Review

Possibilities, Problems, and Perspectives of Data Collection by Mobile Apps in Longitudinal Epidemiological Studies: Scoping Review

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Abstract

Background: The broad availability of smartphones and the number of health apps in app stores have risen in recent years. Health apps have benefits for individuals (eg, the ability to monitor one's health) as well as for researchers (eg, the ability to collect data in population-based, clinical, and observational studies). Although the number of health apps on the global app market is huge and the associated potential seems to be great, app-based questionnaires for collecting patient-related data have not played an important role in epidemiological studies so far.

Objective: This study aims to provide an overview of studies that have collected patient data using an app-based approach, with a particular focus on longitudinal studies. This literature review describes the current extent to which smartphones have been used for collecting (patient) data for research purposes, and the potential benefits and challenges associated with this approach.

Methods: We conducted a scoping review of studies that used data collection via apps. PubMed was used to identify studies describing the use of smartphone app questionnaires for collecting data over time. Overall, 17 articles were included in the summary.

Results: Based on the results of this scoping review, there are only a few studies that integrate smartphone apps into data-collection approaches. Studies dealing with the collection of health-related data via smartphone apps have mainly been developed with regard to psychosomatic, neurodegenerative, respiratory, and cardiovascular diseases, as well as malign neoplasm. Among the identified studies, the duration of data collection ranged from 4 weeks to 12 months, and the participants' mean ages ranged from 7 to 69 years. Potential can be seen for real-time information transfer, fast data synchronization (which saves time and increases effectivity), and the possibility of tracking responses longitudinally. Furthermore, smartphone-based data-collection techniques might prevent biases, such as reminder bias or mistakes occurring during manual data transfers. In chronic diseases, real-time communication with physicians and early detection of symptoms enables rapid modifications in disease management.

Conclusions: The results indicate that using mobile technologies can help to overcome challenges linked with data collection in epidemiological research. However, further feasibility studies need to be conducted in the near future to test the applicability and acceptance of these mobile apps for epidemiological research in various subpopulations.

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Introduction

Worldwide, there were 2.39 billion smartphone users in 2017, and this number is predicted to exceed three billion by 2021 [1]. Undoubtedly, smartphones have become part of everyday life for many people around the world. Alongside the increase in smartphone use, the market for smartphone apps has risen massively in recent years [2]. In health care, it is anticipated that apps have the potential to decrease both spatial and administrative barriers [2]. However, removing barriers is only one potential outcome resulting from the use of these applications. The market for mHealth apps is growing rapidly. In 2015 alone, there were more than 100,000 new health apps published in relevant app stores, with approximately three billion downloads of apps related to health, fitness, and medicine [2]. In comparison to 2013, the number of downloaded apps has almost doubled [2]. Consumers use apps to track steps, heart rate, sleep patterns, and so forth. Smartphones also function as new tools for measuring the health of individuals. Moreover, smartphone apps may deliver data at the population level. For that reason, smartphones are expected to be beneficial to health care research and epidemiological studies. Over the last two decades, surveys have ceased to exclusively use traditional methods of data collection, such as paper or telephone-based questionnaires; questionnaires have instead been developed using electronic systems, such as internet-based surveys and personal digital assistants. Although there has been a huge rise in the use of smartphones, issues regarding the benefits and potential uses of app-based questionnaires still need to be addressed [3]. Various studies have developed smartphone apps for educational or communication purposes for medical school students and clinicians [4]. However, only a few questionnaires on smartphone apps have been used in clinical settings, such as in sleep disorder tracking and for the administration of psychiatric questionnaires [5-7]. Beyond epidemiology, public health, and health services research, there are approaches in the field of cognitive science that have also detected the potential for data collection via smartphone apps [8].

Although data collection using smartphone apps has not yet been comprehensively studied and is not very frequently used, the availability of and access to smartphones among the world's population raises the potential for large-scale surveys in (longitudinal) population-based studies. This scoping review focuses on studies investigating the acceptability, feasibility, and performance of mobile apps for data collection in longitudinal studies, irrespective of the studies' purposes (eg, measuring vital parameters, providing questionnaires) or the types of apps in question (eg, apps that are medical products prescribed by physicians or those that are lifestyle products selected by users). To guide the scoping review, we focused on the following 4 overarching research questions: 1) which types of studies (feasibility/pilot vs full-scale) have been conducted to date, 2) over what period of time has data been collected within these studies, 3) which specific target groups (eg, children, elderly, migrants) have been included in the studies, and 4) what potential benefits and challenges to app-based data collection are described in the studies?

