JMIR mHealth and uHealth

Impact Factor (2022): 5.0
Volume 2 (2014), Issue 1 ISSN 2291-5222 Editor in Chief: Laurie Buis, PhD, MSI

Contents

Viewpoints

Original Papers

Review

Viewpoint

Indoor and Outdoor Social Alarms: Understanding Users' Perspectives

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Abstract

The elderly population is increasing and there is a need to provide care and safety at a high level with limited resources. New social alarm solutions may contribute to safety and independence for many elderly. However, it is important to understand the needs within the user group. This work studied social alarms in a broad sense and from several user perspectives. In the first study, social alarm use and its aspects were investigated. To understand where there may be problems and weaknesses, users, caregivers, managers of municipalities, and personnel at alarm centers were interviewed. The interviews helped identify a number of problems. For municipalities, the processes of procuring new alarms and managing their organization were found to be complex. The effect of this was that the same social alarm systems had been ordered over and over again without taking into account new user needs or new technical solutions. For alarm users, one large problem was that the alarms had very limited reach and were designed for indoor use only. This has resulted in users hesitating to leave their homes, which in turn has negative effects due to lack of physical activity and fewer social contacts. One important result from the first study was the need for a social alarm solution that worked outdoors. In a second study, needs regarding outdoor social alarms were investigated. The results from this study showed that wearable outdoor alarms must be easy to use, provide communication, and be well designed. Finally, these alarms must work both indoors and outdoors, and the user should not have to worry about where he/she is or who is acting on an alarm.

(JMIR Mhealth Uhealth 2014;2(1):e9) doi:10.2196/mhealth.2730

KEYWORDS

health services for the aged; technology; man-machine systems; computer communication networks; caregivers; social alarm; security; safety

Introduction

Safety

The elderly population is increasing and there will be a growing number of elderly living in their own homes. To be able to live an independent and active life with social interaction, elderly people need to feel safe both indoors and outdoors. One way to increase the feeling of safety for them is through social alarms. A variety of alarms exists, both for indoor and outdoor use.

The feeling of being safe is very complex and can be viewed from many perspectives. Social alarm systems are very fragile because the entire chain, from when an alarm holder presses the alarm button until home care staff arrives, must constantly operate. If it fails once, then the feeling of being safe is lost [1]. To discover critical aspects, it is important to get an overall view of the social alarm area, especially the alarm system chain. It is important to understand how the alarm holder experiences security and how it might be affected by different circumstances.

Indoor Alarm

A social alarm (Figure 1) is an alarm device that is installed in a user's home and makes it possible for a user to call for help in urgent situations, such as if the person has fallen. The alarm often consists of a base unit and care phone, which is connected to the analogue telephone network or via the digital

infrastructure in an apartment or house. An alarm button, which is worn on a necklace or around the wrist, is connected to the base unit. When a user presses the alarm button, a signal (alarm) is sent to an alarm receiver, home care staff, or a relative. Social alarms also have a speech function at the base unit that makes it possible for the person who raised the alarm to talk to the alarm receiver.

In Sweden, social alarms are provided both to people living in ordinary housing and in nursing homes. The municipalities usually provide social alarms. Traditional social alarms are connected to an alarm center that forwards the alarm to the home care or in some cases to a relative or neighbor.

The use of social alarms is similar in many countries. In the United States, for example, social alarms are called personal emergency response system (PERS) and are available in almost all parts of the country. There are both national and local providers, including private companies, hospitals, and social service agencies. PERS acts similarly to social alarms in Sweden, but usually the alarm center contacts a neighbor or a relative; it is the alarm holder who chooses which person to call.

Regardless of differences in organization around the alarms, the most important aspect is the feeling of being safe. In several studies from the United States, Porter et al [2,3] showed that the users wanted PERS to feel safe, knowing they would receive help if anything should happen. In England, research regarding alarms and safety has provided the same result, that is, increased quality of life and increased opportunities for safe living [4]. In Sweden, Lindén [5] conducted a study in which the aim was to investigate seniors' experiences and perceptions of social alarms. This study reported similar results as previous studies and also showed that social alarms have become a part of users' daily lives and not perceived as an intrusion or something negative.

For the elderly, it is important to feel safe in their homes. According to the results from the described studies, the elderly usually felt safe in the home when they had a social alarm. However, there is also a need for the elderly to be more active and feel safe outdoors as well. Because of this, we wanted to go one step further and investigate needs and implications for the use of outdoor alarms.

Figure 1. A social alarm – base unit and an alarm button.

Outdoor Alarm

Traditional social alarms only work in a home environment. For this reason, older people hesitate to leave their homes because they do not feel safe. This was shown in a study by Boström et al [6], which showed that social alarms could create a feeling of insecurity rather than security, and that it could restrict the elderly from moving around free in society. The elderly felt that they did not dare go out because the social alarm only had a reach within the house or just around the house. This led to limited integration into society and less social interaction. Physical activity and social contacts are important for health and disease prevention. An outdoor alarm could help people to feel safe even when outdoors, and thereby enable them to have an active life with better health and improved quality of life.

Taylor et al [7,8] have done several studies within the social alarm area or as they call it "community alarm service." In one of the surveys, changes to the social alarm were suggested. The most frequent comments were that the social alarm should send a call for help if the wearer falls and that it should work outside the home. Taylor et al [7] presented a design list for the next generation of the social alarm and the alarm button. One of the design features was "long-range operation" which means that the social alarm would work outside home and equipped with a global positioning system (GPS) and mobile communications.

There are several outdoor alarms on the market that can locate a person via GPS. This kind of social alarm enables an alarm receiver to see where the person is located. With this service, you can enter a geographic security zone for a person. When

the person goes outside the zone, an alarm is sent to the alarm receiver's mobile phone to indicate the user's position. Relatives can either call or seek the user at the given position if they become anxious. This type of alarm can be used passively (violation of the security zone as described above) and actively by the use of an alarm button (which a user can press to call for assistance). These solutions can also have other functionalities such as detecting falls or lack of action (a passive alarm that sends alarm calls based on user actions or absence of those). For example, within the project MyHealth@Age [9], a mobile phone-based solution that consisted of both active and passive alarm functionality was developed.

One problem with outdoor alarms is that they are based on different technologies than the indoor alarms and are not integrated into the same alarm solution. A social alarm that can handle both indoor and outdoor environments in the same alarm solution is something that both the elderly and their relatives have requested [1]. However, these solutions are difficult to find on the market. This means that a person having a traditional social alarm at home needs to bring another alarm with him or her when he or she goes out. When it comes to alarms that can be positioned, users can be anywhere when the alarm is set off. This leads to challenges with respect to organization regarding acting on alarms, because home care staff usually only come and assist when the alarm holder has alerted in his or her home with a traditional social alarm.

Needs and Challenges in the Social Alarm Area

The social alarm area has a strong tradition regarding functionality and design. In recent years, however, the area started to undergo changes that involved both challenges and opportunities. One challenge is, for example, the replacement of the analogue network with a digital infrastructure. Sweden has reached far within the digital social alarm area in terms of the development of alarms, the use of the digital infrastructure for the alarms, and management of the alarm solutions. We will not describe this infrastructure and the implications for the alarms in this paper but it opens up new possibilities in the field of social alarms that can be helpful to meet user needs in the future.

Two studies are presented in this paper. To understand how the future alarm area should work, it is important to address the social alarm area in a broad sense and from several perspectives. In the first study, we investigated needs and attitudes among all relevant stakeholders. The study also examined the interaction between the stakeholders and how the entire alarm chain worked. From the alarm holder's perspective, needs and attitudes toward safety were investigated. The method we used addressed user needs in an explorative way and from a broad perspective.

Based on the results from the first study, which showed a need for increased mobility, the next step was to investigate user needs with respect to alarms that work outdoors. There are challenges that need to be addressed to meet the needs and to find solutions to the organization around outdoor social alarms.

Social alarms work similarly in the rest of Europe and in the United States [10]. Results and conclusions presented here could also be relevant in other countries.

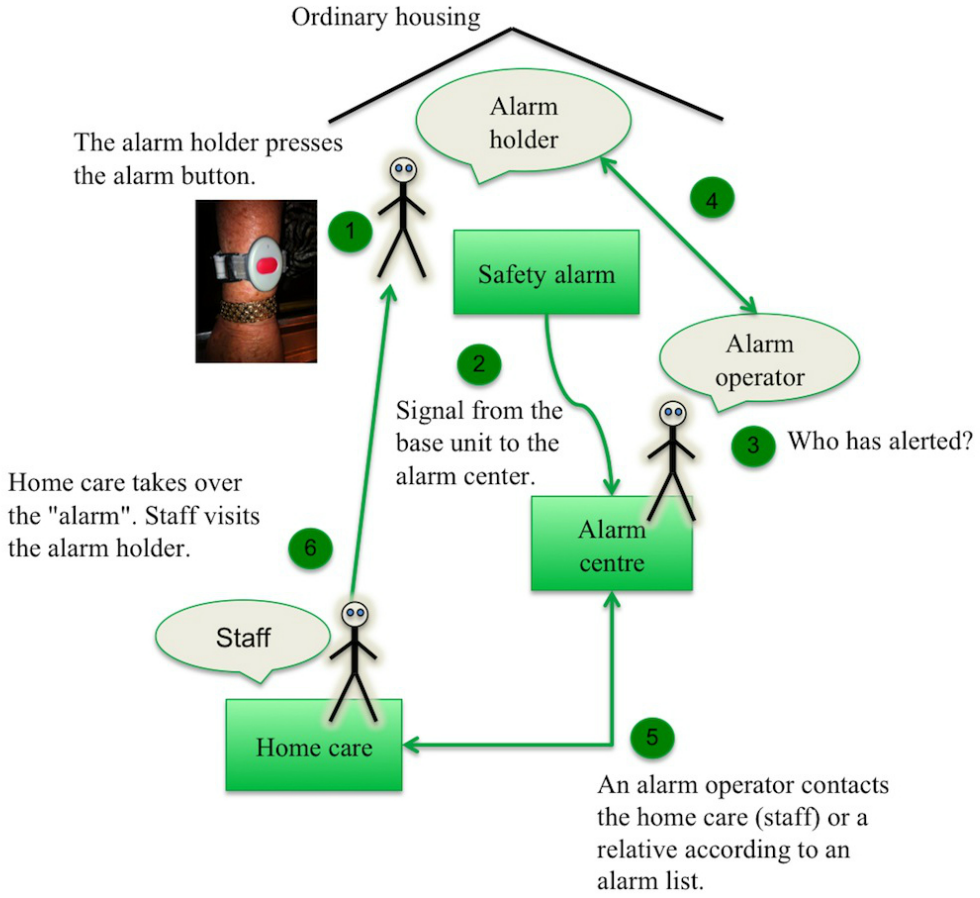
The aim with this work was to understand how social alarms were used, and identify shortcomings and how the users experienced safety. Further, this paper addresses future functionality and better design. We provide suggestions for requirements to be met in future indoor and outdoor social alarm solutions.

Study 1: Indoor Alarms and User Needs

Objective

In this study, the objective was to investigate the use of the alarms and the alarm chain (Figure 2) from a user perspective. It was important to obtain a view of the social alarm processes—from procurement to when an alarm holder presses the alarm button until home care staff visits the alarm holder and assists—to understand what might affect/increase security.

Figure 2. The Alarm Chain - it starts when an alarm holder presses the alarm button and ends when staff from home care visits the alarm holder.



Method

Overview

This study was divided into two phases, which were conducted sequentially. In the first phase, we started with an overview of the systems and investigated existing alarm solutions from a user perspective. Finally, previous purchases made by municipalities were studied.

In the second phase, four municipalities participated. It was important to understand attitudes toward the alarms and how they were used. Further, we wanted to understand the organization around the social alarms, and how this differed between urban and rural areas. Open-ended interviews with senior users and with staff from the municipalities were conducted. The process of procurement and the requirements around the social alarm were investigated by interviews with responsible personnel. During the interviews, the researchers took notes. A qualitative analysis was conducted based on a grounded theory approach [11].

Phase 1

To begin, a comparison was made of 15 procurements (from municipalities in Sweden 2011) for social alarms and alarm receiving for ordinary housing.

The aim was to get a better understanding of the content in these procurements so that we could develop relevant questions for the municipalities. In particular, we investigated to which extent the focus was placed on users' needs in the procurements.

In parallel, a survey was conducted to develop an overview of the existing alarm solutions from a user perspective. Based on these results, we could then take it a step further and highlight weaknesses and what municipalities should consider when procuring social alarms.

The entire chain (Figure 2) must constantly work. If it fails once, then the feeling of security is broken [1]. In our work, we focused on use and user aspects of these processes. There are several actors involved and there are complex processes with respect to procuring new alarms and managing the organization around them. To understand the social alarm area, key members of the alarm chain were interviewed, including alarm users, home care staff/managers, and operators at alarm center.

Phase 2

In this phase, the work was conducted as a collaboration between SICS Swedish ICT and four municipalities in Sweden . The municipalities were selected to reflect the social alarm field from diverse needs and different circumstances (Figure 3). Botkyrka is an urban municipality with challenges of different needs based on many different cultures. Värmdö is both urban municipality with its conditions, but also a rural municipality because the municipality covers large parts of the archipelago of Stockholm. Furthermore, Örnsköldsvik represents both rural and smaller city. Pajala has participated as a rural municipality with special circumstances this means. Open-ended interviews were used to understand how municipalities procured social alarms and to get an overall perspective of the alarm chain. One

further purpose of the qualitative interviews was to detect lesser known phenomena and properties in the social alarm area. Most of the interviews were conducted at the municipality offices or at the home care facilities. All interviews with staff in Pajala municipality were conducted by telephone because of the distance. Interviews with some of the elderly alarm holders (in all municipalities) were conducted by telephone. Notes were taken during the field studies.

In the study, both needs of users (of social alarm) and requirements from municipalities were investigated. Interviews were used to understand how municipalities procure social alarms today and to get an overall perspective of the alarm chain. The interviews were conducted with managers in the municipalities, personnel at alarm centers, and alarm holders. Furthermore, alarm users in ordinary housing were interviewed. Alarm operators and other personnel were interviewed at alarm centers. Approximately 2-3 alarm holders, in each municipality, 1-2 heads of unit, staff members, and alarm operators were interviewed. We had a contact person at each municipality who arranged with participants for the interviews.

In 2 of the municipalities, some alarm holders were interviewed in their homes. The interviews were conducted by telephone and included open-ended questions that focused on the social alarm (the alarm button and care phone/speakerphone), situations when they alerted, if it was indicated that the alarm had been sent away, and advantages/disadvantages with the social alarm.

In all municipalities, the unit manager for home care (for the elderly) was asked open-ended interview questions about how social alarms were handled, procurement/purchasing, any problems with social alarms, future prospects, etc.

In all municipalities, the staff within home care was interviewed; open-ended questions were about how they experienced the social alarms and how it worked, how their job was, how the alarm was received from the alarm center, and how the staff acted when they received an alarm. It was important to know how the staff thought that the management of the social alarm system worked and how they felt it worked for alarm holders to alert.

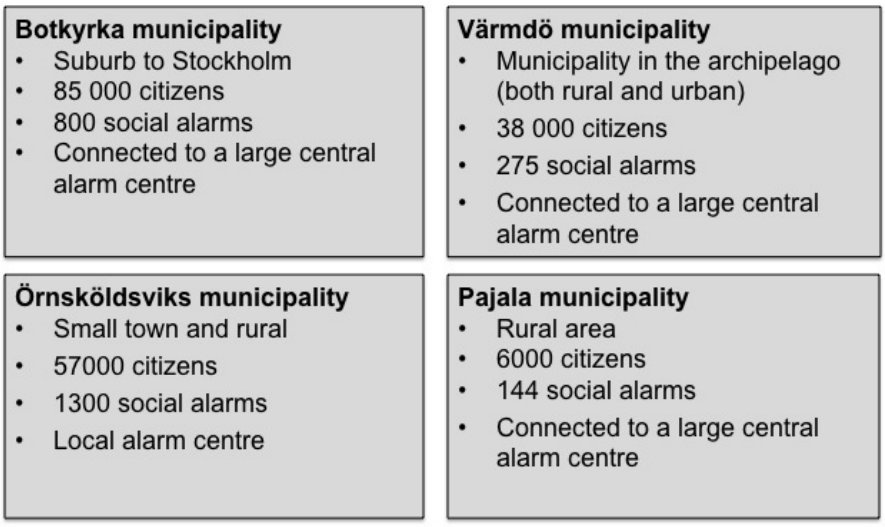
In 1 of the municipalities, alarm operators were interviewed at the municipality's own alarm center. This was a relatively small alarm center, but the principle of how alarms were received and forwarded to responsible staff at the home care were the same. Observations of the work were also conducted at the alarm center.

In all municipalities, people who worked with the procurement of social alarms were interviewed with open-ended questions. The aim was also to gain a broader understanding of how they defined the "shall requirements." There were also questions about the dialogue between the municipality and companies within the social alarm area.

Because the aim of the project was to address the social alarm field from a holistic perspective, it was important to interview people with different responsibilities within the social alarm process and users of the alarm. To understand what worked well, what changes needed to be made, where there were problems, lack of knowledge, etc, it was important to gain an understanding of the whole process.

The results presented below are a summary of the most frequent topics from the material.

Figure 3. Field studies in four municipalities.



Results and Conclusions

Some general observations based on the interviews with the municipalities are highlighted here. It should be noted that all 4 municipalities that participated had similar problems and shortcomings. The municipalities had inadequate knowledge about the new technology in the social alarm field. It was shown that it was a complex process to procure social alarms and extensive knowledge within the municipalities was required. Three of the municipalities trusted the suppliers regarding requirements on the alarms. For the municipalities, it was difficult to know what products that exist on the market, and difficult to know the needs of the users. As a result, the same social alarm systems were ordered repeatedly without taking into account new user needs or new technical solutions. Two of the municipalities said that they needed more knowledge

about the new digital social alarms to procure social alarms of good quality. The other 2 municipalities had made more progress in gaining knowledge about the new digital social alarms. One of the municipalities had employed a person with the skills, and the other one participated in a larger project on digital social alarms together with other municipalities in northern Sweden.

Based on the study of the previous procurements and interviews with the municipalities, it was found that many municipalities prioritized to meet the basic specifications at the lowest price. This has the implication that innovative solutions, from small companies, have difficulties to enter the market. These products are unable to compete for the lowest price. Smaller companies are also excluded when the municipalities repeatedly return to the larger companies for products similar to what they already have

In the future, it will be important to analyze the users' need for security and how this need could be met by new solutions. It will also be important for the municipalities to ensure that the safety and quality of social alarms really address the users' needs, both with respect to alarm holders and personnel.

Several problems were revealed during the interviews with the users. One large problem was that the alarms had a very limited reach and were designed for indoor use only. If a user was too far away from the base unit, the alarm did not work. Furthermore, in the traditional indoor alarms, the speaker is located in the base unit and the user had to be quite close to the unit to communicate with the alarm center. The ability to have voice communication via the alarm unit (which could be worn on the wrist) would remedy this problem. This would also increase the users' mobility indoors. Improvements relating to feedback were mentioned, for example, different feedback about when the alarm was sent and when the alarm was received by the alarm center or by home care staff. The problems regarding the traditional social alarms in terms of being unable to use the alarm outdoors had the effect that some elderly people hesitated to leave their homes. In the analysis of the interviews, we could see there was a great need for an outdoor alarm. No existing alarms can handle both traditional indoor alarm usage and outdoor alarm usage in the same solution. The explanation to this is that the alarm solutions are based on different technologies and different organizations in terms of acting on alarms.

Study 2: Outdoor Alarms and User Needs

Objective

For the elderly population to live an active life and exercise in a safe way, social alarms must operate outdoors. The aim of this study was to investigate needs among elderly users and their relatives regarding outdoor social alarms. In this paper, we investigated appearance, functionality, and aspects related to responsibility and payment.

Method

In this study, the material was gathered in two ways through focus groups and open-ended interviews. Focus groups were used to gather new ideas from a broad perspective. The aim was to encourage the participants to evolve new ideas together with others. Interviews were chosen to detect phenomena, properties, and meanings of using outdoor social alarms with respect to safety. The interviews were conducted individually to give participants the opportunity to express their views without the influence of others.

