects have also been encountered, such as the use of private data and ethical issues (Gasser et al., 2006). The mHealth related features in this study are *multimodal presentation*, *interactivity*, *integrated in daily life*, use of other hardware, and use of software.

Although there are already existing mobile applications for informal caregivers that have been shown to be effective, such as PROTÉGÉ (Ferreira et al., 2013) and SafeBack (Kajaks et al., 2015), there has been no study about the exact features that can make the mobile applications more effective. Moreover, there is no study about the amount of available mobile applications for this target group including what kind of content the mobile applications have, and which mHealth features are used. That is why mobile applications for informal caregivers are interesting to investigate: they give new opportunities for global access of health services and medical care, especially for patients with chronic diseases and their informal caregivers (Chiarini et al., 2013).

Study aim

The aim of this study is to conduct a systematic review to find out three things: First of all, what kind of mobile applications already exist for informal caregivers who care for someone with a chronic disease? Second, what is the content of these mobile applications? Third, what are the mHealth features of these mobile applications?

2. Methods

A systematic review was conducted to get insights into the existing mobile applications for informal caregivers, their content and integrated mHealth features.

Search strategy

The search was conducted in Apple's App Store on an iPhone 6 in the period from the beginning of October 2017 until the end of November 2017. The search was conducted using the following search terms: caregiver, mantelzorger, informal caregiver, mantelzoger, and informal care. Certain inclusion and exclusion criteria were made. Only English and Dutch mobile applications that aimed to help and support informal caregivers who give care to someone with a chronic disease were included. Mobile applications about every other topic such as pregnancy, nannies, fitness or vaccines were not included in this study. Also, mobile applications dealing with finding (senior) care homes and caregivers, or those with technical problems or needing a special identification number or code to log in, were excluded. In addition, paid mobile applications, mobile applications only for patients, other languages than English and Dutch were excluded. Figure 1 shows a flow diagram of all included and excluded mobile applications. Mobile applications were downloaded based on their description in Apple's App Store and if they fitted in the inclusion criteria or not. After downloading them, 45 mobile applications were checked once more to see if they matched all inclusion criteria. From the total of 45 mobile applications, 14 had to be excluded from the sample for different reasons (seven were not related to the study topic, three had technical problems, two were only aimed at patients, one was in another language, and one was an online magazine which had to be paid). After that, 31 mobile applications remained. The sample consisted of 35 mobile applications, 31 English and four Dutch. Table 5 shows all included mobile applications with a short description, target group and year of publishing.

Total found mobile applications

Search terms: Caregiver (N=247), Mantelzorg (N=15), Caregiving (N=9), Mantelzorger (N=4), Informal Caregiver (N=0), Informal Caregiving (N=0)

N=275



After check for in- and exclusion criteria

- Different topic N=120
- Needed special login ID N=37
 - Home care services N=21
 - Technical problems N=20
 - Caregiving finders N=15
- Paid mobile applications N=15
 - Different language N=10
 - Only for patients N=2

In total N=240 excluded mobile applications



Included mobile applications for this study

N = 35

Figure 1. Flow diagram of included and excluded mobile applications of this study (N=35)

Data extraction

To review the mobile applications, two systematic data extraction sheets were developed. One was related to the content of the mobile applications related to the caregiving tasks including the main categories information, facilities to improve contact with professionals, practical tools, and related to informal caregivers' own well-being including the main categories peer support, psychological exercises, recreation, and practical tools (see Table 1). The other sheet is related to the mHealth features with five main categories: multimodal presentation of content, interactivity, integrated in daily life, use of hardware, and use of software (see Table 2). Next to this, a short description, target group and year of publishing of the mobile applications were extracted. Based on the two extraction sheets it was decided if the content or mHealth features were included or integrated in the mobile application (present = 1, not present = 0). All mobile applications were rated by one rater.