Methods

We conducted a scoping review using PubMed. In the first step, we employed a broad search strategy to include all articles dealing with apps, smartphone devices, or mHealth in the context of data-collection activities. Hence, the following search algorithm was used:

> *(app[Title/Abstract] OR apps[Title/Abstract] OR smartphone*[Title/Abstract] OR mHealth[Title/Abstract] OR "mobile health"[Title/Abstract] OR mobile phone*[Title/Abstract]) AND (cohort*[Title/Abstract] OR survey*[Title/Abstract] OR questionnaire*[Title/Abstract])*

All articles published up to December 31, 2017 were considered by two independent reviewers. This led to 1922 matches after incorporating the predefined filters for studies conducted among humans and those written in the requisite publication language(s) (English or German). The following main exclusion criteria were defined a priori:

- SMS-based approaches (including SMS reminders and supportive text messages in interventional studies)
- Web-based approaches/questionnaires, which can also be conducted on smartphones
- Nomophobia (fear of being out of cellular phone contact)
- Distraction by smartphones while driving
- "App" as an abbreviation for unrelated issues (eg, amyloid precursor protein)
- Screen media time usage among children or adolescents
- Mobile phone access and usage in various populations
- Validation of paper-based compared with software/app-based questionnaires
- Articles dealing with Electronic Health Records
- mHealth interventions using apps only for treatment or educational purposes (eg, limited to disease treatments)

After screening all article titles and abstracts against the criteria listed above, 1808 articles were excluded. This led to 114 articles for which a review of the full text was performed. Due to the large number of articles still remaining, further exclusion criteria were defined and the particular reason for exclusion was documented. Using this procedure, 97 further articles were excluded for the following reasons:
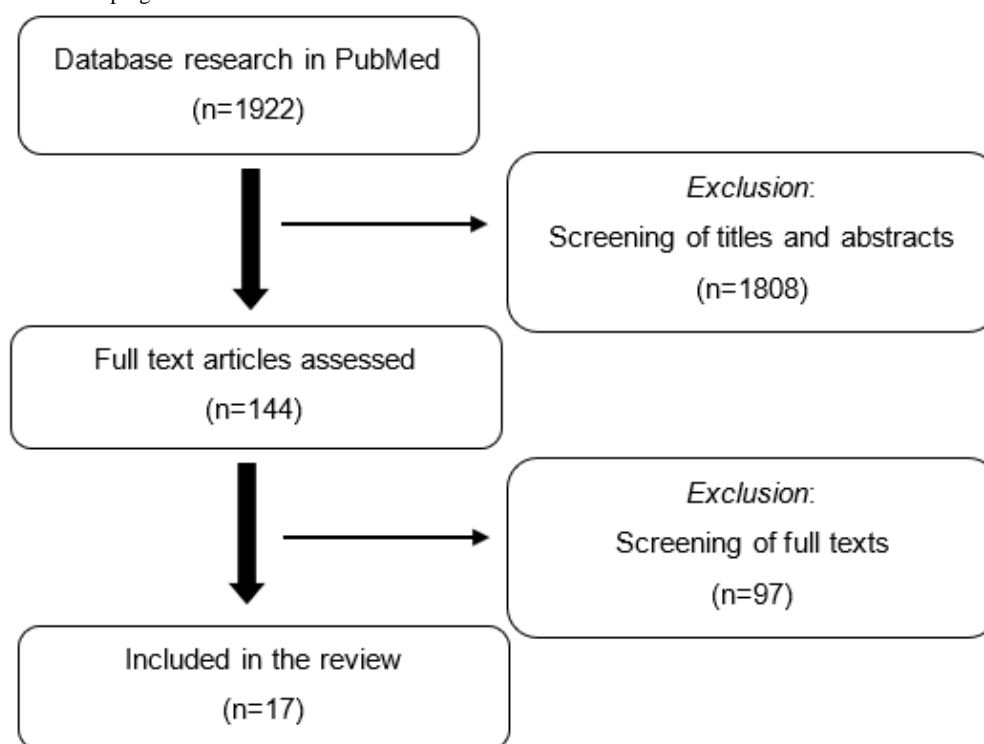
- Cross-sectional study design [9-15]
- Qualitative study design [16]
- Study protocol [17]
- App without purpose of data collection [18-26]
- App only for self-monitoring or willingness to self-monitor disease or certain lifestyle measures (no data storage for researcher) [27-48]
- Mobile-type programs/programmed phones, personal monitors, or ecological momentary assessment protocols displaying on mobile phone screens (without the involvement of an app) [49-52]
- Advanced data-collection systems without the need for data entry by the patient/interviewee (eg, using Global