In the interviews, 15 participants from 3 user categories were included: elderly, middle-aged people who took care of their elderly relatives, and young people who helped a grandfather or a grandmother. The questions in the interviews addressed attitudes toward safety and the use of outdoor social alarms. Furthermore, we asked what the participants thought about how and by whom the alarms should be received and acted upon.

Two focus group sessions were carried out, one with elderly people, and one with middle-aged people taking care of one or more elderly relatives. The aim with the sessions was to gather material regarding needs, functionality, and appearance of outdoor alarms. The work in the focus groups started with broad questions regarding the need for safety and social alarms. In the next step, 3 existing alarms were showed to the participants. Each of these alarms solved different aspects of the need for safety. After each presentation, the alarm was discussed based on its advantages and disadvantages, and a wish list was created. The list consisted of features the participants wanted in this kind of alarm. The participants had ideas on new functionality that they thought the alarms lacked. They also pointed out functionality that they thought could be excluded in alarms. As a final step, the participants were asked to prioritize among the functionalities that were described. The result of the session was a list of functionalities, a wish list, for outdoor social alarms.

During the focus group and the interviews, the researchers took notes. The material from the focus group and the interviews was analyzed and categorized with a grounded theory approach [11]. The results presented below are a summary of the most frequent topics from the material.

Results and Conclusions

When adding outdoor functionality, it becomes much more complex regarding receiving and acting on alarms. In the interviews, the participants were asked about the relatives' role in receiving alarms. One important result from the interviews was that the relatives were reluctant to receive the alarm calls. Both middle-aged and young relatives wanted to be there for their elderly relative. However, the responsibility of receiving and acting on alarm calls was too great with too many difficult decisions to make. The participants thought that the alarm primary should be connected to an alarm center, but that the relatives should be notified when an alarm call had been made.

In the focus group sessions, both the elderly participants and the relatives pointed out that the wearable alarm unit must be something other than a mobile phone. It has to be a device that would not be forgotten as easily as a mobile phone. It should also have a separate alarm button that is easy to see and press. Even though the alarm should be something other than a mobile phone, the elderly participants pointed out the importance of being able to speak/communicate with the receiver when they had raised the alarm.

The lack of feedback reduced the feeling of safety and increased the uncertainty regarding whether someone would help. A solution suggested by the participants, was to receive differently labeled information if someone actually had received or acted on an alarm call. However, as pointed out by the relatives, it might be difficult to understand too many kinds of feedback,. The feedback must be easy to understand if it should be assigned to all actions in terms of send, receive, and act on alarms. For example, different buttons and/or different lights could be used. The buttons could also have pictures for those who have difficulty remembering which button to press.

When it comes to the design of the alarms, both the elderly and the relatives thought that it was important to make the alarms more personal. For example, it should be possible to choose among different styles and colors. The relatives also pointed out the importance of personalizing the alarm with respect to functionalities.

Finally, we discussed integrity with the participants. In line with previous research [12], none of the participants thought that the use of their geographical location was an invasion of their privacy. The benefits were seen as far greater than the disadvantages to be located using GPS.

Conclusions and Future Challenges

To summarize the results from the two studies, it was difficult for the municipality to know/understand user needs. The technology was complex and required considerable expertise in the area. There were usually no methods within the municipalities to include user needs in the process when the social alarms were procured. Mangers for social alarms within the municipalities need more knowledge about the technology and user needs to be able to offer tomorrow's new technology to its population. Better dialogue with users about their needs, and new methods in gathering these needs are required to be successful in introducing new types of alarms.

The results showed that the experience of safety did not correspond with the needs that the elderly had. Similar results were also found in other studies [1-5]. One limitation with today's traditional social alarms is that the user only can alert from his or her home and not outdoors. This means that many elderly do not come out on walks because they feel unsafe outside their homes. With aging usually comes memory loss, and it can have devastating effects on the quality of life for older people. Ertel et al [13] found evidence that elderly people in the United States who had an active social life had a slower rate of memory decline.

We believe that to increase the elderly's quality of life, social alarms also need to operate outdoors. In our studies, we found that there was a great need for outdoor alarms among both users and relatives. Relatives requested alarms with functionality that handled the situations in which the residents risked ending up in danger if he/she left his or her home. In particular, families with an elderly relative with dementia who lived in his or her home felt great insecurity regarding this.

Today, there are examples of outdoor alarms that communicate via mobile networks and have GPS receivers. These alarms also have voice communications, which means that an alarm receiver can talk with the person who has alerted. When adding outdoor functionality, it becomes much more complex regarding receiving and acting on alarms. The municipalities don't always have resources and routines to take care of this type of alarm. One important result from the interviews showed that it was not obvious that the relatives would like to receive the alarm calls. Both middle-aged and young relatives wanted to be there for their elderly relative, but to be responsible for receiving and acting on alarm calls was too great of a responsibility with too many difficult decisions to make. Participants indicated that the wearable alarm unit must be something other than a mobile phone; that is, it should be a device that will not be forgotten as easily as a mobile phone.

To conclude, there was a great need for alarms that could handle both indoor and outdoor environments. Both our results and other studies indicate this [6-8]. The elderly and their families requested social alarms that could handle both indoor and outdoor environments in the same alarm system. One problem with current indoor and outdoor alarms is that they are based on different technologies and are not integrated into the same alarm solution. With an increasing elderly population and fewer resources, new types of technology solutions are needed for older people to feel safe even when outdoors, which is a prerequisite for an active life with better health and improved quality of life.

Future work will include development of a new combined alarm solution. One important feature will be that the alarm solution consists of a base unit in the home and an alarm device that a user can wear both indoors and outdoors.

Furthermore, the alarm solution should consist of functionalities such as an automatic switch between indoor and outdoor position for increasing battery capacity. When a user is at home, the alarm unit communicates with the base unit just like a traditional alarm and when the alarm holder leaves home, the alarm unit switches to a global system for mobile communications mode with GPS functionality. The wearable unit should have a speaker for communication with the alarm receiver and an alarm button. For outdoor use, it should be possible to use services such as "geofencing" [14] for setting up a geographical zone based on GPS coordinates, and if a user (the wearable unit) crosses the border of this area, an alarm is activated.

Development of such an alarm solution entails a number of challenges, particularly regarding hardware and battery capacity. Furthermore, for these solutions to work, new ways of relating to both the alarm receiving and responsibilities, and for payment, are required. We believe that new ways of allocating these aspects between the private and the public will be required. Despite of these challenges, it is essential that we approach the task. To succeed in designing this type of alarm, cooperation among companies that develop social alarms, municipalities, home care, and end users is needed. However, the most important issue is, and will be, to address the different user groups' needs and to involve the users in every user-related aspect of development.

Acknowledgments

We thank The Länsförsäkringar Alliance research fund and VINNOVA (Swedish Governmental Agency for Innovation Systems) who funded this work. We would also like to thank the participating municipalities and the end users that have contributed.

Conflicts of Interest

Conflicts of Interest: None declared.

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Abbreviations

GPS: global positioning system
PERS: personal emergency response system

Edited by G Eysenbach; submitted 24.05.13; peer-reviewed by M Bostrom, T Luger2, M Perez-Zepeda; comments to author 18.06.13; revised version received 06.12.13; accepted 16.01.14; published 07.03.14.

Please cite as:
Sjölinder M, Avatare Nöu A
Indoor and Outdoor Social Alarms: Understanding Users' Perspectives
JMIR Mhealth Uhealth 2014;2(1):e9
URL: http://mhealth.jmir.org/2014/1/e9/
doi:10.2196/mhealth.2730
PMID:25099060

Original Paper

Privacy-Related Context Information for Ubiquitous Health

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Abstract

Background: Ubiquitous health has been defined as a dynamic network of interconnected systems. A system is composed of one or more information systems, their stakeholders, and the environment. These systems offer health services to individuals and thus implement ubiquitous computing. Privacy is the key challenge for ubiquitous health because of autonomous processing, rich contextual metadata, lack of predefined trust among participants, and the business objectives. Additionally, regulations and policies of stakeholders may be unknown to the individual. Context-sensitive privacy policies are needed to regulate information processing.

Objective: Our goal was to analyze privacy-related context information and to define the corresponding components and their properties that support privacy management in ubiquitous health. These properties should describe the privacy issues of information processing. With components and their properties, individuals can define context-aware privacy policies and set their privacy preferences that can change in different information-processing situations.

Methods: Scenarios and user stories are used to analyze typical activities in ubiquitous health to identify main actors, goals, tasks, and stakeholders. Context arises from an activity and, therefore, we can determine different situations, services, and systems to identify properties for privacy-related context information in information-processing situations.

Results: Privacy-related context information components are situation, environment, individual, information technology system, service, and stakeholder. Combining our analyses and previously identified characteristics of ubiquitous health, more detailed properties for the components are defined. Properties define explicitly what context information for different components is needed to create context-aware privacy policies that can control, limit, and constrain information processing. With properties, we can define, for example, how data can be processed or how components are regulated or in what kind of environment data can be processed.

Conclusions: This study added to the vision of ubiquitous health by analyzing information processing from the viewpoint of an individual's privacy. We learned that health and wellness-related activities may happen in several environments and situations with multiple stakeholders, services, and systems. We have provided new knowledge regarding privacy-related context information and corresponding components by analyzing typical activities in ubiquitous health. With the identified components and their properties, individuals can define their personal preferences on information processing based on situational information, and privacy services can capture privacy-related context of the information-processing situation.

(JMIR Mhealth Uhealth 2014;2(1):e12) doi:10.2196/mhealth.3123

KEYWORDS

ubiquitous health; privacy; context information; trust; policy

Introduction

Overview

Ubiquitous computing makes it possible to collect all kinds of data anywhere and anytime [1] and allows integration of health care delivery and services into people's everyday lives [2,3]. This paper builds on a conceptual framework [4] in which ubiquitous health is defined as an open and dynamic ubiquitous information space. The space is presented as digital systems that consist of one or more information systems, their stakeholders, and environments. These systems create a dynamic network that offers and provides services to citizens. In the information space, individuals and service providers can select, tailor, and combine services and systems that belong to the network. To enable access to personal information, individuals and providers need to discuss trust, privacy level, and proffered service.

Ubiquitous health services can be offered by providers that are licensed and regulated by medical ethical codes and health care–specific legislation and other juridical norms and by actors that are not affected by health care–related regulations. To separate these two groups, we divided them as regulated health care services and other services. Providers offering regulated health care services have strict defined responsibilities and obligations concerning service provision, care, professionals, documentation, and information processing. There are also general regulations on privacy and security requirements (eg, data protection and processing directives) and business domain–specific regulations. Regulations cover laws; norms; good practice guidelines; and other rules controlling, constraining, or limiting activity of participants. These regulations can affect ubiquitous health services but they often do not meet the challenges of technological innovations well.

In ubiquitous health, trustworthiness and privacy are key challenges [4-6]. There are privacy threats created by autonomous and hidden processing of information and rich contextual metadata. There is no predefined trust between participants, and the business objectives, needs, interests, and policies of stakeholders may be unknown to the individual [4]. Information in ubiquitous health is highly sensitive and confidential, and the existence of services and actors that are not strictly regulated by health care-specific legislation creates threats and risks for individual privacy. In addition, information processing can happen in multiple systems and situations with different regulations, and risks of secondary use exist. The lack of predefined trust and privacy risks emphasizes the importance of an individual's ability to control his or her privacy.

For trusted information processing in ubiquitous health, we follow the principles presented in Ruotsalainen et al [4] and according to them, an individual should have the right to verify dynamically the trustworthiness of the ubiquitous health network and any system that requires or processes the individual's personal information for secondary purposes; control personal health information processing, inside systems and between them; be notified of all situations and contexts in which personal information is collected, processed, stored, and/or disclosed; and create situation-specific, context-aware, and granular personal privacy and trust policies, which control how personal information is collected, processed, disclosed, shared, stored, or destroyed.

Systems and stakeholders should have the responsibility to ensure trust verification by publishing their privacy policies and environmental and contextual features; openness of interests, business needs, and policies as well as their relationships with other systems; and transparency of information processing.

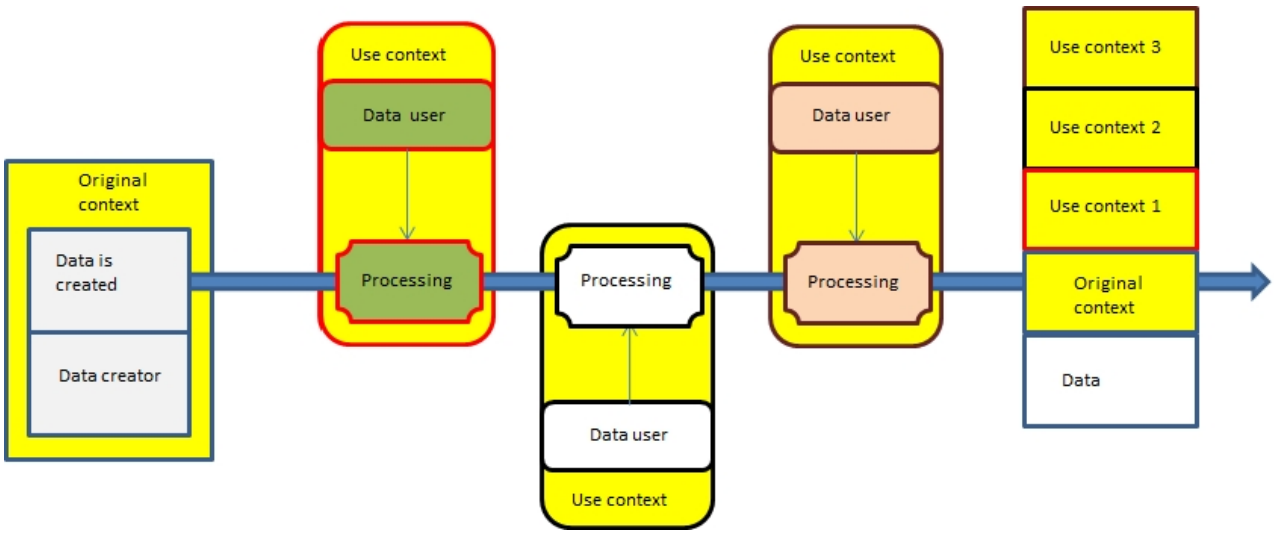
To protect his or her rights, an individual needs information about privacy, that is, privacy attributes, to define his or her personal privacy preferences. Privacy attributes enable privacy to be a concrete issue for individuals. In Nykänen et al [7], we defined privacy attributes as benefit, benevolence, capability, competence, confidence, context, reliability, and value. Privacy attributes and their contents have not generally been researched widely. The focus in this study is the context attribute, which refers to the situation in which data are created or processed. The objective is to analyze and define privacy-related context information components and their corresponding properties.

When data are created, a continuum of data is born. During the different processing situations, data or its properties may change. Original context refers to a situation when data are created. In various use contexts and processing situations, context information is incrementally created and it describes the current context and enables tracking of the context history. Thus, data have embedded context information that can be used by privacy services for trust calculation and to decide whether processing is allowed (Figure 1).

An individual's privacy preferences can be implemented with adaptable privacy policies. In previous work [8], we concluded a formula for privacy policies to contain (1) trust information that is a value of a system- or environment-specific calculation of regulatory compliance and trustworthiness; (2) sensitivity of the data; (3) situation of the information use; and (4) purpose of the data collection or use.

Policy formulation is a decision process in which an individual selects privacy rules and services and how much information can be traded compared to the offered service and the level of privacy attributes. In this study, our hypothesis is that context information enables formulation of context-aware privacy policies hence enabling trustworthy processing of personal health and wellness information and realizing individuals' rights for privacy in ubiquitous health. In Ruotsalainen et al [8], we presented a privacy architecture that could use context information in trust calculation and in context-aware privacy policies to control an individual's personal information. With this study, we add knowledge to our earlier research by studying the privacy-related context information and by defining the corresponding components and their properties that support privacy management in ubiquitous health.

Figure 1. Data continuum and context information.



Prior Work

Privacy and Trust

Privacy refers to an individual's ability to control information about him- or herself [9]. Privacy is a very personal concept and dependent on the context, because it may vary among jurisdictions, cultures, economies, time, and individuals [10-12]. Smith et al [13] claim that privacy is so bound to the specific context that it cannot be conceptualized as a single and unambiguous concept; rather it should be treated as a set of interests. Clarke [14] argues that it is useful to understand privacy as the interest of keeping personal space free from inference and has divided privacy into four dimensions: person, personal behavior, personal communications, and personal data. Information privacy means that personal information should not generally be available to other persons or organizations and an individual should have major control or influence over the personal data controlled by others and its use [14]. In this research, we refer to privacy as an individual's personal view within the legislative boundaries.

Trust is a concept closely related to privacy, and usually, the higher the value of trust, the lower the need for privacy [4]. Trust implicates the willingness to share personal information with others [15]. Schoorman et al [16] emphasize that trust is based on a relationship and the level of trust expresses the level of risk an individual is willing to take. Abdul-Rahman and Hailes [17] have defined three characteristics of trust: (1) trust is subjective, (2) actions we cannot monitor affect trust, and (3) trust level is dependent on how others' actions affect our actions. Several trust models has been developed for calculating trustworthiness [16,18-20].

Ubiquitous computing systems should be open and dynamic, because pre-identification of participants is impossible and they might change regularly [21]. In these kinds of distributed environments, collaboration is vital because multiple systems together try to achieve goals and perform tasks and it is crucial for systems to know which entities they should or should not interact with [22]. Traditional privacy and security solutions are not adequate for ubiquitous environments because there is no central control or predefined users or policies [19,21,23]. Privacy and security architecture and decisions need to be based on trust and its properties [19,21,24].

Context and Context Awareness

Context has been mostly defined with user profile, user emotion, and user location and identities of nearby people and objects and changes to those objects [25-28]. According to Dey et al [29], the three most relevant entities are places, people, and things. These entities have to be considered from different viewpoints such as location, activity, and identity. Dourish [30] proposes that context and content cannot be separated; the context arises from the activity itself and it cannot be an external description of the setting. He claims that context is a relational, interactional property between objects and activities and the scope of features must be defined dynamically [30]. Dey and Abowd ([28], pp. 3-4) defined context as: "Context is any information that can be used to characterize the situation of an entity. An entity is an individual, place, or object that is considered relevant to the interaction between a user and an application, including the user and applications themselves."

This definition is open and it considers that any information that is relevant for information processing in a situation can be used as a context. Context information can, for example, be information about the user, device, environment, or situation. Thus, it is meaningful to talk about context related to something that exists. There are three main uses for context information [29]: (1) presenting information and services to a user or using context to propose actions to be performed, (2) execution of a service automatically on behalf of the user, and (3) applications can tag context to information for later retrieval.

In context-aware computing, applications and systems are able to perceive their surroundings and environment, adapt according to the context, and perform autonomously. Context awareness refers to adaptability, which means that applications and systems exploit perceived context information and adapt their behavior accordingly [31]. In this view, context information is information that enables behavior modification based on this information and its relations. The systems, applications, and entities have to define the scope themselves.

According to Viswanathan et al [32], the key point for successful ubiquitous health is context awareness, and there are already several context-aware applications in the health and wellness domain. A lot of research has been done to support personalized actions and services in home care, chronic disease management, and ambient assisted living [33-37] with different personalized health status, body sensor networks, activity or behavior monitoring, decision support, and reminder applications [32,33,35-40]. In the hospital environment, many professionals are very agile, and context-aware technologies may help by personalizing services for them by location, time, and social context [41]. According to previous studies [33,42], there are several experiments on context-aware computing that have been created in hospital environments to improve patient record management, communication among professionals, and information sharing by including context awareness in patient room equipment.

Policies

In ubiquitous environments, privacy requirements can be expressed with policies. Privacy policy can be understood as a personal statement on privacy. With policies, individuals can set computational rules explicitly stating their personal privacy preferences on how their information can be processed, used, disclosed, and shared [21,43,44]. Policies are typically expressed with a policy language [45]. To enable personal privacy policies with computational rules requires definition of privacy attributes. Privacy policies can be implemented with setting values on privacy attributes. Context-aware policies based on context information enable dynamic adaptation of privacy control strategies and tailored privacy decision support services. A technique called sticky policy enables attaching policies into data to ensure that data are processed according to an individual's wishes [44].