Table 1. Content of Mobile Applications with Sub-categories and Definitions

Main categories	Sub-categories	Short definitions
Related to the caregiving tasks		
Information	Information about caregiving	Information about caring including communication between caregivers and patients, tips on caring, how to react in certain situations, and how to behave in a certain situation.
	Medical information News	Information on medication and medical details. Information about the latest news on caring and illness-related news.
Facilities to improve contact with professionals	Contacts around List with professional contacts Chat contact with professionals	Personal contacts of users linked to their own location (if so wished). A list with professional contacts, such as health professionals, hospitals pharmacies and 24/7 helplines is given. Users can get in contact with professionals via text message.
Practical tools	Creating a plan/schedule	A function to create a plan or schedule all important things related to caregiving.
	Managing appointment	A function to make and share appointments with others, such as family members or other informal caregivers.
	Creating a care team	A function which connects different people (informal caregivers) to create a care team.
	Drug and disease search	Integrated dictionary to look up unknown words, which are related to drugs and disease.
	Saving prescriptions Making a to-do list Managing medication	A function which allows the user to save all prescriptions. A function which helps the user to create a to-do list. A function which helps the user to manage the medication intake of the
		patient. A list with people and professionals to contact in an emergency. An option to be led to other web-sides for additional (caregiving and disease related) information.
Related to informal caregivers' own well-being		
Peer support	Social support	Getting in contact with others via a chat function and sending for example "well wishes".
	Linking/sharing on social media	Sharing files, such as photos or videos, on social media, e.g. Facebook.
Psychological exercises	Mindfulness Relaxation	Exercises based on mindfulness. Relaxation exercises.
	Self-compassion	Exercises based on self-compassion, which consists of self-kindness humanity, and mindfulness.
	Meditation Inspiring quotes Prayers	Meditation exercises. Motivational and inspiring quotes to stimulate positive thinking. If religious, prayers can be requested.
	Goal setting	Users can set their own personal goals.
Recreation	Events Quiz and questionnaire	Caregiving events are listed. Questions about knowledge of giving care and the informal caregiver feelings.
	Music	A function to listen to music.
Practical tools	Calculators	Calculator function, which calculates the Body Mass Index, Body fa percentage.
	Own health records	An option to write down one's own health records.
	Symptom checker Stress test	An option to check one's own symptoms. The user can conduct a short stress test.
	Tips	A list with all kinds of tips for the informal caregiver.
	Maximizing personal energy	Exercise to maximize energy.

Table 2. mHealth features of Mobile Applications with Sub-categories and Definitions

Main categories	Sub-categories	Definitions
Multimodal presentation of content (system to user)	Information by video, text, audio Download information Awards and rewards Making a personal account	Information given in video, text or audio form. The possibility to download videos, photos or other files. Awards or rewards for the user after completing something. Creating a personal account including name, email, gender and password to be allowed to use the mobile application.
Interactivity	User to system - Uploading pictures, videos, other information User to developer User to professional User to user	The mobile applications interact with the user. The user can upload files such as pictures, videos or other information via a certain function. The developer of the mobile applications interacts with the user. Health Professionals can interact with the user. Users can interact with each other.
Integrated in daily life	Push notifications Reminders/alarms Calendar Vibration Offline usability	A function to set up push notifications. A function to set reminders and alarms. Integrated calendar in the mobile application. The option to turn the vibration on/off. The mobile application can also be used offline.
Use of other hardware on mobile device	GPS Connectivity with other devices	The mobile application can be connected to GPS. The mobile application can be connected to other devices, such as a weight scale or Fitbit.
Use of related software	Data mining Analysis of user patterns, such as voice or movement	The mobile application makes use of big data. The mobile application can save user data, such as their voice, texts or movements.

3. Results

In the following, the results of the systematic review will be presented. First, a general description of the existing mobile applications will be given. After that the results regarding the content of the mobile applications and their mHealth features will follow.

Overview of mobile applications

In total 35 mobile applications were found and used for further analysis. An overview of all mobile applications including their names, short description, target group and year of publishing is presented in Table 3.