Positioning System location and phone usage data automatically) [53-55]

- App as assistive working tool for researchers or medical staff (no data entry from interviewees/patients) [56-73]
- Study duration less than one month or one-time data entry [47,74-100]
- No possibilities, problems, or perspectives mentioned in the study [101]
- Reviews dealing with smartphone apps, mobile phone surveys, and new data-collection methods in general [102-105]

Thus, studies included in the review met the following criteria:

- Data collection with a smartphone app, including apps used for disease screening
- Apps either prescribed by a physician or selected by the user
- More than self-management functions
- App available on smartphone

- Data entry completed by the interviewees/patients (or close relatives)
- Repeated data entry on a longitudinal basis (more than one month)
- Possibilities, problems, and perspectives of data-collection apps described
- Feasibility studies with attitudes toward sharing health information (with researchers or physicians) within smartphone apps or smartphone devices

The final summary consisted of 17 studies, which were summarized using content analysis (Figure 1). There were 3 guiding questions for the content analysis: (1) in which settings have apps for data collection been used so far, (2) what challenges and requirements exist regarding the implementation of apps, and (3) what potential does data collection with smartphone devices have? These aspects are synthesized in the Results based on those aspects described in the primary articles.

Figure 1. Flowchart of the scoping review.

Results

Overview: Studies Collecting Patient Health Data Over Time

A total of 17 studies were included in the synthesis of the scoping review (Table 1). These studies were conducted for the following reasons:

- To track real-time changes in symptom(s) (severity) or other disease-related patterns (for creating modified/redefined treatment plans) [106-115]
- To determine users' compliance and engagement with technology adoption, patient data collection, and provider communication with smartphone app [107,111,112,114,115]

- To test an app for aftercare assessment [116-118]
- To screen for certain (disease or patient-related) outcomes [119]
- To develop an app-based participatory surveillance system for collecting syndromic data [120]
- To provide a practical guide to developing and implementing a longitudinal study with an app [121]

Of these 17 studies, 7 were feasibility or pilot studies. The country with the largest number of studies was the US (7/17); 2 studies based in Sweden and 2 more were based in the Netherlands. All (feasibility/pilot and full-scale) studies on data collection over a longer period of time using smartphone devices used a medical or health-related indication, with a wide range of indication areas. The two main indication areas were

psychosomatic disorders (eg, depression, mood, post-traumatic stress disorder) and neurodegenerative diseases (eg, Parkinson Disease). The other studies focused on indication areas such as respiratory diseases (eg, asthma), cardiovascular diseases (eg, acute stroke, atrial fibrillation), malignant neoplasms (eg, prostate cancer), sleeping disorders (eg, insomnia, sleep apnea), infectious diseases (eg, acute febrile illness and gastroenteritis),

weight loss in obese people, gestational diabetes mellitus, abdominal surgery, chronic pain, and drinking behavior in adolescents. Target groups were related to pregnancy (breastfeeding [108], depression [109], and gestational diabetes mellitus [122]) or focused on children [120] and young people [119].

Table 1. Overview of studies included in the scoping review.

Reference	Feasibility or pilot study	Country	Indication area	Study design	Duration of data collection	Participants at baseline, n	Specific target group
Bot et al (2016) [106]	✓	US	Parkinson disease	Observational	6 months	8320	N/A[a]
Burke et al (2017) [121]	✓	US	Obesity	Observational	12 months	151	N/A
Chan et al (2017) [107]	X[b]	US	Asthma	Observational	6 months	7593	N/A
Cooray et al (2015) [116]	X	Sweden	Stroke	Cohort	2 months	48	N/A
Demirci and Bogen (2017) [108]	X	US	Breastfeeding	Observational	8 weeks	61	Pregnancy
Faherty et al (2017) [109]	X	US	Depression	Cohort	8 weeks	36	Pregnancy
Horsch et al (2017) [110]	X	Netherlands	Insomnia	RCT[c]	6-7 weeks (with 3-month follow-up)	151	N/A
Isetta et al (2017) [111]	✓	Spain	Obstructive sleep apnea	Observational	6 weeks	60	N/A
Jamison et al (2017) [112]	✓	US	Chronic pain	Observational	3 months (with option for 6 months)	105	N/A
Labhart et al (2017) [119]	X	Switzerland	Alcohol consumption	Observational	7 weeks	176	Young people
Noe et al (2017) [113]	X	Wales	Mood tracking	Observational	8 weeks	76	N/A
Olson et al (2017) [120]	X	Guatemala	Acute febrile illness and acute gastroenteritis	Cohort	9 months	469	Children
Pavliscsak et al (2016) [117]	✓	England	PTSD and/or TBI in rehabilitation	RCT	36 weeks	95	N/A
Peleg et al (2017) [122]	✓	Italy and Spain	Atrial fibrillation and gestational diabetes mellitus	Cohort	9 months	29	Pregnancy
Silva de Lima et al (2017) [114]	X	Netherlands and North America	Parkinson disease	Observational	6-13 weeks	953	N/A
Sundberg et al (2017) [115]	X	Sweden	Prostate cancer	Intervention	11 weeks	130	N/A
Symer et al (2017) [118]	✓	US	Abdominal surgery	Observational	4 weeks	31	N/A