Behrooz and Devlic [46] propose a context-aware privacy policy language based on two design considerations: (1) situations and privacy rules are defined separately, and (2) a context requestor can be specified based on its identity or social relationship to a user. These principles mean that privacy policies are set for different situations. Ghosh et al [47] presented a semantically rich policy-based system that can reason on user's context and thus protects a user's privacy dynamically during runtime. Schaub et al [23] presented a privacy context model with three major entities—user, user's environment, and user's activities. Their model takes into account information, physical, and territorial aspects of privacy. Blount et al [48] proposed a context-dependent policy model in which field context contains information when conditions for the policy are valid. These values may be from either the subject or the requestor.

Methods

Scenarios and User Stories

Scenarios are means to describe the system's intended usage. Scenario-based design techniques produce descriptions of how people do things and how they can accomplish different tasks with the system. With scenarios, designers can find new ways of doing things and new things to do. Scenarios capture goals, entities, behavioral information (eg, actions, activities, and events) and what people are trying to accomplish with the system [49,50]. They can also describe different related actors with their own objectives. Typically, scenarios have a plot that consists of several events, things that happen during activities, changes in the setting, etc. Scenarios are work-oriented analysis methods; thus, they are suitable for our purposes, because we are analyzing typical activities of an individual in an ubiquitous health environment to recognize the needs for context information.

In our previous articles, we analyzed privacy threats and the principles for trusted information processing [4], defined privacy attributes [7], and analyzed the requirements for information that should be used in privacy policy formulation and common threats and challenges concerning privacy in ubiquitous health [8]. Our previous results created the framework for the scenario development and analyses and for the requirements for context information. In this research, we created scenarios that were based on materials collected in our earlier empirical research on personal wellness [51-53] performed with focus groups and literature studies focusing on health and wellness activities and technical applications on chronic disease management, self-health management, ubiquitous health, and wellness approaches. Scenarios were designed to capture the characteristics of different situations, such as a general wellness management situation without any specific needs and a specific setting with a chronic disease. With scenarios, we could identify a wide selection of typical activities in ubiquitous health.

We first created two textual scenarios describing the main actors, their backgrounds, and current health and wellness situations and next, we determined the main goals, activities, and entities. Then, we further divided both scenarios into 10 user stories that described in more detail the activities and services the individuals needed in their situations. Each user story focuses on 1 activity of a scenario and it is a short textual and informal description of a user case. Because context arises from activity [30] with the user stories, we could capture activities in ubiquitous health to identify information-processing situations and privacy-related context information.

At first, scenarios described typical wellness approaches emphasizing services that are not regulated by health care regulations, for example, lifestyle management and health-related behaviors. The objective was to recognize activities and entities outside regulated health care services. Then we approached chronic disease management scenarios with a focus on identifying collaboration between regulated health care services and personal attempts to manage health outside the provider networks with other services. These scenarios were analyzed to recognize activities and information-processing situations. To summarize, these scenarios helped us to analyze the aspects of two different situations in ubiquitous health: (1) ubiquitous health without regulated health care providers' participation; and (2) ubiquitous health with regulated health care, for example, service portfolio is a combination of services produced by a regulated health care provider(s) and other health and wellness providers.

An Example Scenario

As an example, we present the following scenario. Peter is a 23-year-old healthy student who begins to feel tired and ill and he decides to seek help from student health services. After a few tests and doctor visits, Peter is diagnosed with type 2 diabetes mellitus. From now on, Peter has to pay attention to his habits and choices concerning healthy living for the first time in his life. We divided this scenario into more detailed user stories describing activities related to chronic diseases in a ubiquitous health environment. In Table 1, we present an example analysis of a user story. In Table 2, we present a detailed example of a single activity in ubiquitous health with its related privacy concerns, Peter's policies, and the context information that a policy example requires.

Table 1. An example analysis of a user story in chronic disease scenario. User story 2.1: Peter receives a medical device with sensors to manage and care for his disease and automatically measure and monitor his condition. Devices can also automatically inform his doctor about the results and major changes.

Role	Individual and information controller with rights for privacy, to control processing and secondary use of information. Peter can decide who can access data created by the device. Peter needs privacy policies to control his own personal health system (PHS) use and the information it contains.
Activities	Data is created in the sensors and transferred to PHS. PHS analyzes the information and compares it to past information. PHS informs Peter's doctor about a major change in a value. Doctor accesses the information and makes a medical decision.
Environment	Anywhere. No health care–specific regulations concerning the environment. Information sharing is based on Peter's known consent and privacy policies. All information created by the certified device is trusted. The device is regulated by specific legislation (eg, the European Union directive on medical devices). In case of a major change in measurement information, regulated health care service will participate and then the environment will be strictly regulated by health care–specific regulations.
Information systems	Medical device, Peter's own PHS and possibly electronic health record system. Sensor and measurement data is stored in PHS and Peter's health records are in regulated electronic health record system. Peter has total control over his PHS.
Stakeholders	Peter, medical device, PHS, and licensed medical professional (doctor) with responsibilities concerning care and patients privacy
Services	Certified medical device measuring blood sugar levels PHS diabetic information analysis Regulated health care service activated by Peter's PHS in case of a major change in Peter's measurement values
Information content	Measurement and monitoring data from sensors and medical device Health and wellness information in PHS is controlled by Peter. The medical information is regulated in health care organization's electronic health record system.
Original context of the information	Information is created by a certified medical device controlled by Peter. The environment does not have any specific domain regulations. Information is in Peter's control and he has full rights for it. Peter's personal context-aware privacy policies are the main source for limitations and constraints on information processing.
Requirements for context properties	Peter's PHS is a trusted information system in his control so it has full processing rights and can activate other services if needed following Peter's privacy policies. Peter has defined in his policies that different measurement and sensor data is very sensitive and sets limitation for what purpose information can be used. In other cases, PHS cannot grant access to information without Peter's authorization. Other than regulated health care, services have to share their principles for information processing, security and privacy policies, and for what purpose they want to process the information.

Table 2. An example analysis of an activity: data is created in the sensors and transferred to the PHS.

Privacy challenges and threats [8]	Peter's policies	Required context information for policy 1
Lack of awareness	1. Peter thinks that this kind of data is highly personal and can only be accessed automatically by a health care professional participating in Peter's care service.	Situation: activity, processing type, actor, target, information sensitivity, and purpose for processing
It is difficult to know how data is used in the future	2. To use the data, transparency of processing is needed; therefore, the provider has to publish detailed privacy and security policies and allow third-party auditing.	Environment: general privacy and security regulations, location, and society
Relationships between systems may be unknown	3. To prevent secondary use, copying data is not allowed. If copying is required, Peter has to be notified and his known consent is required.	Service: type, role, provider, location, and objective
Potential secondary use of information	4. Health care professionals are not allowed to disclose data without Peter's known consent.	Individual: role, rights to control information, relation to the activity, confidentiality requirements
Users want to control how systems use personal health information		Stakeholder: identity, type, role, purpose, and justification for processing
How to guarantee that data is processed following the legal constraints and according to the individual's policies		IT system: identity, type, controller

Results

In an open and dynamic ubiquitous health information space, there are no possibilities to predefine entities or activities and most aspects of information processing are dynamic. In the scenarios and user story analyses, we recognized how different activities are reasons for information-processing situations in ubiquitous health, how several entities can create and use information, and how the same information can be used later to support different activities. In addition, scenarios showed that activities could happen autonomously with information systems even without human participation; for instance, based on some measurement of vital signs or monitoring of data. Thus, information processing happens because some entity performs an activity in a certain environment. Situation describes this occurrence and therefore is chosen as the core component defining privacy-related context information. It is linked to a certain activity; that is, the reason for information processing. Context information needs to include the whole situation and all participants because of the dynamic nature and limitations in predefining activities and stakeholders in ubiquitous health.

As a result of our scenarios and user stories, we present the two kinds of basic models for ubiquitous health: ubiquitous health without regulated health care providers, and ubiquitous health with regulated health care service providers.

The first case is an open environment with multiple entities with different kinds of domain environments and interests. All participants are by definition untrusted. Health care–specific regulations do not apply, but regular privacy and security legislations set limitations for information processing. In addition, different domains may have their specific legislations (eg, social care, wellness services, medical devices, or pharmacy). Environment and entity-specific regulations and an individual's personal context with privacy preferences are necessary for adaptable privacy policies. An individual's role, environment, and privacy requirements may vary between used services or information systems and information sensitivity influences heavily on personal policies. An individual's rights to control data and information must be discussed with service providers.

In the second case, there are also entities that are affected by health care–specific regulations. Depending on who or what provides service and/or controls information, there might be strict health care–specific regulations for service provision, organizations, professionals, information systems, and information processing. Regulated health care services are to some extent trusted and privacy threats and risks occur especially when information is transferred from them or processed beyond their authority. It is very critical to capture who is responsible for what, where and how services are provided, what information and sources are used, how sensitive the information is, and who controls participating information systems.

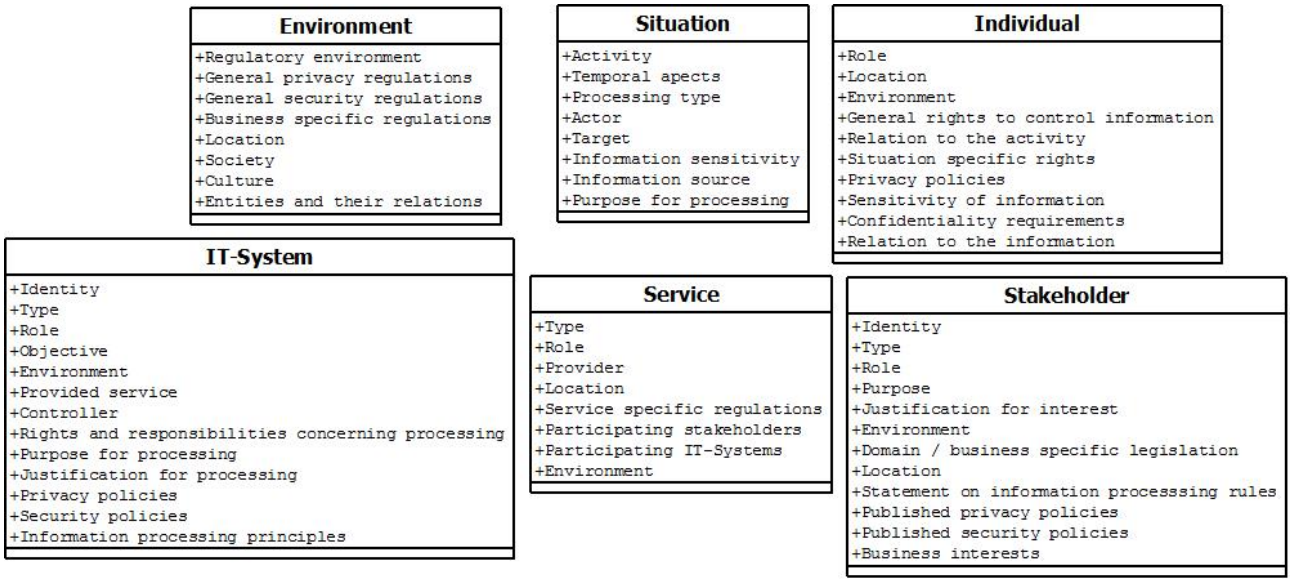
In a previous study [4], we defined ubiquitous health to be composed of services, information systems, stakeholders, and their environments. In addition to these, we have to capture the contexts of the information-processing situation and its object and/or subject. We should capture the following components and their properties on privacy, regulations, and requirements for trusted information processing: what happens (situation); who is the subject or the object (individual); what services are related to the situation (service); where this situation happens (environment); what social actors are active in the situation (stakeholder); and what computational entities participate (IT system).

In this research, the properties of the privacy-related context information components and their properties are derived by combining the results of the scenario analyses and the principles and requirements presented in the earlier research. We analyzed the results of the scenario analyses to explicate concrete properties for our components. In the example, we derived the context information that is needed to fulfil the requirements for

policies and to minimize known privacy threats. In this example, policy 1 in the Table 2 means that Peter sets a general policy that data created by sensors is highly sensitive and can only be automatically accessed by health care professionals participating in his care. Peter has total control over his data and the future use of data is based solely on Peter's wishes. The situation occurs when a regulated health care professional tries to access Peter's data to support Peter's care and to follow his condition. To manage his privacy, Peter needs information about the data user's environment and processing wishes. If parties other than a health care professional in Finland taking part in Peter's care service want to access the data, Peter's known consent is required. The data user is a regulated health care professional in Finland; that is, predefined as somewhat trusted and he/she can use the information only to make medical decisions and to follow Peter's condition. The data can only be accessed within Peter's PHS and the data cannot be copied or distributed. From the example, we can see how Peter needs several kinds of context information to create the example policy.

From the scenario analyses, we have defined the properties that are needed to fulfil the principles of trusted information processing and requirements set for privacy formulation concerning context information (Figure 2).

Figure 2. Privacy-related context information components and their properties for ubiquitous health.



A situation describes information processing that happens in a certain context because of some activity and by/for a certain individual. From the scenarios, we learned that environments might vary a lot; therefore, we need to understand the environment where the situation happens and component-specific environments (eg, individual, services, stakeholders, and IT systems) to capture all privacy aspects. With the environment, we do not only mean location and other position-based information, but especially important is to capture the type of environment. We have to perceive the properties of environment such as privacy, security, trust-related information, and information-processing rules and responsibilities. Regulations may differ a lot between environments and different businesses are affected by their specific legislation. Capturing environment is crucial because technological advancements such as cloud computing and big data create new types of privacy risks. For example, if a service is offered in the European Union but the data are stored or processed in an information system located in the United States, there are differences in legislations concerning privacy, security, or secondary use of data. People should be able to control where and why their data are processed.

An individual component describes the actual subject and/or object of health and wellness activities in ubiquitous health. It is linked differently to situations; an individual can create them, participate in them, and/or is an object. Properties needed from the individual are the role he/she has in the situation, location, and environment and what relation he/she has with the activity. Also, an individual's rights for controlling information processing (eg, content, disclosure and access to information), privacy policies, sensitivity and confidentiality requirements and what is his/her relation (eg, owner, controller, or subject) to information should be acknowledged. All these things affect how and on what basis systems can process information.

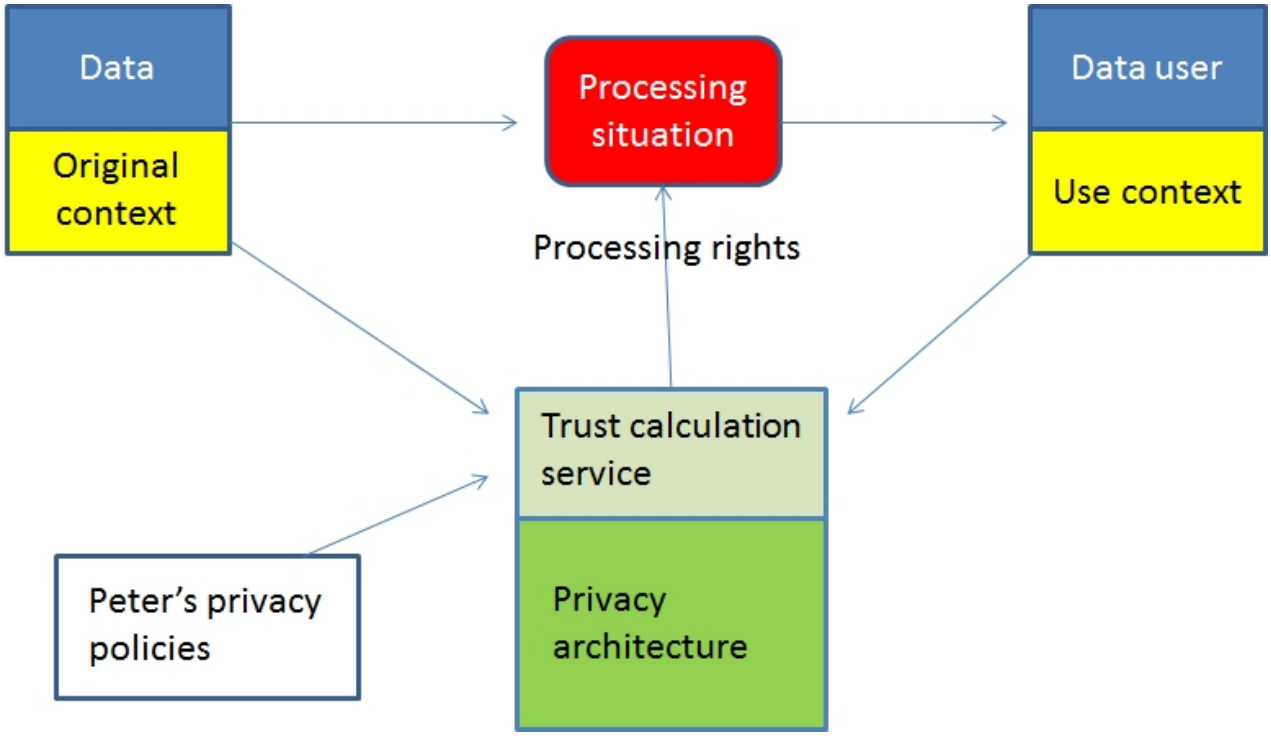
A service component describes regulated health care services and/or other services that can be offered by IT systems and/or stakeholders. An IT system component refers to all computational entities, which can include health information systems, personal health systems, ubiquitous systems, devices, sensors, etc. IT systems should be open about their processes and publish their privacy and security policies including how an individual's privacy is protected, relevancy of processing and actual data protection specifications, and detailed information-processing principles. This would improve transparency of information processing and increase trustworthiness. If an IT system does not publish necessary information, this has to be captured in the context information. Because information processing can happen anywhere, it is vital to capture its context because there are several characteristics affecting privacy that may differ between IT systems; for example, type, location, or regulative background. For example, there are big differences in regulations among information

systems, regulated medical devices (eg, have to be certified), and wellness devices. Stakeholder is the social component describing organizations and possible human participants. They can be actors or interested parties in a situation. They offer, participate, or are interested in services offered to individuals.

Our components can be used to increase trustworthiness of information processing because privacy policies can be adaptable and based on constraints, limitations, rules, rights, and responsibilities set with situational information. Components can also be used to analyze that the information processing follows the preferences set by an individual's privacy policies and the requirements from the original context of the information. For example, in our user story Peter may disclose medical and lifestyle data to a service provider to receive a selected service. Peter has set privacy policies using privacy properties. Before disclosure, Peter (his privacy architecture) needs the context information from the service provider to calculate if processing is according to the requirements set by Peter's own context-aware privacy policies and the original context of the information. Privacy architecture can then confirm that the use context is valid according to Peter's personal preferences and allow access to the information (Figure 3).

Our hypothesis was that privacy-related context information could be used to formulate context-aware privacy policies hence enabling trusted processing of personal health and wellness information. In this study, we analyzed contents of a privacy attribute context and presented components and their properties that can be used as part of privacy policies by setting situational constraints and limitations. These characteristics are also needed to capture information-processing contexts from the privacy perspective. All components or properties are not necessarily needed in all situations. In addition, if some systems refuse to cooperate in publishing context information, this has to be captured and acknowledged.

Figure 3. The use of privacy-related context information in ubiquitous health.



Discussion

In this research, we present an approach using privacy-related context information for privacy protection in ubiquitous health. Privacy is a business-enabler because individuals will not use these services if they cannot manage their privacy and trust. People need simple tools to manage their privacy and we have started this by defining the components situation, environment, individual, service, stakeholder, IT system, and their properties. These components describe the crucial privacy-related context information needed to improve trustworthiness of ubiquitous health. We present new knowledge by defining context, which is one of the main privacy attributes used in privacy policy definition. The results of this study can be used as a basis to create more formal models defining privacy-related context information in a computer-understandable format. Our results are in line with the preferred privacy level model by Lederer et al [11] but we have taken it a step further and divided context into original and use context and defined more detailed and concrete properties that could be valued and measured and used by privacy architecture for trust calculation.