Twenty-four out of 35 mobile applications were not specific for one group of patients with a certain chronic disease, such as cancer, but for more general use. This means that all informal caregivers can use these mobile applications no matter which chronic disease their loved ones have. Out of the other eleven mobile applications, six were aimed for informal caregivers of Alzheimer or dementia patients, two for informal caregivers of cancer patients, one for informal caregivers of stroke patients, one for informal caregivers of patients with autism, and one for adults with parents who have a chronic disease in general (see Table 3). Further, all analyzed mobile applications are from no earlier than 2011 and do not have any ratings in Apple's App Store. Five mobile applications are relatively new, as they were published last year (2017).

Table 3. Overview of Included Mobile Applications (N=35)

	Applications' names	Description	Target group	Year of
				publishing
1.	genieMD	Mobile application, which allows connection to other devices and data, such as Apple HealthKit.	General	2013
2.	Tender loving Elderly- Family Caregiver's guide	Mobile application, which focuses on caregiving including "how-to's".	General	2016
3.	Alzheimer's Association Caregiver Buddy	Mobile application, which gives tips, support in areas of daily routine, communications, and behaviors.	For caregivers of dementia patients.	2015
4.	American Caregiver Association	Mobile application, which provides information for caregivers.	General	2015
5.	Med Helper- Pill Reminder and Medication Tracker	Mobile application, which helps to keep all appointments and medication information in one place.	General	2011
6.	S3 Care-giver Wellness (Stroke-Support-Station)	Mobile application, which gives information, useful links, and enables the caregiver to keep track of their own (mental) health. It includes mindfulness exercises.	For caregivers of stroke patients.	2015
7.	The Caregiver- PeaceHealth News	Mobile application, which gives an overview of information and news all about caregiving.	General	2015
8.	Caregiver Community about Cancer	Mobile application, which helps to learn how to communicate about the fact of knowing someone who has cancer.	For caregivers of cancer patients.	2016
9.	Caregiver Prayer	Mobile application with daily encouragement.	General	2016
10.	OHCA caregiver (Oregon Health Care Association)	Mobile application, which gives access to the Oregon Caregiver, which is a magazine about caregiving.	General	2016

Table 3	Overview of	Included Mobile	Annlications	(Continued)