[a]N/A: not applicable.

[b]Studies marked with an "X" are not feasibility or pilot studies.

[c]RCT: randomized controlled trial.

The sample sizes differed greatly, ranging from 29 to 8320 study participants at baseline. The participants' mean ages ranged from 7 years [120] (although children did not enter data unsupervised, and so parents were necessarily involved) to 69 years [115], although not every study provided information on the (mean) age of study participants. The majority of studies (10/17) had an observational design, with one using an ecological momentary assessment [121]. Of the observational

studies, 4 were cohort studies, 2 were randomized controlled trials, and 1 was a nonrandomized controlled intervention trial. The duration of data collection varied between the studies from 4 weeks to 12 months. Further details are provided in Multimedia Appendix 1.

Potential of Using Smartphone Devices for Data Collection Over Time

Within the reviewed articles, several potential benefits of using smartphone devices for data collection are described. Firstly, automatic push notifications offer the potential to provide daily, weekly, or monthly reminders or any kind of information [117]. This can be linked to multiple further functions, showing advantages for researchers as well as for users. For that reason, an app can be used as a data-collection tool or as a reminder for the elderly, has potential for self-interventions (eg, when users can track their symptoms), and can be used for real-time information transfer. Patients tracking their symptoms, for example, can use apps to help themselves monitor their diseases, as well as help physicians to create tailor-made treatment plans [117]. Some other advantages can be derived from sharing real-time data between researchers via (secure) platforms as well as storing and replacing data from one software function to another without data loss or mistakes in data entry [106,116]. Rapid data synchronization between data entry (from the user) and demand-oriented provision of the data (for the researcher or the physician) is also possible [116]. Data entry occurs almost simultaneously with its storage and access, which saves time and increases effectivity. With the support of smartphone devices, data collection is possible on a daily basis over long periods of time, and questionnaire responses can be tracked longitudinally [117]. Smartphone-based interventions, or aftercare assessment via the smartphone (in lieu of going to a hospital or seeing a physician), remove barriers and save time; they also remove administrative barriers and travel difficulties (eg, for aftercare assessment). Furthermore, data loss due to reminder bias can be prevented [116].

With sensitive (health) data, there is always a need for data protection. When using secure data storage and unique random codes for user identification, anonymity and data security can be ensured by using apps [106,117].

Challenges in Using Smartphone Devices for Data Collection Over Time

Although data collection with smartphone apps has great potential, there are also challenges and disadvantages. As is the case for traditional methods of data collection, follow-up with smartphones can be nonuniform [106]. For that reason, users' (or patients') engagement and compliance over longer periods of time is a critical issue. Optimally, for conducting studies on smartphone devices, people need to own smartphones with an available mobile internet connection. Otherwise, it is necessary to provide these devices to the participants. This might be feasible for a cross-sectional study of short duration, but for large sample sizes and over longer periods of time this is an obstacle [110]. Furthermore, participant-related preferences are to carry no more than one device [109,121]. Overall, a risk of loss to follow-up exists [108], as in other longitudinal data collections, which might be due to either lack of motivation or technical issues, such as poor data signal or participant discomfort using mobile phones [120]. Therefore, interactive and feedback elements and rewards may lead to greater adherence [112,113].