Ubiquitous health is still an emerging field combining highly regulated health care with personal health and wellness services and systems. In health care, legislation and regulations define what privacy is and what kind of rights individuals have; that is, privacy is a state-defined property. Considering services and systems outside the regulated health care privacy is a personal property of an individual; that is, free will. The individual has the right to choose the use of his/her information and define policies as to how, where, and to what extent the information can be processed. In ubiquitous health, a privacy model is a combination of these two models and can be controlled with

policies. Policies can be personal preferences or defined by regulations. Using the scenarios, we could identify situations outside regulated health care to recognize requirements and characteristics of ubiquitous health. With organization-centric health care processes or workflows, we cannot really model ubiquitous health as a whole because there are many services and systems without predefined and regulated processes or workflows.

In ubiquitous health, service provision is based on customer relationships and trading on benefits of services against reducing personal privacy. Individuals should be able to verify the trustworthiness of service providers and decide if they are prepared to disclose personal information and reduce privacy. Because services are often offered as distributed, personalized and even autonomous, the privacy architecture should offer automatic privacy services and adapt dynamically to the situation. Scenarios and user stories showed that ubiquitous health is multidimensional with limitations of predefining situations. The amount of information needed and created in these situations can be huge, and the content and its sensitivity vary depending on the activity performed. Ubiquitous health is an open, dynamic, and collaborative environment and privacy needs to be based on trust and its properties [19,21,24].

In health care, privacy is mainly protected with access control and consent management. Access control is merely one tool to protect privacy. Managing privacy in ubiquitous health is a much broader issue than just controlling health care professionals' access to data. Access control with predefined rights, roles, and consents cannot really function because there is no central control or necessarily predefined processes, situations, or actors. To ensure privacy in ubiquitous computing, access control should be dynamic because of multiple changing entities. Context information enables dynamic management of rights [54]. Consent is an example of a personal policy but in ubiquitous health, policies are needed to cover several different situations that are more complex than those that consents are designed for. Policies have to be dynamic and context-aware. Corradi et al [55] present a dynamic and flexible security middleware that uses context as a basic concept in security policy specification and permissions are linked to the contexts instead of user identities or roles. Most research on privacy of context-aware computing focuses on capturing user's context or certain actors and using that information to adapt to privacy preferences [23,47,54].

In this study, we followed the approach of Behrooz and Devlic [46] to separate situations and privacy rules. We identified the necessary information to capture privacy aspects in information-processing situations. Then, privacy architecture can capture the situation and the conditions where data are created; that is, the original context and combine that with individual's policies and control future use contexts such as how, where, and by whom the information can be used. Our approach needs information from participating systems and currently its availability depends on the goodwill of participants. Additional to this information, privacy architecture can use external sources for estimating trustworthiness of systems (eg, recommendations from others, history, trust values, and trust calculations).

In the European Union, organizations are required to inform individuals about use of their data and publish privacy policies that should be comprehensive with high-level descriptions of their privacy practices [43]; however, these are not enough to safeguard individuals' rights. These privacy policies do not generally consider how data are actually processed after collection. So, one of the main challenges in privacy protection is how to enforce all relevant parties to explicate their detailed privacy policies [43]. Current legislation is not fully prepared to handle privacy threats of ubiquitous computing and does not obligate organizations to disclose their detailed privacy policies or information-processing principles. In the future, legislation needs to include the needs of privacy, citizens' rights, and ubiquitous computing. Citizens have to be able to control processing and secondary use of their personal information. Future privacy principles and norms need to progress from high-level principles to detailed regulations concerning the processing and use of information. This would bring openness and transparency to information processing and new kinds of responsibilities for organizations and informed rights for citizens. In addition, authorities or certificate organizations should be able to audit providers and offer recommendations about their trustworthiness.

The components defined in this research may have some limitations and may not be conclusive; however, based on the scenario analyses these are needed. In addition, some properties are hard to define explicitly or in measurable format. They have to be analyzed in more detail and formal models are needed to implement them in computational format. Also, we need more detailed analysis of what organizations should publish about their processes and privacy and security policies and principles. To create context-aware privacy services and policies in practice, we need to develop ontologies that explicate components, properties, and requirements that we have presented in this research. Ontologies are formal representations and should cover different activities, services, IT systems, stakeholders, information content, and especially relevant regulative environments. With ontologies, we can create computational rules that can be used to enforce regulations and personal policies into ubiquitous applications.

Because it is practically impossible for individuals to evaluate the trustworthiness of a system, and to understand detailed privacy and security requirements and set personal policies, we developed trust-based privacy management architecture for ubiquitous health [8]. This architecture model describes what privacy and security services are needed to enable trusted information processing in ubiquitous health. The architecture will apply privacy-related context information to create privacy and security policies that will ensure that information processing will not happen against the wishes of the individual and the original context of the data. The architecture contains decision support and policy services for individuals to help them define personal policies. This research adds to the architecture model by defining the required privacy-related context information components and their properties that are needed to create implementable tools and means for individuals to manage personal information privacy.

Acknowledgments

We acknowledge funding of the Trusted eHealth and eWelfare Space (THEWS) research project by the Finnish Academy of Sciences in the MOTIVE Research Programme during 2009–2012. The first author acknowledges the support of the Tampere Doctoral Programme in Information Science and Engineering (TISE).

Conflicts of Interest

Conflicts of Interest: None declared.

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Abbreviations

IT: information technology
PHS: personal health system

Edited by G Eysenbach; submitted 21.11.13; peer-reviewed by S Koch, J Zvarova, S Mohammed; comments to author 16.12.13; revised version received 26.01.14; accepted 12.02.14; published 11.03.14.

Please cite as:
Seppälä A, Nykänen P, Ruotsalainen P
Privacy-Related Context Information for Ubiquitous Health
JMIR Mhealth Uhealth 2014;2(1):e12
URL: http://mhealth.jmir.org/2014/1/e12/
doi:10.2196/mhealth.3123
PMID:25100084

Original Paper

The Schisto Track: A System for Gathering and Monitoring Epidemiological Surveys by Connecting Geographical Information Systems in Real Time

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Abstract

Background: Using the Android platform as a notification instrument for diseases and disorders forms a new alternative for computerization of epidemiological studies.

Objective: The objective of our study was to construct a tool for gathering epidemiological data on schistosomiasis using the Android platform.

Methods: The developed application (app), named the Schisto Track, is a tool for data capture and analysis that was designed to meet the needs of a traditional epidemiological survey. An initial version of the app was finished and tested in both real situations and simulations for epidemiological surveys.

Results: The app proved to be a tool capable of automation of activities, with data organization and standardization, easy data recovery (to enable interfacing with other systems), and totally modular architecture.

Conclusions: The proposed Schisto Track is in line with worldwide trends toward use of smartphones with the Android platform for modeling epidemiological scenarios.

(JMIR Mhealth Uhealth 2014;2(1):e10) doi:10.2196/mhealth.2859

KEYWORDS

epidemiological survey; schistosomiasis; public health

Introduction

New Tools for Public Health Studies

Among the traditional aspects of the structures of public health studies, information is a fundamental element in planning and carrying out the actions. With the worldwide movement toward new technologies, new tools are being incorporated within public health studies in order to make information more dynamic and increasingly accessible to health care system users [1].

The growth of the Internet has popularized information within health care as mobile systems like smartphones have become more accessible among the population [2]. Mobile phones with remote access to the Internet also have other functional features; they can receive signals from the global positioning system, store files and data in flash memory, and manipulate text, among other functions. With the evolution of open source development platforms for smartphones, users with knowledge of software programming can develop specific applications for these devices

and make them available on the Internet for download. Using these applications for health care services has the great advantage of direct contact between the administration and the population, taking these parties to be participants in the processes at the locations where the manifestations of health and illness develop.

The Android Platform

The Android platform (the operating system for smartphones developed by Google) has provided a new alternative for computerizing epidemiological studies, through using this, the data gathering process in the field is facilitated, errors are reduced, instantaneous communication is enabled, and a virtual database can be stored on the Internet [2]. The advances among operating systems, computing platforms, programming languages, and development frameworks are becoming integrated and being reapplied to mobile devices. This is improving the way in which epidemiological investigations are conducted, thereby supplying scenarios and responses for resolving public health problems [3]. The Epi Schisto Risk Modeling research group has been working on the development platform called "A New Kind of Simulator", in which a variety of computing tools form instruments for routine use in public services that deal with epidemiological and environmental surveillance. In this regard, one of the products conceived for exploitation of these services was developed with the aim of gathering and transmitting epidemiological data on schistosomiasis in real time, using the Android platform, with a view to future use of electronic tools to optimize the routine of health surveillance sectors.

Schistosomiasis as a Case Study for the Instruments

Schistosomiasis was chosen as a backdrop and case study on using and validating these instruments since it has considerable epidemiological representation in relation to diseases occurring in different regions of Brazil, and its control and elimination is a challenge. Snails of the genus *Biomphalaria* transmit this disease, and its etiological agent is the parasite *Schistosoma mansoni* [4]. In Pernambuco, this disease is expanding to coastal areas used for vacations and tourism. Several studies on these areas have diagnosed human cases and new concentrations of the vector mollusks of the disease [5,6], and have shown that there is a need for investments in tools for rapid and precise epidemiological diagnosis that might prevent or minimize outbreaks of acute cases.

Aim of the Study

The aim of the present study was to construct and present a tool to be used by field workers for use in epidemiological surveys in order to collect and transmit data in real time. In this manner, emerging technologies and their application to public health would become aligned and greater security and speed in consolidating and storing the data would be promoted. The "schistosomiasis model" was used to construct this tool, and its system was fed with all the variables (biological, environmental, and operational) used in epidemiological surveys that would be related to the parasite, vector mollusk, and human cases. This study was conducted through a partnership between the Department of Information Technology of the Federal Rural University of Pernambuco and the Schistosomiasis Reference Services and Laboratory of the Aggeu Magalhães Research Center, Oswaldo Cruz Foundation.

Methods

The Schisto Track Application

The Schisto Track application is a data capture and analysis tool comprising a combination of a mobile application and a server. Its construction was designed to meet the needs of a traditional epidemiological survey. Hence, it was planned in four segments: (1) registration of homes/individuals, (2) registration of breeding sites, (3) consultation of registered data, and (4) registration of paths followed. The first two of these segments used the *SQLite* database model. This database was fed with variables that had been validated in other epidemiological surveys that had aimed to identify foci of vector mollusks, diagnose human cases, and spatially locate information relating to schistosomiasis occurrences [5-8]. For each set of variables, information fields were set up (Tables 1 and 2).

Table 1. Variables to be gathered for registering breeding sites and foci of vector mollusks.

Field of information	Description	Epidemiological relevance
Photography	Direct observation and visual storage of macro-environmental elements.	Evaluation of the vegetation type, substrate, water surface dimensions, and proximity to homes and sewage ditches.
Number of snails collected	Quantification of the number of mollusk specimens collected.	Analysis on the snail population density per breeding site.
Collection station number	Coded register of each component station of the breeding site.	Reference for mapping each breeding site and systematizing collections.
Location	Recording of a pair of coordinates for each breeding site.	Composing of georeferenced points in the geographical information system, available on the Internet.
Observation	Open field for recording additional information on the location and completing the address.	Social representation of the area through localization recognized by people living nearby.
Breeding site classification	Permanent or temporary	Identification of whether the breeding site structure allows flooding or continual water collection, or whether it is of limited nature regarding its permanence in the environment (for example, only existing during rainy periods).
Type of breeding site	Ditch/canal; stream/small river; marsh/bog; lake/river	Identification of the type of snail habitat.
Water level	Deep; medium; low; dry	Viability of mobility and permanence of snails in the breeding sites.
Salinity level	0 to 0.4; 0.5 to 0.8; > 0.8	Snail resistance in habitats of low, medium, and high salinity.
pH	< 7; = 7; > 7	Snail resistance in acidic or basic environments.

Table 2. Variables to be gathered for registering homes and individuals participating in the study.

Field of information	Description	Epidemiological relevance
Municipality	Identification for simultaneous surveys in several municipalities.	Study territory
Locality	Identification of official and unofficial geographical territories.	Identification of areas covered by the Family Health Strategy, Community Health Agent Program, or Endemic Disease Agent Program.
Home number	Specific identification for each home participating.	Registration for mapping the area.
Number of receptacles handed out	Quantity of collecting receptacles handed out to participants.	Analysis to estimate prevalences and sample losses.
Name	Identification of study participants by name.	Preparation of parasitological reports.
Date of birth	Identification of participants' ages.	Data for analyses according to age group, descriptive statistics, and other analysis models.
Sex	Male or female	Data for analysis according to sex, descriptive statistics, and other analysis models.
Sample number	Registration of the epidemiological sample to be analyzed.	Coding in the database.

The Structure of the System

The structure of the system was divided into two modules: (1) the application (app), and (2) the server, thus making it possible to add and extract functional features in accordance with the needs imposed by the study in question. For this to be developed, the Android software development kit had to be used, and the Java language was used with a view to optimizing the results. This language was used because of its properties of robustness, security, distribution, portability, neutral architecture, and interpretability, while also presenting high performance [9,10].

The app was constructed in the Eclipse environment (Helios version), by means of the Android development tools (ADT) plugin, in order to facilitate production, tests, and project compilation. By using the ADT, it was possible to perform Android emulation directly from Eclipse, making use of all its resources, such as debug. It was also possible to control the

emulator, view logs, and simulate sending text messages, or to make telephone calls, in addition to the capacity to view and send files, run the garbage collector, and view the heap memory, along with other possibilities intrinsic to the functioning of the Android platform in the device [11].

As the data were registered, they were instantaneously transferred through the Internet by means of a third generation (3G) or wireless network to the Web server, where the information would form the MySQL database, with the option of generating spreadsheets in the Microsoft Excel format for use in spatial analysis programs by means of ArcGIS (Environmental Systems Research Institute).

The Schisto Track framework enabled interfacing with other systems and had totally modular architecture. It was integrated with the Web mapping service app Google Maps and a three dimensional (3D) cartographic platform, and the app programming interface (API) was available for all the sites that could be accessed, free of charge, by users and developers, thereby facilitating viewing of the spatially distributed data [12].

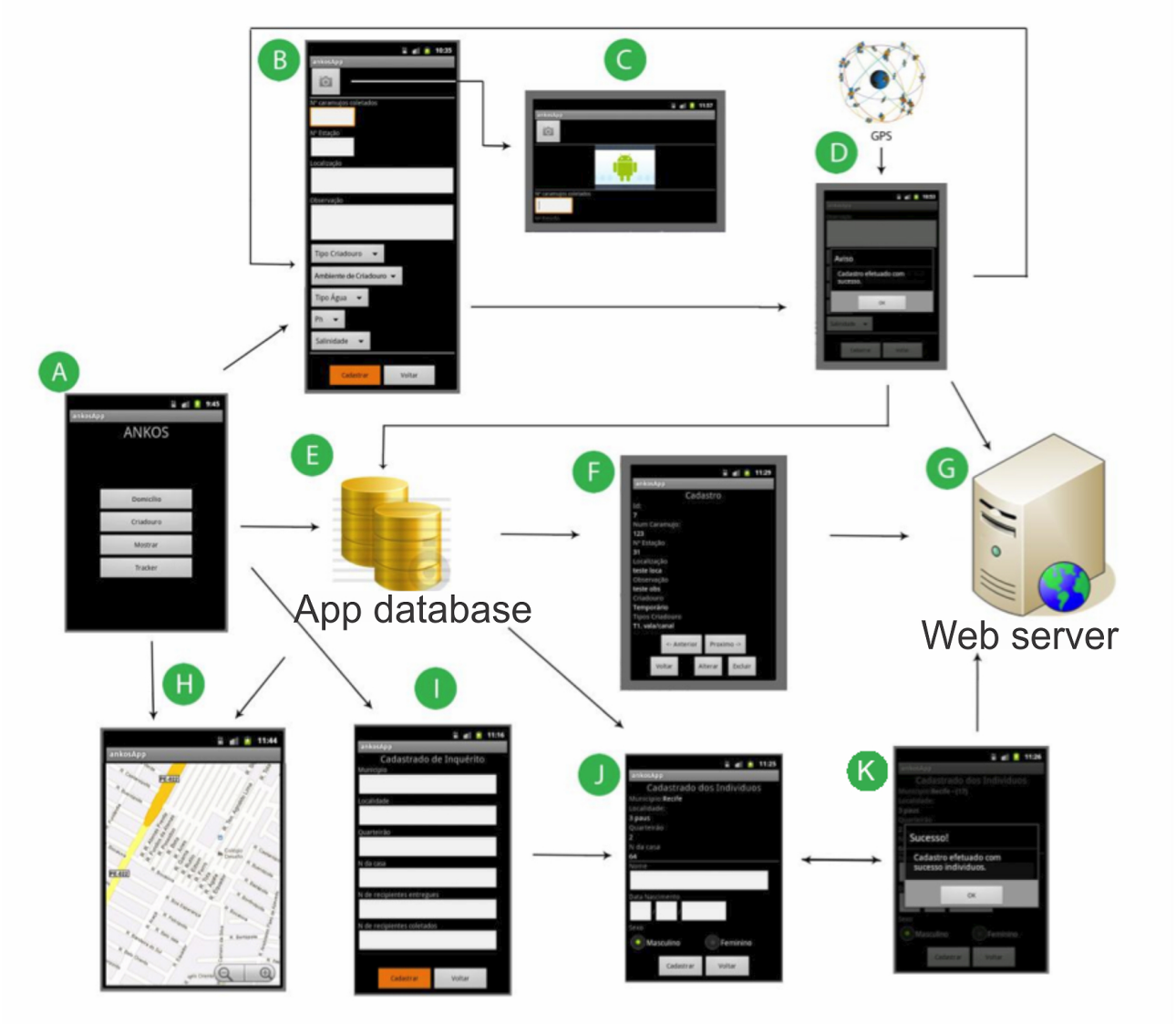
For remote data reception, the Web environment server was divided into a front end or presentation layer, and a back end or administrator panel. Both of these were developed using Hypertext Markup Language 4.01 and Ajax. To view the trails that were generated from the paths followed by the technicians, Google Maps JavaScript API V3 was used.

Results

The Schisto Track Application

The Schisto Track was shown to be a tool capable of automating the activities of registering breeding sites and homes, organizing and standardizing the data, and facilitating information recovery. It enabled interfacing with other systems and had totally modular architecture. It was integrated with Google Maps, and the API was available for all the sites that could be accessed, free of charge, by users and developers, thereby facilitating viewing of the spatially distributed data [12]. An initial version of the Schisto Track app was developed and tested between March and December 2011, using real situations and simulations for epidemiological surveys on schistosomiasis. Figure 1 shows the workflow.

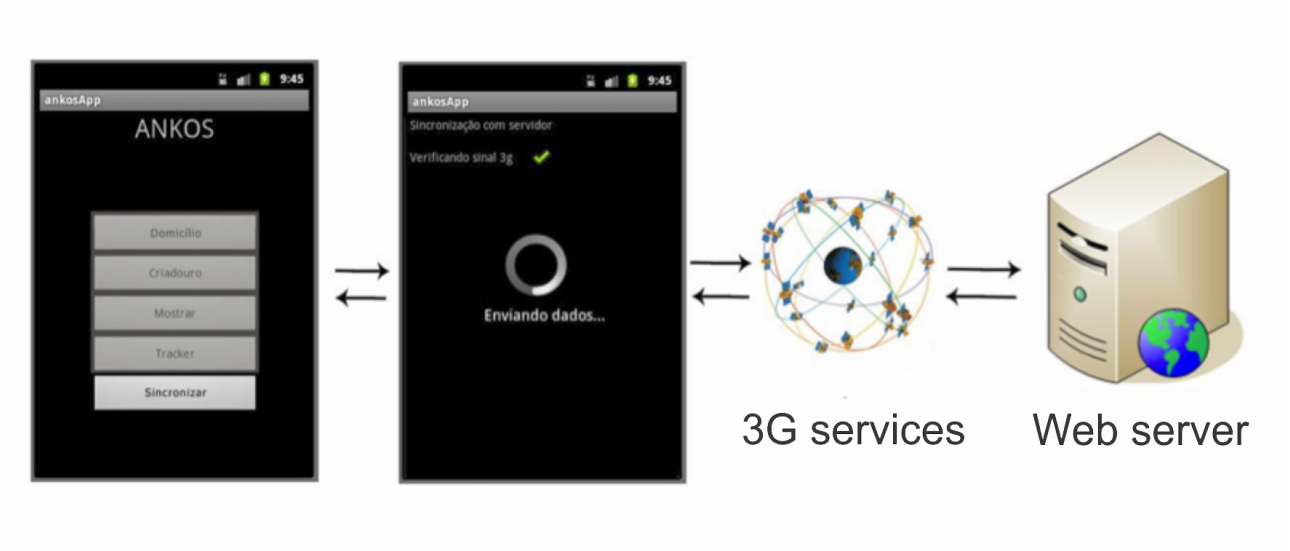
Figure 1. Initial version of the Schisto Track app. Global positioning system (GPS); Application (App); A New Kind of Simulator (ANKOS).