Tips for families (ALZ Videos) 12. My Cancer Circle (MCC) Mobile application, which helps to caregivers and friends. It helps to organize stuff and provides the feeling of being connected. Its connected to My Cancer Circle. Mobile application, which helps parents to get organize the medication, which helps parents to get organize with information about caregiving events, such as conference (ICC 2017) 16. Caregiving Events 17. 7th international carers conference (ICC 2017) 18. Carelocal- Alzheimer's and Dementia Magazine 19. GATSS Mobile application, which helps family members to stay connected with older family members who live alone. The iPhone or iPad works as an automated call for help. This is an alert application, which is an online magazine with information all about Alzheimer's and dementia. 20. CeyHello Medication Adherence & Patient Adherence & Patient Organize the information and management application, which helps family members to you by GLSS 22. SafeWander 23. Carely- Caregiving app for families 24. Flower: Support Registry to help family & friends 25. eCare Vault 26. eCare App Mobile application, which helps to create virtual care tams for loved ones. Mobile application, which helps to read the delarly, the information and management to reduce overal stress and caregivers to get from bed or chair and leaves the room. It monitors the loved one from everywhere and includes a wearable sensor. Mobile application, which help	ients. rs of 2013 rts. 2013 of 2013 2016 2017
My Cancer Circle (MCC) Mobile application, which is a community application, which helps coordinate help, such as transportation to medical appointments or giving support and information to caregivers. This is a calendar mobile application, which helps to coordinate and communicate within family members and friends. It helps to organize stuff and provides the feeling of being connected. Is connected to My Cancer Circle. Mobile application, which helps parents to get organized with everything related to their children's autism. Mobile application, which helps to organize the medication intake and works as a pill reminder. Mobile application, which provides family/care with information about caregiving events, such as conferences. Mobile application, which helps to organize the medication intake and works as a pill reminder. Mobile application about the international carers conference (ICC 2017) Caregivers Alzheimer's and Dementia Magazine General Mobile application, which is an online magazine with information about caregiving events, such as conferences in October 2017. Mobile application, which helps family members to stay connected with older family members who live alone. The iPhone or iPad works as an automated call for help. This is an alert application, which helps tamily members by giving a reminder to taking medicine. Mobile application, which sends an alert to caregivers' mobile phone when the loved one gets up from bed or chair and leaves the room. It monitors the loved one from everywhere and includes a wearable sensor. Caregivers Matter brought to you by GLSS Carely- Caregiving app for families Carely friends C	2013 2013 2016 2017 2017 2016 2014 2016 2017
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27. Old Smarts Mobile application, which is aimed to help the elderly, General	2016
that can help the elderly in daily life.	2016
28. CareZapp Mobile application, which supports the user in caregiving, General helping him/her to share the care and bring peace of mind.	2015
29. CareZone Health organizer Mobile application, which helps to manage caring of a General loved one.	2017
30. Caregiving Quiz Mobile application about a quick quiz including several General questions on the topic of caregiving.	2012
31. Caregiving groups Mobile application, which helps to create caregiving General groups.	2016
32. Fello Mobile application, which helps to create caregiving General (Dutc groups and manage/divide tasks related to it, including a calendar.	ch) 2015
33. Alzheimer Assistent Mobile application with all kinds of information about Alzheimer's. It helps to connect with others and gives patients with Dementia (Du	
34. Zorgsamen Mobile application, which helps to create tasks and divide General (Dutc them with others; including a logbook.	
35. Empowerment Mobile application, which helps young adults (10-20 years) to learn how to deal with a parent who has a chronic disease. This mobile application includes information and a test. For caregivers have a parent chronic disease (Dutch)	

Content of mobile applications

Eighteen out of 35 mobile applications, used integrated information related to caregiving tasks, which means how to give care, what to do in emergency situation, what to say to the loved one or in general what it means to be an informal caregiver (see Table 4).

Table 4. Overview of Content offered in the analyzed Mobile Applications (N=35)

Main categories	N=35	%	Sub-categories	N	%
Related to caregiving tasks					
Information	18	51		N=27	
			Information about caregiving	13	48
			[3;4;5;7;8;11;12;18;21;24;27;33;35] Medical information [1;11;12;20;21;33]	6	22
			News [1;7;10;18;27]	5	19
			Psycho-education [11;27;33]	3	11
Facilities to improve contact with	9	26		N=12	
professionals			List with professional contacts [1;3;5;20;29;33]	6	50
F1-1-1-1-1-1-1-1-1-1-1-1-1-1-1-1-1-1-1-			Contacts around [1;17;31]	3	25
Describedia	00	00	Chat contact with professionals [4;17;20]	3	3
Practical tools	29	83		N=64	
			Useful links to other websites	17	27
			[1;3;4;6;9;10;11;12;17;18;21;24;26;27;32;33;35]		
			Creating a planning/schedule	14	22
			[1;5;12;13;14;15;17;20;22;23;24;26;31;32] Creating a care team [1;12;13;19;22;23;24;25;28;31;32]	11	17
			Managing appointments [5;12;13;14;15;22;23;32]	8	13
			Drug and disease search [1;8;24;27]	4	6
			Managing medication intake [5;15;20;29] Making a to-do list [8;29;34]	4 3	6 5
			List of emergency contacts [1;5]	2	3
			Saving prescriptions [5]	1	2
Related to informal caregivers' own well-being					
Peer support	10	29			
			0 11 110 10 11 17 00 01 00 01	N=11	70
			Social support [12;13;14;17;20;24;33;34] Linking/sharing social media [4;10;14]	8 3	73 27
Psychological	6	17	Linking/sharing social media [4,10,14]	3	21
exercises				N=7	
			Inspiring quotes [1;9;26] Mindfulness [6]	3 1	43 14
			Meditation [8]	1	14
			Requesting prayers [9]	1	14
D ('	4.4	0.4	Relaxation [21]	1	14
Recreation	11	31		N=11	
			Events [7;16;17;24;31]	5	45
			Quiz and questionnaire [6;12;28;30;35]	5	45
Practical tools			Music [21]	1	10
i ractical tools	10	29			
				N=14	
			Tips [3;8;21;26]	4	29
			Own health records [1;20;29] Calculators [1;20]	3 2	21 14
			Symptom checker [20;29]	2	14
			Stress test [27;35]	2	14
			Maximizing personal energy [2]	1	7