Discussion

Overview

Although the studies identified in this scoping review claimed significant potential for health-related data collection using smartphone devices, it is obvious that very few approaches have integrated these devices into clinical or epidemiological research activities so far. This is particularly true for the data collection in longitudinal study designs. Although apps can be simply tailored to the needs of target groups [12], only a few studies [108,109,120,122] focused explicitly on specified groups. Most of the articles identified in this review dealt with a particular medical or health-related issue. However, apart from pregnancy and childhood, the study participants consisted of nonspecific target groups. For example, we were not able to identify any study particularly focusing on migrant populations. Therefore, the main result of this overview about mobile apps for data collection in epidemiological research is that further studies and, depending on the results of such studies, adequate solutions for implementing modern technologies for data collection in a priori defined target groups is urgently needed. This is also a requirement for achieving high usability. Although it is possible to design an app using free or low-cost development tools, this can be difficult when app designers are unfamiliar with these tools. In such cases, a pilot test with a subpopulation is highly recommended [11]. This is particularly important because a previous study [10] has indicated greater commitment and engagement in using app-based data collection tools, especially among young and middle-aged populations as compared to older populations.

General population surveys frequently do not adequately represent population subgroups. This challenge is reinforced by the fact that specific groups, such as migrants or refugees, are difficult-to-sample populations. These challenges apply to the fact that such difficult-to-sample populations can be rare, difficult to locate, difficult to enumerate, and/or difficult to interview [123]. Therefore, the implementation of mobile apps for data collection might be particularly suitable for vulnerable but also highly mobile populations, such as migrants, in general, or refugees in particular. Accurate data about health status, health determinants, use of health-care services, and risk behaviors among migrants are needed in order to monitor health and improve health services among this population subgroup [124]. As of yet, health-related data on migrants, and refugees in particular, are scarce, and data-collection approaches face several methodological limitations.

As already highlighted in a narrative review of data-collection practices for monitoring migrant health in Europe [124], there are several legal obstacles related to data protection which need to be taken into account. Due to the recently enforced European General Data Protection Regulation [125], aspects of informed consent, privacy and confidentiality, and the right to withdrawal or omit items will receive further attention in the future. These new data protection regulations need to be kept in mind when developing and implementing data-collection tools. These tools should provide additional information to already established instruments such as the census, death registers, and disease

surveillance systems. These established instruments only partially include information on migration status, and if they do, the information is only available at a highly aggregated level [126]. Further information on the health of migrants is available based on epidemiological studies of population samples using medical diagnoses [127]. However, these analyses face the challenge that migrants may encounter barriers in accessing health services. This may lead to an underestimation of the disease burden [127].

To overcome these challenges, which lead to an underrepresentation of specific subgroups and, therefore, insufficient data for action [128], several measures have already been taken. These measures include, but are not limited to, disproportionately allocated sampling, multiplicity sampling, and the use of multiple frames. However, it has to be noted that oversampling of people with a migration background is not sufficient to avoid systematic bias in the sample due to nonparticipation. Further measures, such as personal contacting, multilingual instruments and interviewers, and extensive public relations, have to be taken into account. All of this can be done within smartphone-based apps. For the target groups of migrants in epidemiological studies, no singe simple solution exists [123,129,130]. However, studies indicate that constant communication and follow-up of study participants enhances the response rates in longitudinal studies and improves the quality of data [131]. For that reason, mobile apps may provide solutions for overcoming common challenges in epidemiological data collection.

Limitations

Overall, the results of this scoping review need to be interpreted with caution. We were only able to provide a broad overview of challenges and potential benefits linked with data collection using mobile apps described in the literature. The scoping review was not focused on a specific topic in epidemiological research, in order to capture all the ideas and experiences previously described in the literature. Due to the comparatively broad (but not concrete) search algorithm that included terms related to mobile apps in combination with study designs, we might have missed some studies which have applied mobile technologies in epidemiological data collection. For example, mobile phone surveys have been excluded. However, although this scoping review was conducted in only one literature database (PubMed), we anticipate that it will provide a comprehensive overview of the potential benefits and challenges that researchers may face when using mobile apps for data collection in epidemiological studies. We were not able to identify studies specifically dealing with the target group of migrants or refugees.

Conclusions

It appears that the challenges connected to data collection among migrant subgroups can be overcome by using the innovative technologies of mobile apps. These approaches allow the recruitment of study participants from diverse ethnic backgrounds when designed in a migration-sensitive, cross-language, and cross-cultural fashion. Continuing contact with study participants can be ensured during longitudinal studies. This is of particular relevance for mobile populations, such as refugees, who might not have reached their place of destination at the time of recruitment. Furthermore, due to the cost-effectiveness of app-based data collection, the challenges of small sample sizes and low response rates can be at least partially overcome. However, feasibility studies need to be conducted in the near future to test the applicability and acceptance of mobile apps for epidemiological research among various subpopulations.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Supplementary appendix.
[PDF File (Adobe PDF File), 96 KB-Multimedia Appendix 1]

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