Web Server

To view the information registered in the field that was sent remotely to the Web server, two access levels were created: (1) open access for ordinary users, and (2) restricted access for project researchers. The information made available through open access related to the spatial distribution of the breeding site points that had been demarcated, which were viewed on the 3D cartographic platform of Google Earth. Restricted access, obtained through a registration module with identification using a log-in and password, enabled consultation and editing of the database containing all of the information from the study, and also allowed exporting of files to specific formats that could be used in geostatistical analysis software. The Schisto Track was designed for use by several users and in several locations at the same time. The different access levels ensured that the information stored in the database remained secure and trustworthy, thus avoiding inclusion of false information or access by unregistered individuals. This information was stored in databases located inside the device (SQLite) and, when a 3G mobile network or equivalent (EDGE, HSPDA) was present, the data were synchronized and sent to the Web server (Figure 2 shows this synchronization).

Figure 2. Synchronization of the Schisto Track with the Web server. A New Kind of Simulator (ANKOS); application (App).



Registration of Mobiles and Field Technicians

To ensure data identification and security, the functional features of the system required registration of the smartphones by means of the standard number of each device on the Android platform (identification-ID and serial). In addition, the ID of each field technician who was going to conduct the epidemiological survey was linked to the work tool. Thus, it was possible to make an association with the person responsible for the data collection.

From the initial screen of the Schisto Track, one can see that the data gathered in the field were transmitted and could be viewed in real time by any individual who wished to access the electronic address of the study. This artifice promoted dissemination of information warning about the areas at risk that had been identified, thereby ensuring that the communities were empowered and mobilized to take the individual and collective preventive measures that might be needed (see Multimedia Appendix 1).

Discussion

Operational Stages of Data Gathering

The operational stages for data gathering in epidemiological surveys constitute an arduous and onerous process involving a large amount of manpower for manually filling in record cards and data sheets that are later on transcribed in order to enter the data into computerized spreadsheets. This is a tiresome practice that is liable to involve transcription errors and information bias. An epidemiological survey conducted in the coastal locality of Porto de Galinhas, in the municipality of Ipojuca [6], registered 5800 participants and, for this, it was necessary to maintain a workforce of 10 data gatherers in the field for 11 months. This demonstrates that managing the process of field data acquisition, consolidation, and analysis is an exhausting challenge. In light of situations like this, the Schisto Track app constitutes a valuable tool since it imprints dynamism, speed, and precision on the data gathered, thereby avoiding transcription errors and bringing greater benefits to population based studies, in terms of security and logistics.

The Schisto Track Proposal

The Schisto Track proposal is in line with the worldwide trend toward using smartphones with the Android platform for modeling epidemiological scenarios [1,13,14]. Moreover, use of mobile phones has already been highlighted as a solution for transmitting health care information from remote areas, and as a tool for managing logistic processes, as well as serving as a tool for producing crowdsourcing and other health care activities [2,15-19].

The Google Maps platform, which is included in the app, provides immediate spatial positioning of the events, the vector foci that are detected, and the human cases that are diagnosed. The use of this platform as the base map for epidemiological and environmental studies is considered to be a modern trend. This platform has also been used by researchers around the world who have done so from the perspective of constructing

dynamic epidemiological scenarios [20-22]. The information technology used in epidemiology and surveillance of health problems has evolved from concepts such as “Infodemiology” and “Infoveillance”. In addition to the integration with electronic media [23,24] that is represented by open platform mobile devices, the Internet, and social networks, information technology promotes the dissemination of information by the health care system, service agents, and users because of the speed and quality of the information generated. These advances in health care information technology are in line with the proposal for participative epidemiology, in which it is recommended that indicators and situations should be made available on social networks, so that these can be explored by health care sector administrators and users. In this manner, a set of new tools and trends for coping with public health problems is enabled [25].

In Brazil, few tools for this purpose are available, and none of them present the robust characteristics that are as suitable for health care services as the Schisto Track proposal. This app brings together the practicality of a low cost tool that is easy to use with the importance of a public health instrument that aims to improve the processes of data capture and spatial environmental diagnosis in epidemiological surveys. For epidemiology, this is an instrument that is also applicable to other disease models, thus constituting an alternative for improving routine practice in health care and health surveillance services.

Acknowledgments

This study is part of the project Infodemiology & Infoveillance applied to the study of Schistosomiasis - Use of the Android platform for epidemiological surveys, funded by VI Strategic Program to Support Health Research (Papes) / Oswaldo Cruz Foundation (Fiocruz), registrant 407683/2012-7. We want to thank the support of field activities and the technicians of the Schistosomiasis Laboratory Reference Service.

Conflicts of Interest

Conflicts of Interest: None declared.

Multimedia Appendix 1

Screenshot from the ANKOS website, showing the possibility of making real time consultations for each breeding.

[PNG File, 816KB - mhealth_v2i1e10_app1.png]

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Abbreviations

3D: three dimensional
3G: third generation
ADT: android development tools
ANKOS: A New Kind of Simulator
API: app programming interface
app: the application
ID: identification
GPS: global positioning system

Edited by G Eysenbach; submitted 31.07.13; peer-reviewed by E Gomes, T Katapally; comments to author 10.09.13; revised version received 30.10.13; accepted 18.01.14; published 10.03.14.

Please cite as:
Leal Neto OB, Albuquerque CM, Albuquerque JO, Barbosa CS
The Schisto Track: A System for Gathering and Monitoring Epidemiological Surveys by Connecting Geographical Information Systems in Real Time
JMIR Mhealth Uhealth 2014;2(1):e10
URL: http://mhealth.jmir.org/2014/1/e10/
doi:10.2196/mhealth.2859
PMID:25099881

Original Paper

Teenagers and Texting: Use of a Youth Ecological Momentary Assessment System in Trajectory Health Research With Latina Adolescents

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Abstract

Background: Adolescent females send and receive more text messages than any others, with an average of 4050 texts a month. Despite this technological inroad among adolescents, few researchers are utilizing text messaging technology to collect real time, contextualized data. Temporal variables (ie, mood) collected regularly over a period of time could yield useful insights, particularly for evaluating health intervention outcomes. Use of text messaging technology has multiple benefits, including capacity of researchers to immediately act in response to texted information.

Objective: The objective of our study was to custom build a short messaging service (SMS) or text messaging assessment delivery system for use with adolescents. The Youth Ecological Momentary Assessment System (YEMAS) was developed to collect automated texted reports of daily activities, behaviors, and attitudes among adolescents, and to examine the feasibility of YEMAS. This system was created to collect and transfer real time data about individual- and social-level factors that influence physical, mental, emotional, and social well-being.

Methods: YEMAS is a custom designed system that interfaces with a cloud-based communication system to automate scheduled delivery of survey questions via text messaging; we designed this university-based system to meet data security and management standards. This was a two-phase study that included development of YEMAS and a feasibility pilot with Latino adolescent females. Relative homogeneity of participants was desired for the feasibility pilot study; adolescent Latina youth were sought because they represent the largest and fastest growing ethnic minority group in the United States. Females were targeted because they demonstrate the highest rate of text messaging and were expected to be interested in participating. Phase I involved development of YEMAS and Phase II involved piloting of the system with Latina adolescents. Girls were eligible to participate if they were attending one of the participating high schools and self-identified as Latina. We contacted 96 adolescents; of these, 24 returned written parental consent forms, completed assent processes, and enrolled in the study.

Results: YEMAS was collaboratively developed and implemented. Feasibility was established with Latina adolescents (N=24), who responded to four surveys daily for two two-week periods (four weeks total). Each survey had between 12 and 17 questions, with responses including yes/no, Likert scale, and open-ended options. Retention and compliance rates were high, with nearly 18,000 texts provided by the girls over the course of the pilot period.

Conclusions: Pilot results support the feasibility and value of YEMAS, an automated SMS-based text messaging data collection system positioned within a secure university environment. This approach capitalizes on immediate data transfer protocols and

enables the documentation of participants' thoughts, feelings, and behaviors in real time. Data are collected using mobile devices that are familiar to participants and nearly ubiquitous in developed countries.

(JMIR Mhealth Uhealth 2014;2(1):e3) doi:10.2196/mhealth.2576

KEYWORDS

texting; data collection; intervention research; longitudinal; trajectory

Introduction

Adolescents and Texting

Adolescents text more than they talk. No one communicates by text messaging more than adolescent females 12-17 years old, who *average* 4050 texts per month [1]. Boys of the same age average 2539, and to give context to this magnitude, the next highest texting average is 1630 texts per month among 18-24 year olds [1]. Among researchers, text messaging is growing in popularity as a strategy for collecting ecological momentary assessment (EMA) data. EMA are data reported in real time such that the respondent indicates in the moment of contact what they are feeling, thinking, or doing (eg, mood, alcohol use). EMA approaches also allow for collection of data in respondents' natural settings [2,3]. EMA data help overcome challenges associated with recall-dependent data collection methods (ie, survey respondents reporting how they have felt the past two weeks, months, or years). Reducing recall bias by collecting data on emotions and events as they happen, EMA provides information and insights into the real life, in vivo experience of adolescents [4]. Using EMA allows an insider view on the range of emotions, thoughts, and activities that adolescents engage in throughout a single day. The challenges associated with recall-dependent data collection methods are well known, yet few valid and reliable alternative approaches exist. Until recently, those that have existed (eg, direct observation, hand-written diaries) have been costly, time consuming, susceptible to deceptive reporting (ie. falsified dates of when diaries were completed), and often unsustainable beyond the initial grant-funded project [2-6].

EMA Data Collection

With technological advances, researchers have collected EMA data using electronic diaries completed with hand-held computers (ie, Palm Pilots), and more recently, cell phones. Interestingly, most researchers have used cell phones to collect and store momentary data, but have relied on manual, in-person uploading of data from the phone rather than taking advantage of the capacity of cell phones for real time data transfer, or wireless uploading that occurs at scheduled times during the study. For example, Shrier et al [5] collected momentary assessments of sexual health behaviors of adolescents using cell phones that were locked and programmed to probe the adolescent randomly for a week. The data were stored and later uploaded to a computer when the phone was returned to researchers. More recently, cell phones were used to capture real time data from youth about moods and physical activity with responses stored until the phone was returned [6].

Some researchers have reported using cell phones and real time text messaging technology to collect and transmit EMAs about adolescents' alcohol use (N=26 [7]; N=20 [8]), children's bleeding episodes (N=104) [9], overweight children's self-management behaviors (N=141) [10], adolescent health information needs (N=60) [11], young adults' drinking patterns (N=44 [12]; N=70 [13]), undergraduates irritable bowel symptom management (N=43) [14], and adults' smoking cessation behaviors (N=31) [15]. However, published reports to date lack details regarding the system structure and the technicalities involved in transmitting EMA data. Other recently published reports describe the use of text messaging as a method for disease prevention intervention in developing countries [16], immunization reminders [17,18], asthma symptom management [19], prenatal care [20], and weight management [21]. These studies, while demonstrating the popularity of the use of text messaging in heath promotion, prevention, and intervention research, do not focus on the novel use of text messaging as a method of EMA data collection.

To augment the small but growing literature on the use of texting as a data collection tool, our team undertook a study to pilot and determine the feasibility of using an automated system for collecting EMA data from adolescents. We evaluated mood and related constructs four times a day for two weeks at a time. To accomplish this, a custom system had to be built within the university setting to securely and automatically send unique surveys to participants. Our study is the first, to our knowledge, to custom build a short messaging service (SMS; also known as texting assessment delivery system) for use with adolescents. This system was created to collect and transfer real time data about individual- and social-level factors that influence mental well-being. Benefits of this system include ease of data exchange, automation to reduce errors related to human effort, contextualized understanding of health behaviors, and the ability to capture data across numerous data points for longitudinal and trajectory data analysis.

In this article we describe the collaborative development of Youth Ecological Momentary Assessment System (YEMAS), and the specific features, including linkage to a cloud communication service provider, that foster efficient data collection, management, and storage. We present feasibility and compliance data from our pilot study of 24 Latina adolescents, and conclude with suggestions regarding the ways in which this system can be used in behavioral health research with adolescents.

Methods

Latina Adolescent Females in this Study

This was a two-phase study that included development of YEMAS and a feasibility pilot with Latina adolescent females. Relative homogeneity of participants was wanted for the

feasibility pilot study. Adolescent Latina youth were sought because they represent the largest and fastest growing ethnic minority group in the United States [22]. Females were targeted because they demonstrate the highest rate of texting [1] and were expected to be interested in participating. In fact, findings from a 2012 study suggest that SMS and social media are pervasive among Latino youth and that the youth view text messaging as a credible and essential method of communication [23].

Phase I–Development of YEMAS

Our multidisciplinary team was comprised of academic faculty representing the fields of nursing, public health, and psychology. Also on the team were information technology (IT) professionals and graduate students. The research team identified features of the system that would yield useful data, and the IT team members were able to advise the research team on which features could be accomplished given the realities of technological capabilities. There were two options for the system that were explored: (1) development of all aspects of the system within the university structure, and (2) involvement of a nonacademic third party (ie, telecommunication system) to support the secure transfer of texted data. The pros and cons of both scenarios were carefully considered in the context of security concerns, priorities for protecting research study participants, and the data they share via text. Importantly, the nonacademic third party Twilio, a cloud communication service provider that facilitates both the text messaging and data management/exporting, was able to document texting patterns, but their staff was not able to access actual text content. This was important to ensure that only the research staff at the university had access to the raw, texted data, rather than staff at the telecommunications company. Creating a full SMS delivery system requires tremendous financial investment and resources including purchasing the hardware, software systems, and phone numbers in addition to the time intensive development of the application. By utilizing a cloud communication service such as Twilio, a system like YEMAS can offer a cost-effective way to achieve the primary goal of delivering and receiving content via SMS. YEMAS was developed to leverage this cost-effective strategy. Also, with a university-based system, we were able to capitalize on internal security and server features, establish the Web-based assessment management system on a university Web address, and use secure university log-in systems to control access.

Via eight in-person meetings and regular electronic communication, the research team identified key system features and worked through challenges that were encountered. For example, an early idea was to use the email infrastructure to deliver and receive text messages; however, it became clear that the scope of data being collected, along with limited capacity of data management and organization via email, necessitated an alternative approach. Our initial meeting identified what the researcher was envisioning, and provided the programmer with information from which to research possible solutions. Follow-up meetings presented the possible solutions, with their respective pros and cons. Discussions were open with everyone on the team expressing opinions and preferences, using previous literature and the state of technology as guides. Thus, YEMAS was developed as a Web-based survey application that facilitates the sending and receiving of SMS texts by integrating with a Web-service application programming interface (API) solution, Twilio. Upon implementation, the research team communicated regularly so that the programmer became quickly aware of any challenges being encountered by the implementation team members during the pilot study.

YEMAS is a custom built SMS-based EMA delivery system comprised of four components (see Textbox 1). Technically, YEMAS operates in a Windows 2008 Server environment utilizing Oracle as the database and ColdFusion as the programming language (contact the authors for additional technical inquiries).

Textbox 1. YEMAS components.

- *Questions*–This is where all survey questions and corresponding response options are entered and stored.
- *Surveys*–This section houses all of the surveys created from the question bank. Each survey can be configured with the following parameters–
  - Delivery type (daily or weekly)
  - Delivery time schedule (in 5 minute increments)
  - Question order (random or predetermined)
- *Messages*–This section has three parts–
  - *SMS Queue*, where surveys are sent once they have been assigned a day and time for release and have been made active.
  - *SMS Results*, which captures each of the individual survey responses, from whom each response came, and the time each response was sent.
  - *SMS Log*, which displays the real time delivery log.
- *Participants*–The researcher enters the name/ID, email address, and phone number of each survey participant in this section. Participants are assigned to surveys so that the research team can select which surveys specific study participants will receive.
- *Admin*–Once a survey is completed, the researcher uses this section to export the data into an Excel spreadsheet.

How YEMAS Works

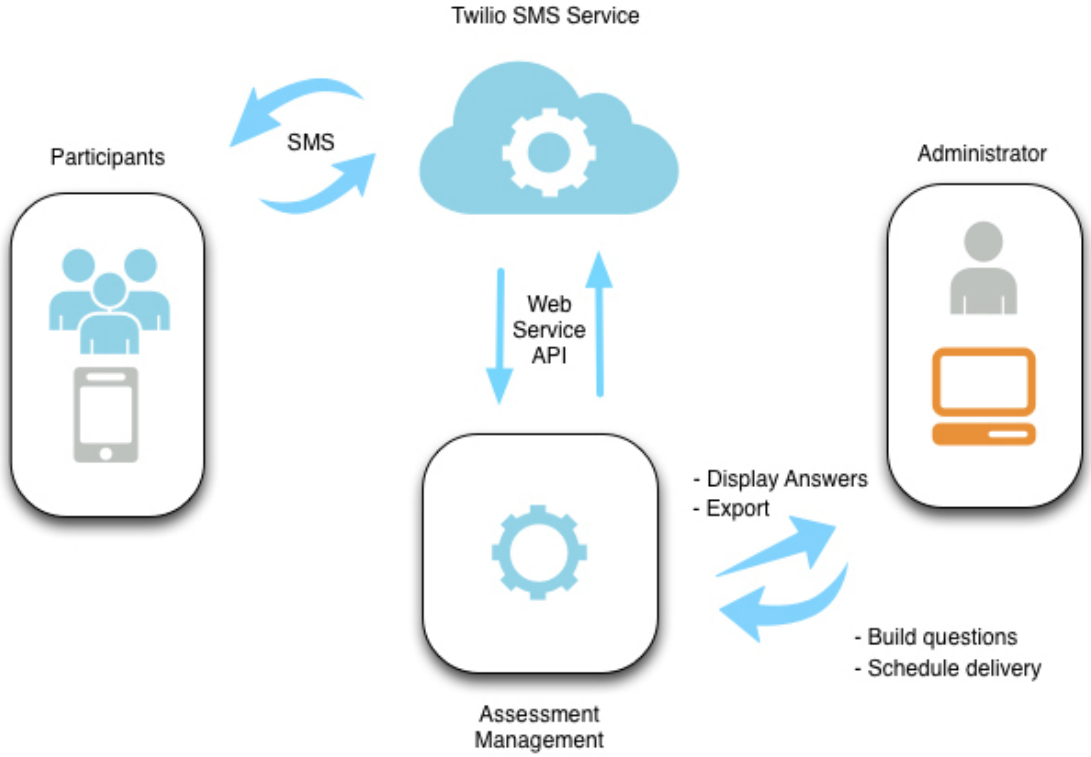
The functional purpose of YEMAS is to send study questions to participants in an automated, scheduled manner and to enable participants to post SMS text messages back to the system in real time (Figure 1 shows the YEMAS data collection process). The process is as follows–The administrator (study Principle Investigator or research team member) constructs a survey with a list of questions and response options that are in a SMS friendly format and then schedules the survey for a specific date and time to be delivered. Each survey is assigned to a "rented" SMS number obtained from the Twilio Service (See Textbox 2 for an example survey, and Table 1 for an example survey schedule. Multimedia Appendix A shows example EMA questions, response options, and delivery frequencies.). The cost of a SMS number (ie, phone number from which the texted questions are sent) from Twilio was $1 per month.