Further, information on how to care for someone with a chronic disease was given in thirteen mobile applications (see Figure 2). Also, medical information, such as side effects and information about the disease itself was given in five out of all mobile applications.



Figure 2. My Cancer Circle (Information)

In addition, nine out of 35 mobile applications used features to facilitate contact with different health professionals, such as psychologists, general practitioners or nurses. This was done by providing a list with professional contacts including addresses or telephone numbers to make it more visible for the informal caregiver. Three out of all mobile applications offered to find professional contacts in the vicinity, located by a GPS function. So, the informal caregivers can access professional help and support not far away. Almost all mobile applications, 29 out of 35, used features as a practical tool related to caregiving. The practical tool used the most is providing links to other web-sites. This was done in 17 mobile applications. Fourteen mobile applications included a function to create a plan or schedule for the informal caregiver and their loved one, eleven for creating a care team with their family members or close friends (see Figure 3), and eight for managing appointments (see Figure 4). Further, four mobile applications included a function to search for drug and disease information and managing the medication intake of the loved one. Only ten out of 35 mobile applications integrated tools for the informal caregiver themselves. Four out of the ten mobile applications, integrated several tips especially for informal caregivers (see Figure 5). Further, informal caregivers could write down their own health records, check their own symptoms (if applicable) or fill in a stress test.





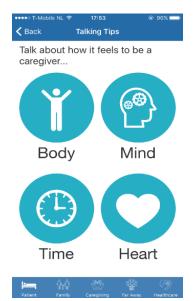


Figure 3. Carely (Creating Care Team)

Figure 4. Lotsa (Calendar) Figure 5. Caregiver Buddy (Tips)

Some mobile applications integrated features related to informal caregivers' own well-being. Ten out of 35 mobile applications used functions to stimulate peer support to get in touch with others. This is usually done by giving users the opportunity to contact other users via the mobile application. Further, it was possible to be linked to others or just sharing personal information, such as files, pictures or videos (on social media such as Facebook) so other users can read and see each other's stories and start to get in contact with each other. Moreover, there is also an option to send "well -wishes" to each other with the hope and support that the loved one will make it through, and just as a support for each other. Remarkably, psychological exercises to increase well-being of the informal caregivers are only offered in six out of 35 mobile applications. Three mobile applications used inspiring and motivational quotes to stimulate positive thinking. Further, only one mobile application integrated a mindfulness exercise, one mobile application a meditation exercise and one mobile application a relaxation exercise. There was also one mobile application giving the user the opportunity to request a prayer from someone else within the application. Self-compassion and goal-setting exercises have not been integrated in the mobile applications at all. The next category, which is integrated in eleven out of the 35 mobile applications, is the recreation and free time of the user. Five out of the eleven mobile applications integrated some information about events and conferences that informal caregivers might visit in their free time. Further, there is one mobile applications with some music function, so the informal caregiver may listen to music if so wished.

mHealth related features

All analyzed mobile applications included some features from the multimodal presentation category. Twenty-eight out of 35 mobile applications included text-based information. Only seven out of 35 mobile application offered information via videos and two via audio files. Twenty-two out of 35 mobile applications integrated the function to create a personal account before starting to use the mobile application. This option included personal details of the informal caregivers, such as name, email address, age, gender, and sometimes also if other informal caregivers are involved.