Once survey questions are scheduled in the system by the researcher, the YEMAS completes an automated server-side schedule task that builds a daily delivery queue. When the survey is due to be delivered, the system sends each question as a SMS text message to the participant's phone number via the Twilio SMS API. The API is a set of programming standards for accessing a Web-based software application or Web service. It is a software-to-software interface, not a user interface. With APIs, apps talk to each other without any user knowledge or intervention. In this way, the YEMAS interacts with Twilio to effectively send and receive text messages with numerous study participants simultaneously.

When the participant sends an answer as a SMS text message, Twilio takes the SMS text message and posts it via hypertext transfer protocol to the Coldfusion-powered SMS end point in YEMAS. The system then looks at the form data to confirm that it can determine the participant's phone number (identification number) and the assigned SMS number (which is unique to the survey delivered at a specific time of day and day of the week). Once both numbers are confirmed, the returned answer (either the number corresponding with the appropriate response option, the word/phrase corresponding to the appropriate response option, a combination of the number and word/phrase, or an open-ended response) is stored in the database. The collected data can be viewed to observe actual responses, response rates, and trends, and can then be exported to a spreadsheet file for further analysis.

Importantly, the subsequent question in the survey will not be sent by the system until the participant provides a text response to the initial question. In this way, a set of questions is not sent all together; rather, questions are sent sequentially following responses that are received (note–this is similar to what many private sector businesses currently use to evaluate their services by text; a question is sent and when a response is provided, the next question is delivered). Therefore, if a participant chooses not to respond to a question, that survey (for that time of day only) is stopped. Investigators can provide the response option, "skip this question," to allow participants to move on to the next question. To avoid receiving responses for survey questions sent the previous day, each survey had a unique phone number from which the survey was delivered and this number changed at midnight, in addition, each text was time and date stamped to allow for monitoring responsiveness.

Figure 1. YEMAS SMS-based ecological momentary assessment data collection process.



Textbox 2. Example survey.

- How HAPPY were u feeling just before u got this txt?

1.Not at all, 2.A little, 3.Quite a bit, 4.Extremely

- How TIRED were u feeling just before u got this txt?

1.Not at all, 2.A little, 3.Quite a bit, 4.Extremely

- How ENERGETIC were u feeling just before u got this txt?

1.Not at all, 2.A little, 3.Quite a bit, 4.Extremely

- WHERE were u just before u got this txt?

Open-ended

- How SAFE do u feel where u r right now?

1. Unsafe, 2. Somewhat safe, 3. Very safe

- Were u ALONE just before u got this txt?

1. Yes, 2. No

- Were u with ur MOM or DAD just before u got this txt?

1. Mom, 2. Dad, 3. Both, 4. Other adult 5. No one

- Describe something stressful u had to cope with since the last txt survey.

Open-ended

- Would u say u r generally healthy 2day?

1. Yes, 2. No

- How many hours of sleep did u get last night?

Open-ended

- Do ur parent(s) know who most of ur friends R?

1. Yes, 2. No

Table 1. Example survey schedule.

Weekdays (Monday-Friday)	Weekends (Saturday-Sunday)
6:30 AM	10:30 AM
2:30 PM	3:00 PM
6:00 PM	6:00 PM
9:00 PM	9:30 PM

Pretest of YEMAS

We pretested YEMAS three times with three teens (not involved in the pilot study) and six research team members. The first pretest with teens consisted of a 12-question survey sent twice in one day (morning and evening), which allowed us to observe how the texting would work and qualitatively assess perceived response burden. At the end of this pretest, the three teens were asked four questions, also by text, to assess their experience. A second pretest with team members allowed us to refine question wording. We also ensured that all survey questions fit into a single SMS text message (met character number restrictions), and that the introductory text for each survey (ie, “Good afternoon. It’s time for a survey”) was sent before the first survey question. A final pretest with teens focused on ensuring that survey times were appropriate, survey questions were sent and received at the programmed time, and that once a response was received, the subsequent question followed immediately.

Phase II–YEMAS Feasibility Pilot Study

A feasibility study was conducted to establish the utility of YEMAS and to test data collection and management over an extended period of time with adolescent participants.

Setting

Recruitment of study participants took place in two urban public high schools in St. Paul, Minnesota. Both schools were similar with respect to the number of Latino students, but one had greater representation of students of color, and students qualifying for free or reduced lunch.

Participants and Recruitment

Girls were eligible to participate if they were attending one of the participating high schools and self-identified as Latina. School records indicated that there were 100 eligible girls across the schools; of these, 96 were contacted by a research team member about the study and invited to participate. There were four girls that did not have confirmed contact, because they were possibly not at school on the days recruitment occurred, and they did not respond to the mailed information about the study. A research team member actively recruited during school lunch periods and at outreach events for Latino parents. There were 27 adolescents that indicated interest; of these, 24 returned written parental consent forms, completed assent processes, and enrolled in the study. Both schools and the University Institutional Review Board provided approval for this study. Participant identifiable information was kept separate from the raw EMA texted data, which were linked to the telephone number from which the texting originated.

Measures and Pre- and Postsurvey Items

Upon enrollment, participants completed a baseline survey including demographics and self-reported health behaviors, mood, perceived stress, coping, social networks, and family and school connectedness. Standardized measures with established reliability and validity with adolescents were used in the survey. The survey consisted of 241 questions ranging from assessment of perceived ability to cope, to connections with family. A postsurvey was administered at the end of the study. A majority of participants completed this survey by computer via REDCap, a secure, Web-based application for building and managing computer surveys and databases [11]. The survey required approximately 40 minutes to complete. Through REDCap, each participant received an individual link sent directly to her email account. Once they clicked the link they could start the survey and stop and come back to it at any time. A minority of participants preferred to complete the survey manually, with their responses subsequently entered by the research assistant.

Procedures

Enrolled girls were given detailed instructions regarding the texting process; those without their own cell phone (n=4) were provided a phone limited to texting capabilities and were instructed regarding its use. A mini-manual was provided to each girl, describing the study, the texting process, example texting items, and how to contact the research team with questions. There were two texting protocols (A and B) that were used to examine different strategies that could optimize response rates. Girls were randomly assigned to start with Protocol A or Protocol B, which they completed for two weeks, and following a two-week break, they crossed-over to the other protocol. Protocol A required the girls to respond as quickly as possible to the texted questions, grouped and sent four times per day (ie, signal sampling). Protocol B advised the girls to provide open-ended texts to describe how they were feeling when particularly positive or negative things were happening in their lives (ie, event sampling). In addition, Protocol B included the four scheduled surveys of Protocol A, but girls were informed they could respond to the texts whenever they wanted. Each morning they received a text reminding them to offer open-ended texts that could be in response to the first scheduled survey that day.

The survey measures delivered via SMS text messages included Likert scales and open-ended questions assessing individual- and social-level factors influencing well-being (eg, affect, social context, parental monitoring). Some of the measures were derived from established longitudinal surveys of adolescents (ie, AddHealth, Minnesota Student Survey), and others were developed explicitly for this study. All questions were adapted for texting purposes, using common abbreviations for specific words (for example, the word “you” shortened to “u”).

How often a survey item was delivered was based on the kind of behavior and/or event being assessed and the likelihood of occurrence throughout the day and week for adolescents. For instance, items assessing momentary mood and activity participation, interest, and motivation were assigned a maximum frequency of two times per day. Alternatively, items assessing parental knowledge of activities and bullying were assigned frequencies ranging from once per week to three times per week. An entire survey instrument (ie, Positive and Negative Affect Schedule feelings scale) was not completed in one survey, but all items were asked via EMA, spread across different times of day and days of week. The response burden was considered (ie, open-ended items that required more effort were not assessed more than once per day), the number of questions for each survey ranged from 11 to 21, with each survey designed so that all questions could be answered in five minutes or less (the Multimedia Appendix A shows the complete list of EMA items and frequency with which they were administered). It is important to note that all participants received identical surveys for the same time period (ie, Monday morning, Friday afternoon) to facilitate comparison of EMA data across participants.

Participants were informed of the date that the SMS text surveys would begin. Additionally, a study research team member provided personalized reminder texts or calls, based on the participant’s preference, to increase response rates and study involvement. Participants were provided with reminders before each protocol resumed after the two-week break and once a week throughout each two-week study period. Text responses were monitored every other day, and if a participant had not responded to texts for up to 2 days, they were contacted to confirm receipt of texts and to determine that there was not a problem with their phone. This monitoring, completed by the research assistant, was not required from a system perspective, but contributed to obtaining high quality pilot study data. On a few occasions a girl’s phone number had changed. When the

system was updated with the correct number their texting responses resumed.

To pilot test the YEMAS, a research team member received all the texts that were sent, in this way system issues were readily identified and addressed. For example, evening surveys were to occur no later than 9:30 pm, but on one occasion the survey was texted around 11:00 pm. On another occasion, the same question was sent multiple times only seconds apart. These problems were identified and corrected with careful monitoring through the study. All problems were not identified during pretesting of the system primarily because selected surveys, but not all 28, were pretested. In addition, telecommunications complications may be specific to phone models or companies, and these may not arise during a pretest.

Compensation Structure

Participants received modest compensation ($5 gift card) for completion of the REDCap surveys. To encourage texting responses, participants were provided entries into a drawing for an iPod touch, the number of entries per person correlated with their percentage of text responses to reward responses.

Results

Participant Demographics

Participants were between 14 and 17 years old (mean age 15). In this feasibility study, four participants required a cell phone to be provided for survey completion. Among those girls who had a phone, all had unlimited texting plans and did not require financial support to upgrade their cell phone service plan. All but one participant had Internet access at home or a friend's house, which was necessary for the completion of the pre- and postsurveys. The Internet was available at both schools and one participant utilized a school computer lab to complete her surveys.

Feasibility

In order to establish the feasibility of YEMAS, we conducted analyses addressing protocol adherence, examining the number of responses to each protocol, the percentage of participants who responded to texts daily, and the percentage of questions completed during a given two-week data collection period.

The number and percentage of participants who responded to texts daily is provided in Table 2 for Protocol A (signal-based sampling) and Protocol B (event-based sampling) for three "rounds" of texting. Girls were recruited over time, and for this reason they entered the study during Round 1 or Round 2. All girls who participated during Round 1 were new recruits who were randomly assigned to receive Protocol A or Protocol B. Girls who participated during Round 2 were a mixture of new recruits and girls who were completing the second protocol (ie, a cross-over design). Girls who participated in Round 3 were all completing their second protocol.

As shown in Table 2, participants completing Protocol A responded to surveys on a greater proportion of days. This adherence to Protocol A occurred regardless of whether participants had been assigned to the sequence of Protocol A followed by Protocol B or vice versa. However, the first group of recruited girls (Round 1) had high proportions of responses regardless of assigned protocol. This could reflect greater interest in the study among girls recruited early as compared with girls recruited in future rounds, or it could be a function of response burden (Round 2 represents new recruits and the cross-over of Round 1 participants, whose interest in the study might have waned over time).

Table 3 provides the percentage of questions completed within each protocol. It is interesting to note that the rate for Table 3 is based on how many questions are responded to at each time point, as compared with the rate for data in Table 2 being based on how many days texts were responded to, thereby offering insight into responses across and within days of texting data collection. The data reveal that Protocol A (signal-based sampling) yielded a slightly higher response rate among adolescents (see Table 3). Figure 2 shows a weekday average response. It is possible that Protocol B (event-based sampling) resulted in greater burden for participants. This is consistent with findings from other studies that have shown greater response rates for signal-based sampling than event-based sampling, even for events that appear well defined, such as asthma attacks [2].

Table 2. Texts and mean percentage of daily responses among participants by protocol and data collection period.[a]

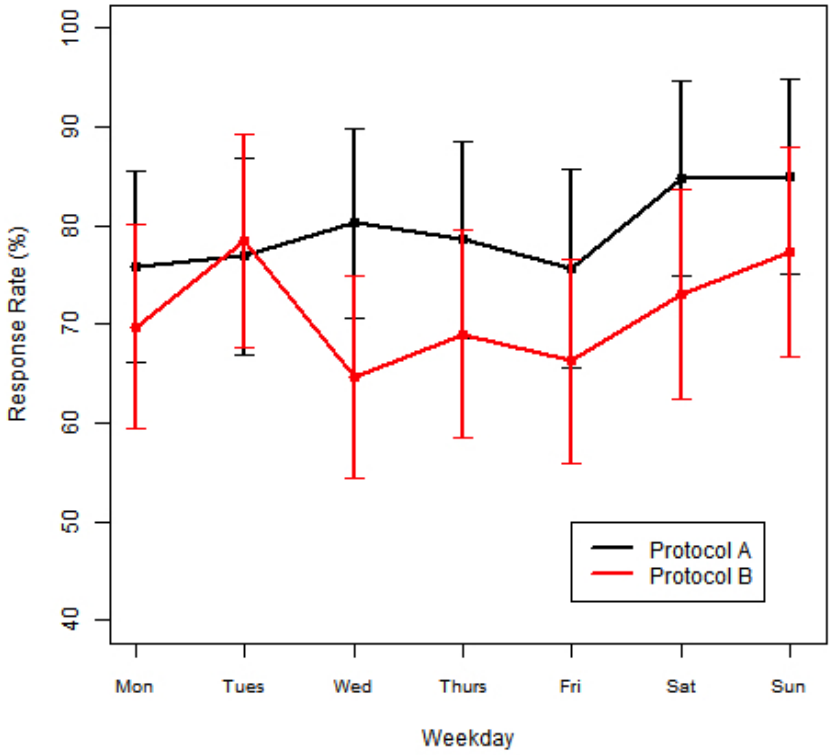
	Protocol A Signal-based sampling		Protocol B Event-based sampling	
	Participants, n (texts, n)	Mean text response rate, % (range, %)	Participants, n (texts, n)	Mean text response rate, % (range, %)
Round 1	7 (4963)	99 (94-100)	7 (2009)	96 (94-100)
Round 2	11 (6328)	84 (47-100)	8 (2746)	11 (11-100)
Round 3	2 (323)	53 (40-100)	5 (1925)	56 (13-87)

[a]Only participants who responded to at least one survey occasion during the round of surveys were included in these numbers.

Table 3. Mean percentage of questions completed by protocol at each time point.

Protocol	Response rate	95% CI
A (signal-based sampling)	79.59	70.53-88.66
B (event-based sampling)	71.21	61.97-80.45

Figure 2. Weekday average response and 95% CI.



Discussion

Purpose of the Study

The purpose of this study was two-fold: (1) to develop a Web-based automated system for real time SMS data collection, and (2) to pilot this system with a subset of Latina adolescents. This preliminary study provided important information, resulting in recommendations for next steps utilizing text surveys for collecting real time longitudinal data.

Our research team developed and pilot tested the YEMAS. This project has moved the field of EMA data collection forward. Previous studies focused on collecting and storing EMA data via Palm Pilots and cell phones [2,5], however, few researchers have reported use of an infrastructure that allows for real time assessments [6,7]. The findings of this study suggest that it is possible to employ immediate data transfer protocols, taking advantage of capabilities of cell phone and texting technology, rather than using outdated methods of storing data that require manual or scheduled remote uploading at various points during the study. Achieving immediate awareness of responses, as well as monitoring compliance daily, allowed timely follow-up with participants.

This study also has implications for the ways in which data are collected from adolescent participants in descriptive and intervention studies. In particular, studies promoting the emotional well-being of adolescents may uniquely benefit from capturing real time, in vivo momentary assessments via SMS text messaging, which promote a more accurate picture of the frequent fluctuations in affect experienced by many adolescents. SMS text messaging data could be used to compare against and augment traditional forms of data collection, such as periodic reports of mood during clinic visits or annual nationally representative cross-sectional surveys of youth. Data triangulation could offer important, new insights informing health behavior promotion and intervention research. In developing and piloting YEMAS, our project team learned many valuable lessons specific to the logistics of ensuring smooth system functioning.

As a population who frequently uses cell phones, many of us have experienced the problems and frustrations associated with sending text messages. Unfortunately, some of these issues will also arise when using SMS text messages and cell phones as a platform for collecting data (eg, EMA data). Even with programming accuracy, the nature of cloud-based SMS telecommunication allows for occasional mishaps, such as text responses arriving out of order. The type of automated system for data collection used in this study proved to be a very useful and important tool that will undoubtedly become more popular for collecting real time information from study participants. This type of system reduces the costs (ie, approximately US $.01/text) and offers capacity for large-scale automated EMA data collection.

Participants' Text Responses

An intriguing aspect of using SMS text messages to collect survey data was that, unlike many computer-based or paper-based surveys, participants' responses were not limited to a single number or rating. Participants frequently provided contextual details to elaborate on their responses. While this type of information will be useful as we create future studies, it also created some difficulty with the initial data analysis, requiring closer inspection of many of the responses because automatic coding proved to be inaccurate (eg, instead of simply

texting “yes,” the respondent said, “yes, I am just hanging out,” which required manual recoding as “yes”). The result was a time-consuming data cleaning process that reduced the 21,000 texted responses to 17,717 in the final cleaned data set. Some common reasons for removing a texted response were duplicates (text of a “y” sent followed by “yes” to the same question), split texts (one answer split across two texts).

The research team had to be familiar with texting shorthand linguistics, which required the occasional input from people outside of the study to determine what some responses meant. Most people are familiar with the term “lol” (“laughing out loud”), but others such as “Idk” (“I don’t know”) or symbols such as <x_x> (“smiling”) required investigation.

One final, and less frequent, problem was responses that appeared to be messages intended for other recipients. This problem is unique to this type of study because we are using text messages sent on participants’ cell phones, which are also being used for any number of other activities (ie, texting friends, talking on the phone, listening to music, taking pictures, or going on the Internet). Given the nature of text messaging and the use of texts as the preferred way for adolescent communication, it is probable that participants received survey questions at the same time they received or were sending messages to their friends or family. Sending a message to the wrong person is possible, especially when someone is interrupted in the midst of writing that message. Therefore, it is likely that some of the responses received were intended for other people (for example, the text message “ok,” which is commonly used in everyday life, did not make sense in response to a “yes” or “no” question, such as “Did a teen threaten u at school 2day?”). This is a potential problem for any study utilizing communication technology; however, in our study these occurrences were rare, and comprising less than 0.5% of the 14,000 responses. In addition, these errors were easily identified during the cleaning process. Future studies could include algorithms prompting automated follow-up when nonsensical or incongruent responses occur.

This pilot study thus yielded many valuable insights. Our study advanced understanding that adolescents respond with higher rates to signal-triggered data collection rather than event-based sampling. Additionally, the development of a university-based system linked to an existing Web-based API (ie, Twilio) proved to be efficient. This pilot study led to discussions with Twilio about customization and potential improvements to their system that could strengthen YEMAS in future studies. Finally, a key success from this pilot study was the creation of the infrastructure for a system that can be used to simultaneously survey numerous participants using SMS, a technology that is very accessible and already in widespread use across all socioeconomic levels nationally and globally.

Uses for YEMAS in Health Research

There are numerous uses for the YEMAS as a research tool in health research. From descriptive studies exploring new phenomena to randomized controlled intervention trials, EMA data collected via text messaging have potential to provide both new and complementary insights. As an addition to traditional self-report pre- and postintervention survey data, EMA data offer real time insights that can be efficiently collected and analyzed within and across multiple time points. Prospectively, these data could be useful in describing day-to-day fluctuations in characteristics or variables that are difficult to capture effectively in traditional survey approaches, including moods, feelings, or fluctuations in social relationships and interactions. Indeed, momentary sampling is more appropriate for factors that do not remain constant over time. Therefore, a system like YEMAS is essential for collecting data on these factors, independently, or as a complement to data collected through traditional methods.