Table 5. Results of mHealth Features

Main categories	N	%	Sub-categories	N	%
Multimodal presentation (user to system)	35	100	Information by: - Text	N=58	
(user to system)			[2;3;7;8;10;12;13;14;15;16;17;18;19;20;22;23;24;25;26;27; 28;29;30;31;32;33;34;35]	28	48
			- Video [1;4;6;11;21]	5	9
			- Audio [5:9]	2	3
			Making a personal account to make use of the mobile application [1;5;12;13;14;16;17;19;20;21;22;23;24;25;26;27;28;31;32;33;34;35]	22	37
			Download information	1	2
			Awards and rewards	0	0
Interactivity	35	100		N=50	
•			User to system [5;6;8;9;15;16;17;21;22;25;26;27;30;31;34;35] Uploading:	16	32
			- Pictures [8;12;17;23;25;29]	6	12
			- Videos [25;29]	2	4
			- Information [8;12;29]	3	6
			User to developer [1;2,7;11;14;18;28;29;33]	9	18
			User to user [1;12;13;19;20;23;24;28;32]	9	18
			User to professional [1;3;4;10;33]	5	10
Integrated in daily life	28	80		N=35	
			Offline usability [5;6;7;8;9;11;15;16;17;18;21;24;26;27;29;30;33;35]	18	51
			Calendar [5;12;13;14;15;22;23;29;31;32]	10	29
			Reminders/alarms [1;8;14;15;19;26;28]	7	20
			Push notifications	0	0
			Vibration	0	0
Use of other hardware	5	14		N=6	
on smartphone			GPS [1;17;31]	3	50
			Connectivity and connections with other devices [1;20;22]	3	50
Use of related software	1	3	Analysis of user patterns, such as voice or movement [22]	N=1	100

Also, all analyzed mobile applications included features with interaction. In total, 16 out of 35 mobile applications had an interaction between the user and the mobile application. That means that the user was interacting and receiving feedback from the mobile application itself. Nine mobile applications integrated an interaction between the user and the developer of the mobile application, and nine mobile applications integrated an interaction between all users. Only five

mobile applications included an interaction or the opportunity for interaction between the user of the mobile application and a health professional, such as a nurse or psychologist.

Twenty-nine out of 35 mobile applications used features which are integrated in daily life. The most integrated feature was offline usability, which means that the user may use the mobile application any time without needing to be connected to the internet. Further, ten mobile applications included a calendar function for all caregiving related appointments. Seven mobile applications had the function of setting reminders or alarms. There was no function to regulate the use of vibration.

Five out of 35 mobile applications made use of integrated hardware on the smartphone. Three mobile applications used a GPS function, which may help the user to find health professionals and other users in their vicinity. Three mobile applications made use of the possibility to connect with other devices or mobile applications, such as the Fitbit or Apple HealthKit (see Figure 6 and Figure 7). Only one of all the mobile applications made use of related software, which is a mobile application that counts and analyzes the foot-steps the user makes. No mobile applications make use of data mining such as big data.



Figure 6. CeyHello

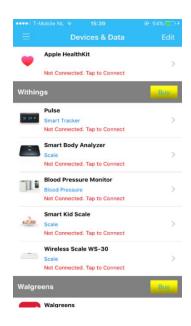


Figure 7. GenieMD

4. Discussion

The aim of this study was to conduct a systematic review of the existing mobile applications for informal caregivers who care for someone with a chronic disease. We wanted to get insights into the existing mobile applications, the content of the mobile applications and the mHealth features of these based on several main- and sub- categories.