Although YEMAS was designed initially for use with adolescents, the structure and system that have been created could be used with any research population. The survey questions and frequency of their delivery can be determined by the research team and guided by specific study aims. Text messaging is a common communication tool in the 21st century among all ages and ethnicities [23,24]. As a Web-based tool, the YEMAS can facilitate data collection from any target study population anywhere in the world. The availability of apps that facilitate texting at no cost (ie, Blackberry Messenger, What’s App) is contributing to the ways in which SMS technology can be combined with Web-based systems for effective contextualized data collection in behavioral health research.

Limitations

The study has limitations to consider when interpreting results. The small sample size was appropriate for a pilot study, but limits generalizability of the findings. Similarly, the homogeneity of the adolescents (Latina females) is a strength, but limits relevance to non-Latina adolescents and males. Finally, items were asked within each EMA survey in a sequential manner, rather than randomized in order. This is a limitation that could be avoided with additional sophisticated programming that would allow for within survey selection of sequential items (ie, those that are in follow-up to a previous question) and randomization of the order of remaining questions. This study was focused on feasibility and therefore provides an important foundation upon which future research can build and establish EMA data collection best practices among adolescents.

Conclusions

This study demonstrates the feasibility of conducting EMA through SMS (texting) among adolescents. This approach capitalizes on immediate data transfer protocols and enables the documentation of participants’ thoughts, feelings, and behaviors in real time. Data are collected using mobile devices that are familiar to participants and nearly ubiquitous in developed countries. Further, our research team has developed YEMAS, a content management system that facilitates efficient and automated data collection, management, and storage. The YEMAS approach to EMA is broadly applicable to studying the health behavior of individuals who use texting technology. The tools and protocols described in this manuscript thus have the potential to complement or transform existing approaches to studying self-reported phenomena among individuals that may fluctuate over time.

Acknowledgments

Funding support was received from a 2012 Midwest Nursing Research Society Seed Grant and a 2011 University of Minnesota Grant-in-Aid award. Research reported in this publication was supported by the National Center for Advancing Translational Sciences of the National Institutes of Health Award Number UL1TR000114. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health. Study data were collected and managed using REDCap, an electronic data capture tool hosted at the University of Minnesota. We acknowledge the adolescents willing to pretest the YEMAS system for us, and the participants willing to engage in this study using texting. We also thank the school-based staff that facilitated recruitment and project site activities (Claudia Perez Inzunza, Kevin Burns, Andrea Dickinson).

Conflicts of Interest

Conflicts of Interest: None declared.

Multimedia Appendix 1

Texted items by days and times administered.

[PDF File (Adobe PDF File), 169KB - mhealth_v2i1e2_app1.pdf]

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Abbreviations

API: application programming interface
EMA: ecological momentary assessment
IT: information technology
SMS: short messaging service
YEMAS: Youth Ecological Momentary Assessment System

Edited by G Eysenbach; submitted 13.02.13; peer-reviewed by K Phillips, K Durant, L Goeuriot, R Schnall; comments to author 26.03.13; revised version received 25.09.13; accepted 29.10.13; published 24.01.14.

Please cite as:
Garcia C, Hardeman RR, Kwon G, Lando-King E, Zhang L, Genis T, Brady SS, Kinder E
Teenagers and Texting: Use of a Youth Ecological Momentary Assessment System in Trajectory Health Research With Latina Adolescents
JMIR Mhealth Uhealth 2014;2(1):e3
URL: http://www.mhealth.jmir.org/2014/1/e3/
doi:10.2196/mhealth.2576
PMID:25098355

Original Paper

Usage of Social Media and Smartphone Application in Assessment of Physical and Psychological Well-Being of Individuals in Times of a Major Air Pollution Crisis

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Abstract

Background: Crisis situations bring about many challenges to researchers, public institutions, and governments in collecting data and conducting research in affected individuals. Recent developments in Web-based and smartphone technologies have offered government and nongovernment organizations a new system to disseminate and acquire information. However, research into this area is still lacking. The current study focuses largely on how new social networking websites and, in particular, smartphone technologies could have helped in the acquisition of crucial research data from the general population during the recent 2013 Southeast Asian Haze. This crisis lasted only for 1 week, and is unlike other crisis where there are large-scale consequential after-effects.

Objective: To determine whether respondents will make use of Internet, social media, and smartphone technologies to provide feedback regarding their physical and psychological wellbeing during a crisis, and if so, will these new mechanisms be as effective as conventional, technological, Internet-based website technologies.

Methods: A Web-based database and a smartphone application were developed. Participants were recruited by snowball sampling. The participants were recruited either via a self-sponsored Facebook post featuring a direct link to the questionnaire on physical and psychological wellbeing and also a smartphone Web-based application; or via dissemination of the questionnaire link by emails, directed to the same group of participants. Information pertaining to physical and psychological wellbeing was collated.

Results: A total of 298 respondents took part in the survey. Most of them were between the ages of 20 to 29 years and had a university education. More individuals preferred the option of accessing and providing feedback to a survey on physical and psychological wellbeing via direct access to a Web-based questionnaire. Statistical analysis showed that demographic variables like age, gender, and educational levels did not influence the mechanism of access. In addition, the participants reported a mean number of 4.03 physical symptoms (SD 2.6). The total Impact of Event Scale–Revised (IES-R) score was 18.47 (SD 11.69), which indicated that the study population did experience psychological stress but not post-traumatic stress disorder. The perceived dangerous Pollutant Standards Index (PSI) level and the number of physical symptoms were associated with higher IES-R Score (P<.05).

Conclusions: This is one of the first few studies demonstrating the use of Internet in data collection during an air-pollution crisis. Our results demonstrated that the newer technological modalities have the potential to acquire data, similar to that of conventional technologies. Demographic variables did not influence the mechanism of usage. In addition, our findings also suggested that there are acute physical and psychological impacts on the population from an air-pollution crisis.

(JMIR Mhealth Uhealth 2014;2(1):e16) doi:10.2196/mhealth.2827

KEYWORDS

crisis; haze; Internet; Web-based medium; social networking; smartphone application

Introduction

Dissemination of Information

Crisis situations bring about many challenges to researchers, public institutions, and governments to collect data and conduct research in affected individuals. In every crisis, communication between the general population and government is the key to enhance survival and reduce harm. This is especially so given the unpredictable nature of the crisis, and when the impact resulting from the crisis is significant [1]. Citizens who are being implicated by the crisis are naturally highly aroused and stressed. Thus, public health organizations have an obligation to keep the general population adequately informed of the latest information, and to provide them with necessary advice based on the changes in the situation [2].

Past research emphasized that the most critical aspect during a crisis was the selection of appropriate communication channels that had the highest degree of coverage and to be able to reach the population at risk. Studies on a cohort of Americans identified that the most trustworthy source of information during a crisis came from the doctors [3]. Studies conducted on people in Southeast Asia or Malaysia during the recent H1N1 influenza crisis identified that newspaper, television, and family members were the most trustworthy sources of information [4]. In comparison, similar studies done in the European population, like the Dutch, identified that the most trustworthy source of information came from the mass media during an outbreak of respiratory infectious disease [5,6]. During the 2011 Enterohaemorrhagic *Escherichia coli* (EHEC) outbreak in Germany, the usage of a Web-based medium as a modality of communication of critical information was reported [7]. The study identified the Internet to be the most popular medium for dissemination of EHEC-related information, with news and newspaper websites as the most often consulted Web-based sources. Participants were noted to be skeptical of information posted on social networking sites and media like Facebook and Twitter [7], but this finding was preliminary due to small sample size (n=18 students).

Case: The 2013 Southeast Asian Haze Crisis

Recently in Southeast Asia, the Southeast Asian Haze has been a major cause of concern for all of the Association of Southeast Asian Nations (ASEAN) countries, due to it being a major air pollution disaster, with significant implications on health, socioeconomic, and even politics. The countries usually affected include Malaysia, Singapore, Brunei, Southern Thailand, and Indonesia. The 2013 haze that occurred from the second half of June was reported to be one of the worst air-pollution crises in Southeast Asia with massive and far-reaching implications.

This large scale, repetitive, air-quality disaster dates back to the early 1900s, with the first serious episode occurring in 1997, when fires started in Kalimantan and Sumatra, Indonesia by farmers who adopted the “slash-and-burn” technique of clearing land for agricultural usage. The estimated economic loss caused by the 1997 haze crisis was estimated to be US $9 billion. In consideration of the massive impact of haze disaster, the ASEAN Haze Technical Task Force was established to implement regional and National Haze Action Plans, as well as strict no-burn policy in ASEAN countries. Despite efforts being taken to avoid future haze disaster, there was a recurrence in 2006. Economists estimated that Singapore lost at least US $50 million during the 2006 haze crisis. Industries like construction (7% of GDP) and tourism (3% of GDP) were severely affected. In addition, the losses were attributed to increase in health care costs, as well as reduction in productivity as a result of sick leave and inefficiency.

Unlike 1997 and 2006, the 2013 haze crisis has led to devastating effects for Indonesia’s neighboring countries, such as Singapore and Malaysia. In view of the poor air quality, the Singapore government has taken measures to safeguard the physical wellbeing of Singaporeans [8]. Even in healthy individuals, the haze may cause medical complications like conjunctivitis, throat irritation, rhinitis, blocked nasal passages, excessive sputum production, and even significant breathlessness, headache, and slow cognition. In addition, those who have preexisting respiratory conditions may find their conditions worsening; those with dermatological conditions like eczema might also find exacerbation of their skin conditions; those with preexisting cardiovascular conditions may suffer an increased risk of myocardial infarction or stroke; and those who are pregnant and are asthmatic may have reduced oxygenation of the fetus, thus affecting fetal growth [8]. The acute onset of such a massive air pollution crisis was what motivated the authors to consider whether conventional technologies, as described in previous research, and newer modalities of technology would be appropriate in reaching out to the general population, in terms of dissemination of necessary crisis information, as well as collation of crucial information from the general population.

Previous research has highlighted the usage of the Internet and in a crisis situation. The recent developments in Web-based technologies such as Facebook and Twitter, have offered government and nongovernment organizations with new means of disseminating vital information. These new technological modalities have the potential to acquire information and feedback from the general population during a crisis as well, which is important in assessing how the population is coping and responding thus far to the crisis. In particular, Keim and Noji [9] stated that the usage of social media initially started out during the 2010 Haiti earthquake, where various technological modalities such as text messaging, Facebook, and other social media were used in the immediate aftermath of the earthquake. Text messages were used as a means to gather donations and funds for relief work. Other technological modalities were used to disseminate information, gather donations, and also provide psychological support. Previous

research has also been done using Facebook technologies to compare the levels of post-traumatic stress symptoms that individuals experienced during the 2011 Fukushima nuclear disaster [10]. These allow the government and relevant agencies to closely monitor the current situation at the ground level and adjust the level of support accordingly [11]. Information acquired from the general population includes physical and physiological symptoms, as well as detecting new cluster of outbreaks of infectious diseases [11].

Apart from the developments in Web-based technologies, there have been further advances in mobile phone technologies, with the increasing popularity of smartphones. Smartphones are equipped with immense computing capabilities and allow individuals to access the Internet on the go. There has been a massive surge in the number of smartphone applications that are made available for downloading. Statistics show an increase from 300 million applications being downloaded in 2009 to over 5 billion in 2010 [12]. In particular, there are 7000 health care-related applications available as of 2011 [13]. Most of these health care applications are able to provide information, advice, instructions, and have various other interactive tools for individuals to monitor, record, and reflect their physical and psychological wellbeing [13]. This application is valuable as the uncertainty and lack of accurate information often lead to psychological distress.

Research looking into how newer Web-based technologies, such as the Internet, advertising on social media like Facebook, and, in particular, the latest technologies, such as smartphone applications, in acquiring crucial information during a crisis is limited. Hence, our study focuses largely on how existing social networking sites like Facebook and newer smartphone technologies could help in the acquisition of crucial research data from the general population during a crisis. We applied our latest technology in the recent 2013 Southeast Asian Haze Crisis. The results that we obtained would be informative in helping researchers, public organizations, and governments to assess and gather information from the general population rapidly during a major crisis. Our research objectives were: did the general population use Internet technologies like social media and smartphone technologies to provide feedback to agencies regarding their physical and psychological well-being during an air pollution crisis, and if so, will these newer mechanisms (social media and smartphone) be as effective as conventional Internet-based website technological modalities?

Methods

Database Development

The questionnaire (Multimedia Appendix 1), which included (1) demographics, (2) physical symptoms experienced during haze, (3) perspectives on usefulness of health care equipment, and (4) Impact of Event Scale–Revised (IES-R) was written in English and was included in both the Facebook direct link as well as in our Web-based, mobile smartphone application. The Web-based questionnaire being featured was coded using a website (Polldaddy). This Web-based database development software was specially chosen, as it is one of the most robust platforms on the market that enables the capture of detailed information, such as the mechanisms of accessing the database (whether via a direct link or from a mobile device) and other pertinent information that is relevant to our current study. The demographics questionnaire comprised of seven items in total, and was used to acquire the baseline characteristics of the participants in the study, such as gender, age, ethnicity, marital status, level of education, occupation, and most importantly, presence or absence of chronic medical illnesses. The questionnaire on physical symptoms assessed the presence or absence of the following physical symptoms: mental slowing, headache, dizziness, eye discomfort, nose discomfort, mouth and throat discomfort, breathing difficulty, heart or chest pain, nausea and vomiting, gastric or abdominal discomfort, slowness in movement, and muscle ache or pain. The participants rated on the range of self-perceived dangerous Pollutant Standards Index (PSI) values, personal possession and perceived usefulness of the N-95 mask on 5-point Likert scales. The IES-R is a 22-item, self-administered questionnaire that has been well validated for determining extent of stress reaction after exposure to stressful circumstances within 1 week of exposure across different cultural groups. Each item on the scale was administered via a 5-point frequency scale (0=not at all, 1=a little bit, 2=moderately, 3=quite a bit, 4=extremely) and higher scores indicate higher level of psychological stress. The IES-R provides three subscores, the mean avoidance, intrusion, and hyperarousal scores, a total mean IES-R score (divided by the total number of items) and a total IES-R score (without division by the total number of items). A total IES-R score greater than or equal to 33 signifies the likely presence of post-traumatic stress disorder.

Smartphone Development

In addition, a Web-based, smartphone-based application was also deployed. The Web-based smartphone application was designed to incorporate the following features: (1) general haze information, (2) events rescheduling system, (3) hospital emergency helplines and 24-hour clinic helplines and locations, and (4) a screening questionnaire, as previously mentioned. The smartphone application was developed to facilitate user's accessibility of our questionnaire on their smartphone devices. The Web-based smartphone application was developed within hours of the commencement of the current air-quality crisis by means of a Web-based toolkit. The Web-based smartphone toolkit enabled the integration of the above-mentioned feature via basic hypertext markup language programming. The authors have developed a previous events rescheduling system that tapped in to a text messaging gateway to disseminate information, and this system was integrated within the application itself, as shown in Figures 1-7.

Figure 1. Overview of SgHaze smartphone application.

Figure 2. Pollutant Standard Index (PSI) information displayed within application.

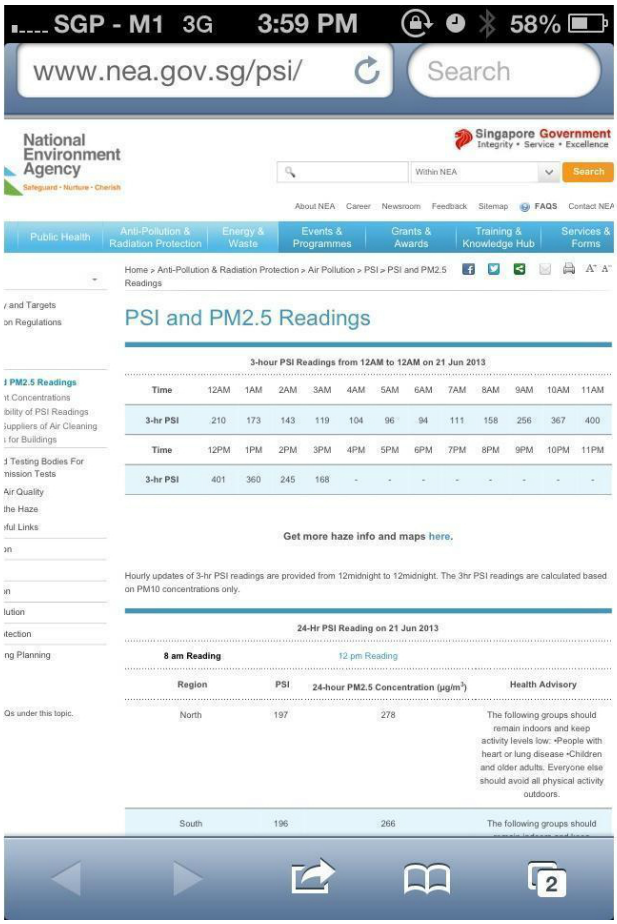


Figure 3. Event management system integrated within smartphone application.

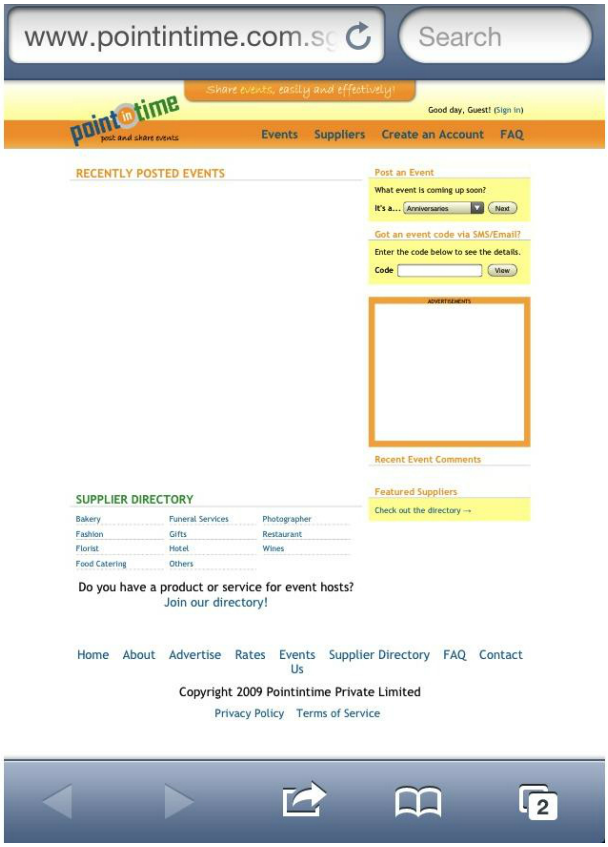


Figure 4. Emergency department and clinic contact details within application.

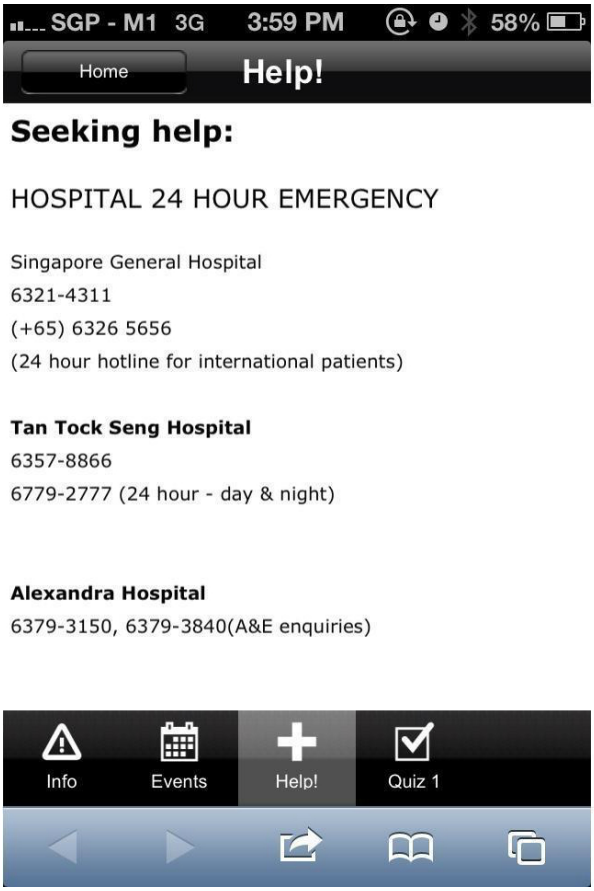


Figure 5. Web-based assessment quiz integrated within application.