First, it is noticeable that there is a low number of mobile applications for this specific target group of informal caregivers of people with chronic diseases. Although the number of informal caregivers is growing and the need for support is too, not many mobile applications exist for this target group. Until now there are more specific web-based interventions for informal caregivers of patients with a chronic disease than mobile applications (Chi, & Demiris, 2015). In their study, Chi and Demiris (2015) demonstrated the positive effects of telehealth interventions for informal caregivers. Their outcomes were satisfying and telehealth interventions had positive effects similar to face-to-face interventions. In their study, they included video, web-based and telephone-based components including only phone calls or text messages and no mobile applications. This demonstrates the new development of mHealth in the field of health, which is why only a limited number of mobile applications for this target group currently exist.

When we have a deeper look at the analyzed mobile applications, we see that the majority work as a practical helping tool for the informal caregivers in terms of how to provide and organize care, but less about how to reduce the caregivers' burdens and to increase their own well-being. This result is in line with studies by e.g. Northouse (2010) that showed that most existing interventions are targeted at the patient or the care for the patient. This is not sufficient, because of the fact that a considerable number of informal caregivers experience high levels of distress due to their caregiving responsibilities. As already mentioned informal caregivers may experience many negative aspects while caregiving (Adelman et al., 2014). That is why it is important that they have a certain tool or intervention which supports their own well-being and helps to increase or compensate the negative aspects such as the mount of stress of physical exhaustion. There are different options to increase their well-being and reduce their burdens of stress including psychological exercises, such as mindfulness or relaxation (Whitebird et al., 2012). These were used in the mobile applications, but in a scare way. Only six mobile applications integrated these exercises. Because informal caregivers experience a lot of stress and have to deal with their new situation and different emotions, mobile applications should integrate more of these practical tools related to informal caregivers' own well-being to help manage caregivers' own health by for example lowering stress (Stenberg, Ruland, & Miaskowski, 2010). This can be done by linking to more psychological exercises, including short or long mindfulness sessions (Whitebird et al., 2012), self-management, coping strategies (Cooper, Katona, Orrell, & Livingston, 2008), and understanding of the importance of self-care (Bardunias, 2016). Most of the mobile applications are not even aimed at a specific group, such as informal caregivers of cancer patients or Alzheimer patients, but more generalized to someone who provides care in general. It would be better if mobile applications were aimed at a more specified target group, more tailored to the needs of target group and chronic disease. The developers of mobile applications could add relevant and more tailored information, tips or recommendations to increase the user satisfaction, quality of caregiving and also the increase of the users' well-being while being an informal caregiver (Brodie et al., 2000). It might be too general if an informal caregiver is using a mobile application not tailored enough for the loved one's chronic disease. As an example, the care for someone with Alzheimer might be partly different than for someone with cancer.

Furthermore, the literature and practice show that supportive interventions or other programmes are crucial for informal caregivers. A cancer diagnosis for example does not only affect the cancer patients, but also their close relatives (Tang, Chan, So, & Leung, 2014). Surprisingly, no German mobile applications for this target group were found although there is a growing number of informal caregivers in Germany too. The reason for this could be that there is no German term which describes an informal caregiver unlike the term "Mantelzorger" in Dutch. Also, the technological development in German healthcare is behind other countries such as the Netherlands. In 2015, 2.9 million people were in need of care in Germany (Statistisches Bundesamt, 2017). From this almost three million people, 73% are cared at home, of whom who 1.38 million are cared for by informal caregivers (Statistisches Bundesamt, 2017). In comparison, in the Netherlands almost 15% of all Dutch people are giving care to a family member or friend (Sociaal en Cultureel Planbureau, 2015).

Further, it would be als possible to add some quality criteria around to mobile applications, because this study deals more with the content of the mobile applications and less about the quality. An idea is to add some more information about different quality criteria to start creating standards in mHealth, which might answer the question "how do you build apps?". Some quality rate scales already exist, such as the Mobile App Rating Scale (MARS) (Stoyanov, Hides, Kavanagh, Zelenko, Tjondronegoro, & Mani, 2015). Unfortunately, the subitems from the MARS do not totally fit to this study, as MARS' subscales refer more to the general use and quality of mobile applications than to the content of this study.

This study also provided some interesting insights into mobile applications and the use of mHealth features. It was found that although mobile applications could offer several unique possibilities for the delivery of information, not many do so. For example, nearly all of the analyzed mobile applications are mostly text-based only. That means that most of the interaction and information is presented by text and only a small number of other features such as the use of videos or audio files is integrated. To make use of the possibilities mobile applications offer, also information about a certain disease could be presented in a short and demonstrative video, for example. As already mentioned, mobile applications have the advantages of providing multimodal information (Vartanian, 2011). The feedback users receive is more based on the system itself. For better and faster communication, a straight interaction between the user and health professionals could be developed by also providing a mobile application for health professionals. Additionally, the interaction between users should be more visible, faster and easier to interact with and allows users to help each other in case of questions. Most mHealth specific features as offline usability, calenders, reminders, push notifications, and uploading or downloading photos, videos or other personal information were little used in the mobile applications. The use of hardware and software is also not ideel. An idea would be to connect the mobile applications to other devices such as Apple HealthKit, FitBit, and weight scales. The use of big data, analysing certain patterns of the user or data mining which might include text messages, online games, blogs, and social media, is not really employed by the analyzed mobile applications (Hashem, Yaqoob, Anuar, Mokhtar, Gani, & Khan, 2015).

Strengths and limitations

As far as we know, this is the first systematic review of existing mobile applications for informal caregivers who give care to someone with a chronic disease. We gained interesting insights into the content and mHealth features integrated in these. This information can be used for further research to reduce informal caregivers' burden, and to create a useful helping tool, not only for caregiving but also for their own well-being. Because of the growing number of informal caregivers worldwide, this information is important and may affect many people across the globe. Next to the strengths of this study, limitations have to be mentioned. In this study, only free mobile applications were used, so the results cannot be generalized to all mobile applications for informal caregivers because paid mobile applications were not included. Furthermore, we only searched in Apple's App Store and not in Google's Play Store. This search could have led to more mobile applications. The extraction sheets of this systematic review were based on the literature and not on valid instruments. Stoyanov et al. (2015) showed

in their study that little mobile application quality assessments are available, even though the number of mobile applications for personal health and well-being has expanded. In their study, the MARS was used to rate the quality of different mobile applications based on the engagement, functionality, aesthetics, and information quality, but not regarding the content. Last, it has to be mentioned that the mobile applications were only rated by one rater and not by two as they should have been. However, to minimize a possible bias, results were discussed in a team.

Further Research

The information from this study can not only be used to improve the existing mobile applications for informal caregivers, but also to create a basis for the development of new mobile applications. Within this improvement and development, the target group may also be included to use their own experience and ideas in creating mobile applications. Mobile applications made together with the target group could be first tested (with prototypes) before being made accessible to everybody in Apple's App Store or Google Play Store. Including the informal caregivers in the process of developing those mobile applications may lead to a more user-centered design, in which developers and informal caregivers working together and share their experiences and may also increase the effectiveness and the adherence of the intervention (McCurdie et al., 2012). Using mobile applications for informal caregivers is a relatively new topic, so more research is needed to make stronger and more generalizable conclusions on this topic.

Conclusion

This study emphasizes the limited availability of mobile applications for informal caregivers of patients with chronic diseases, who could make use of a supportive tool or intervention not only on how to provide and organize care for someone with a chronic disease, but also how to decrease their burdens and increase their own well-being. Most of the mobile applications focus more on being a supportive tool in only caregiving related tasks and less in only focusing on the informal caregiver. Noticeably, the analyzed mobile applications are not fully making use of the potential of mHealth. There are still a lot of features that are not yet fully used in the mobile applications. That is why further research is needed to examine which mHealth features are interesting and effective to incorporate in mobile applications for informal caregivers.

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