Figure 6. Comparison between direct Web-link access versus Facebook/smartphone access to Web-based questionnaire.

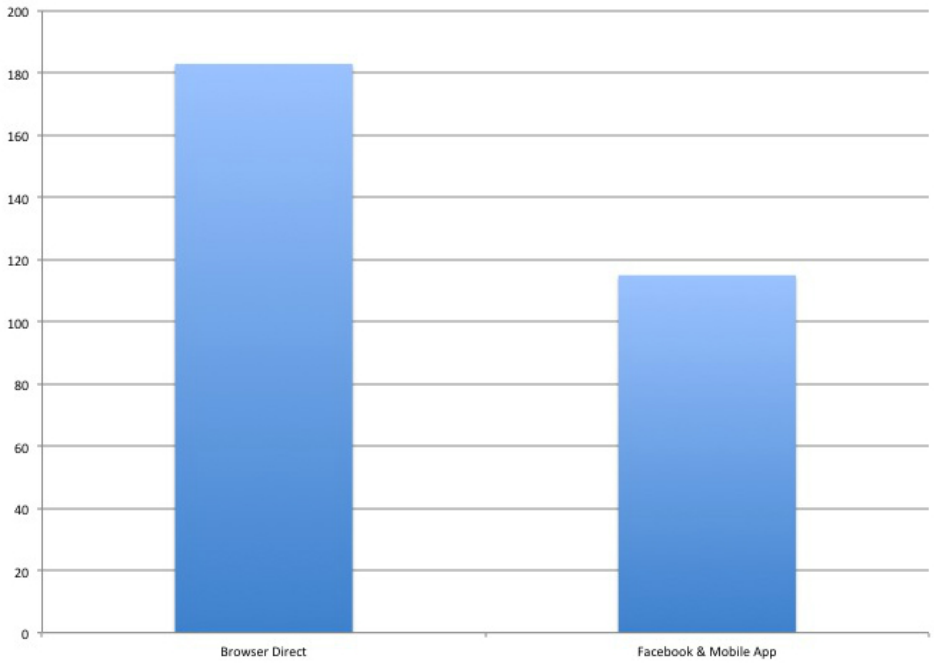
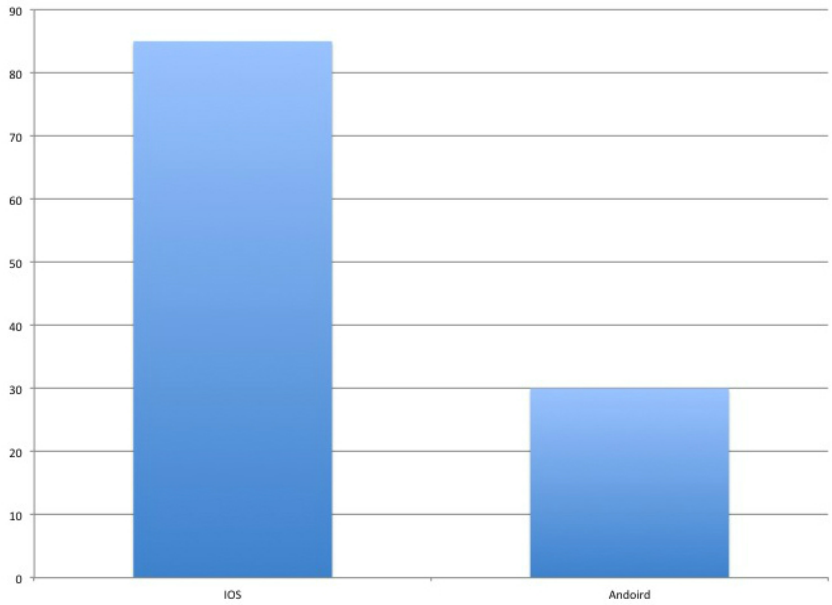


Figure 7. Overview of platform demographics of Facebook and smartphone application access.



Recruitment of Participants

This study was a cross-sectional study and participants were recruited by snowball sampling. The sampling was done either via a self-sponsored Facebook post that featured a direct link to the questionnaire and also the smartphone Web-based application; or via dissemination of the questionnaire link by emails, directed to the same group of participants (participants within the network circle of friends of all the authors, and there were opportunities for interaction between participants on the social network if they were common friends to the authors). The survey was conducted between the periods of June 21st and June 26th, 2013. The end date of recruitment was decided upon as the haze crisis had improved significantly with the air quality in the healthy range by the June 26th, 2013.

Participants who were either the friends of the authors or medical students previously under the supervision of the authors were invited to participate in the Web-based database survey. They needed to fulfill several selection criteria.

These included participants who were (1) above the age of 11-years old, (2) able to comprehend English, (3) living in Singapore during the period of the crisis, (4) had been exposed to the environmental air, and (5) knew how to use technological equipment.

Ethics approval was sought by the members of the Southeast Asian Haze Research Consortium from the institutional review board of the Department of Medicine, Shandong University, People's Republic of China. All participants provided their consent online prior to commencement of the study.

Analysis

The dataset was first extracted from the database and then it was coded. The demographics data were subsequently analyzed using Microsoft Excel, 2013. Basic statistics for each categorical variable, which was matched against the methodology of accessing the database, was computed. Additional statistical analysis involving the other questionnaires was performed using the SPSS statistical program, version 16.0 for Windows. Categorical variables were expressed by number and percentage. Continuous variables were expressed as mean (SD). Chi-square analyses were used to compare demographic data, personal views on the N-95 mask, and presence of physical symptoms across two groups based on gender and perceived dangerous PSI value. Using a subscale of IES-R and total IES-R score as dependent variables, univariate linear regression were performed to identify factors, which determined psychological impact during the haze crisis. Statistical significance was set at $P<.05$ for all analyses.

Results

A total of 298 individuals participated in this Web-based survey. Table 1 summarizes the basic demographic characteristics of all the 298 respondents. Most of the respondents in the current study were between the ages of 11 and 29 years, and the majority were Chinese (210/298, 70.5%). In addition, the majority of the respondents had an undergraduate education.

Table 2 summarizes the demographic characteristics of the participants who took part in our Web-based survey either via a direct link to the Web-based questionnaire, or via our Facebook-sponsored post and smartphone application. The demographics data captured by our Web-based database (Polldaddy) did not manage to distinguish between users who have accessed the Web-based questionnaire via Facebook or via Smartphone application. Most of the respondents in the current study (112/183, 61.4%) selected the option of accessing the questionnaire directly via the Web link that was emailed to them. Only 38.5% (44/115) of the respondents accessed the questionnaire toolkit via our Facebook post or via our smartphone Web-based application, which showed quantitatively that newer mechanisms of access were less popular. Chi-square statistical analysis was conducted to determine whether demographic variables (gender, educational status, and age)

were indeed significant predictors influencing the mechanism of access (direct vs Facebook or smartphone application). Comparisons between the two groups were done and demographic variables, such as gender (χ^2_1=0.101, *P*=.809), educational status (χ^2_1=0.82, *P*=.413), and age (divided into 2 groups: younger than 29, and older than 30) (χ^2_2=2.33, *P*=.311) were found to be insignificant in influencing mechanism of access.

Table 1. Demographic characteristic of respondents (N=298)

Characteristic	Total sample (N=298) n (%)	Men (n=120) n (%)	Women (n=178) n (%)
Age			
11-29	210 (70.5)	82 (68.3)	82 (26.3)
30-69	88 (29.5)	38 (31.7)	38 (31.7)
Race			
Chinese	260 (87.2)	99 (82.5)	161 (90.4)
Others: Indians, Malays, and Others	38 (12.8)	21 (17.5)	17 (9.6)
Educational status			
Undergraduate	251 (84.2)	100 (83.3)	152 (85.3)
Others	47 (15.8)	20 (16.7)	26 (14.7)

Table 2. Demographic characteristics of respondents who accessed the questionnaire directly compared with those who accessed via Facebook or smartphone.

Characteristic	Direct link sample size n (%)	Facebook/smartphone sample size n (%)
Gender		
Men	80 (43.7)	40 (34.8)
Women	103 (56.2)	75 (65.2)
Age		
10-19 years	10 (5.5)	2 (1.7)
20-29 years	114 (62.2)	83 (72.2)
30-39 years	36 (19.8)	17 (14.9)
40-49 years	10 (5.5)	9 (7.8)
50-59 years	11 (6.0)	2 (1.7)
60-69 years	1 (0.5)	2 (1.7)
Older than 69 years	1 (0.5)	0 (0)
Race		
Chinese	154 (84.2)	106 (92.3)
Indian	17 (9.3)	2 (1.7)
Caucasian	3 (1.6)	1 (0.8)
Malays	5 (2.7)	3 (2.6)
Others	4 (2.2)	3 (2.6)
Education		
University	152 (83.1)	100 (87)
Junior college	22 (12.0)	12 (10.5)
Secondary school	9 (4.9)	2 (1.7)
No education	0 (0)	1 (0.8)

In addition, the respondents reported a mean number of 4.03 physical symptoms (SD 2.6) and the total IES-R score was 18.47 (SD 11.69). The five most common physical symptoms among the 298 participants included mouth or throat discomfort (205/298, 68.8%), nose discomfort (183/298, 61.4%), eye discomfort (181/298, 60.7%), headache (149/298, 50.3%), and breathing difficulty (120/298, 40.3%). For the psychological impact, the mean intrusion score (mean 0.96, SD 0.63) was the highest, followed by mean hyperarousal score (mean 0.85, SD 0.74), and the mean avoidance score (mean 0.71, SD 0.5) was the lowest. When comparing the responses between male and female participants, 97.7% of the women were more likely to report usefulness of the N-95 mask (χ^2_1=7.353, *P*=.007) and 66.3% of the women also reported the presence of eye discomfort (χ^2_1=5.718, *P*=.017). There were no significant differences between men and women in demographics variables and scores on psychological impact. Respondents were further classified into two groups based on the perceived dangerous PSI value. Respondents who perceived lower PSI value (<250) as dangerous were more likely to come from other ethnic groups (χ^2_1=9.487, *P*=.002); report the presence of mouth or throat discomfort (χ^2_1=10.236, *P*=.001), nausea or vomiting (χ^2_1= 5.697, *P*=.017), higher number of physical symptoms (t_{296}=2.522, *P*=.012), higher mean intrusion score (t_{296}= 2.198, *P*=.029), higher mean hyperarousal score (t_{296}=2.488, *P*=.013), higher total mean IES-R score (t_{296}=1.990, *P*=.047), and higher total IES-R score (t_{296}=1.990, *P*=.047).

Table 3 in Multimedia Appendix 2 summarizes the factors that determined the psychological impact during the haze crisis. The perceived dangerous PSI level was negatively associated with the mean intrusion score, where B is the effect size and SE is the standard error (B=-0.162, SE=0.074, R^2=.016, *P*=.029), mean hyperarousal score (B=-0.217, SE=0.087, R^2=.020, *P*=.013), total mean IES-R score (B=-0.124, SE0.062, R^2=.013, *P*=.047), and total IES-R score (B=-2.734, SE=1.374, R^2=.013, *P*=.047). The total number of physical symptoms was positively associated with the mean avoidance score (B=0.048, SE=0.011, R^2=.061, *P*<.001), mean intrusion score (B=0.075, SE=0.013, R^2=.095, *P*<.001), mean hyperarousal score (B=0.130, SE=0.015, R^2=.207, *P*<.001), total mean IES-R score (B=0.080, SE=0.011, R^2=.153, *P*<.001), and total IES-R score (B=1.759, SE=0.240, R^2=.153, *P*<.001). The demographic variables, actual PSI score during the survey and views on the N-95 masks were not associated with psychological impact during the haze crisis (*P*>.05).

Discussion

Principal Findings

From our current knowledge, this is one of the few studies to formally assess the application of Internet-based social media and a smartphone-based application to gather data from the general population during a crisis. This study was methodologically feasible and demonstrated the usefulness of social medial and a smartphone-based application during a severe air-pollution crisis, which necessitated individuals to stay indoors, and helped to reduce the barriers pertaining to recruitment. Multiple social activities and events were curtailed, and the general public had to engage in other home-based activities. Engaging in Web-based social networking activities was a popular option. Our current findings showed that more individuals preferred the option of accessing and providing feedback to a questionnaire on physical and psychological well-being by direct Internet Web-link access, as compared with indirect access via Facebook or even a smartphone application. Our results did show, that for our current study, demographic variables such as gender, level of education, and age did not significantly affect the mechanism of access. Our current study showed that for the Asian population surveyed, demographic variables did not predict whether individuals would use either direct Internet access to provide feedback about their physical and psychological well-being, or whether they would use newer modalities of technologies like social media (Facebook) or a smartphone application.

In addition, our findings show that the perceived dangerous PSI value, not the actual PSI value and number of physical symptoms determined the psychological impact during the haze crisis. Furthermore, the higher number of physical symptoms was associated with greater psychological impact. This finding suggests that reduction in the number of physical symptoms may reduce psychological impact during haze crisis. Also, from our analysis, the total IES-R score was 18.47 (SD 11.69). A total IES-R score of 33 or more signifies the likely presence of post-traumatic stress disorder [14]. Our results suggest that the haze did not cause post-traumatic stress disorder in the general population, but it caused mild to moderate psychological impact. Intrusive symptoms such as recurrent thoughts and feelings were more common than hyperarousal and avoidance symptoms in our study population. The local government played a key role in reducing the psychological impact. On June 21, the local government took immediate measures to protect its citizens, including hourly updates of the PSI value on television, cancellation of all school activities, offering medical subsidies to treat physical discomfort associated with haze, and providing 1 million free N-95 masks to the needy households [15]. As a result, the personal possession and perceived usefulness of N-95 masks were not predictors of psychological stress.

As there was no previous study on the physical and psychological impact of the haze crisis, the interpretation of our findings mainly relied on previous studies on infectious disease outbreak, such as severe acute respiratory syndrome (SARS) in the Southeast Asia. Our findings were similar to a study reported by Lee et al [16] on the psychological responses of pregnant women during the SARS outbreak in Hong Kong in 2003. Lee et al [16] reported that anticipatory worries were common among the pregnant women during the SARS outbreak; overestimation of risk led to higher level of anxiety and the levels of depression were similar between the SARS and pre-SARS outbreak cohorts. In our study, the inverse association between the perceived dangerous PSI values and mean scores of intrusion, hyperarousal, and overall psychological impact suggest that people who have lower threshold for health hazard are vulnerable to greater psychological impact when air quality

deteriorates. The low threshold for health hazard and the number of physical symptoms independently determine psychological impact and these factors may contribute to the anticipatory anxiety. Our study did not find a difference in the levels of psychological impact between respondents who filled the questionnaire out during the periods with low and high PSI values. Lee et al [16] found that people tended to receive more social support during the SARS outbreak. We did not measure social support in our study but it may be possible that people would receive more social support from their families during the haze outbreak, as they tend to stay at home or participate in indoor activities with families.

Strengths and Limitations

The main strength of the current study is that we managed to assess the feasibility of acquiring data from a general population using the latest information technology during a crisis. This study managed to evaluate the differences in mechanism of acquiring data and showed that demographic variables like gender, level of education, and age did not significant predict the mechanism of access to either conventional technological modalities or newer modalities like social medium and smartphones.

Nevertheless, there are several limitations in the current study. Our results are preliminary and cross-sectional in nature. The crisis that we have selected to evaluate lasted only for 1 week and participants were recruited over that short duration of time as the haze disappeared. Also, unlike that of other disasters, there was no large-scale consequential aftermath after the crisis, and most individuals were able to get back to normal life immediately, which is also a major limiting factor in our research. In addition, our study has an inherent cohort bias, as the study population consisted of younger and educated individuals, recruited by snowball sampling, which is a nonrandom sampling method. Hence, even though we have identified the preferences of our respondents, the observation cannot be generalized to other populations. Nevertheless, we need to emphasize that we encountered major difficulties with rapid planning of this research, recruiting participants, and gathering data over such a short period of time with uncertainty. As the impact of the event lasted only 1 week, it is difficult to plan for and conduct a proper social media network and smartphone application survey.

Conclusions

This is one of the few studies demonstrating the use of Internet in data collection during an air-pollution crisis. Our methods may apply to future research on a natural disaster or outbreak of an infectious disease. The Internet and recent advancements in information technology allow researchers to capture data during a crisis, which was impossible in the past. Traditional face-to-face interviews come to a halt when people have to be quarantined to avoid spread of infection or staying at home to avoid adverse physical environment. The Internet allows researchers to overcome such barriers. This study compared conventional Web-based methods of acquiring data against the newer methods, including the social networking sites and smartphone applications. Previous studies were limited to comparison of technologies in relation to dissemination of information. Our results demonstrated that the newer technological modalities have the potential to acquire data as efficiently as conventional technologies, and demographic variables did not influence the mechanism of access during a crisis situation. Our current study provides an example for future researchers to develop a platform using the latest information technology to conduct research during any crisis. This is especially important for governments and health authorities to develop such platform in preparation for an unforeseen crisis.

In addition, the current study also highlights that even a short-term exposure to haze could potentially lead to considerable physical and psychological disturbances in healthy individuals. The findings provide guidance to health regulators to reduce the physical symptoms experienced. In addition, it is important to take note that it is the perceived PSI value that would determine psychological impact. Thus, timely governmental actions, which include increasing awareness and educating the general public, would help to reduce the psychological impact experienced.

Authors' Contributions

Authors' Contributions: All authors contributed towards the research and manuscript equally. All the authors are part of the Southeast Asian Haze Research Consortium.

Conflicts of Interest

Conflicts of Interest: None declared.

Multimedia Appendix 1

Sample questionnaire survey.

[PDF File (Adobe PDF File), 94KB - mhealth_v2i1e16_app1.pdf]

Multimedia Appendix 2

Analysis of psychological impact of individuals affected by haze crisis.

[PDF File (Adobe PDF File), 13KB - mhealth_v2i1e16_app2.pdf]

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Abbreviations

ASEAN: Association of Southeast Asian Nations
B: effect size
EHEC: Enterohaemorrhagic Escherichia coli
IES-R: Impact of Event Scale–Revised
PSI: Pollutant Standards Index
SARS: severe acute respiratory syndrome
SE: standard error

Edited by G Eysenbach; submitted 14.07.13; peer-reviewed by S Beidas, F Mora, M Murero; comments to author 04.08.13; revised version received 22.09.13; accepted 13.03.14; published 25.03.14.

Please cite as:
Zhang MWB, Ho CSH, Fang P, Lu Y, Ho RCM
Usage of Social Media and Smartphone Application in Assessment of Physical and Psychological Well-Being of Individuals in Times of a Major Air Pollution Crisis
JMIR Mhealth Uhealth 2014;2(1):e16
URL: http://mhealth.jmir.org/2014/1/e16/
doi:10.2196/mhealth.2827
PMID:25098255

Original Paper

Customized-Language Voice Survey on Mobile Devices for Text and Image Data Collection Among Ethnic Groups in Thailand: A Proof-of-Concept Study

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Abstract

Background: Public health surveys are often conducted using paper-based questionnaires. However, many problems are associated with this method, especially when collecting data among ethnic groups who speak a different language from the survey interviewer. The process can be time-consuming and there is the risk of missing important data due to incomplete surveys.

Objective: This study was conducted as a proof-of-concept to develop a new electronic tool for data collection, and compare it with standard paper-based questionnaire surveys using the research setting of assessing Knowledge Attitude and Practice (KAP) toward the Expanded Program on Immunization (EPI) among 6 ethnic groups in Chiang Rai Province, Thailand. The two data collection methods were compared on data quality in terms of data completeness and time consumed in collecting the information. In addition, the initiative assessed the participants' satisfaction toward the use of a smartphone customized-language voice-based questionnaire in terms of perceived ease of use and perceived usefulness.

Methods: Following a cross-over design, all study participants were interviewed using two data collection methods after a one-week washout period. Questions in the paper-based questionnaires in Thai language were translated to each ethnic language by the interviewer/translator when interviewing the study participant. The customized-language voice-based questionnaires were programmed to a smartphone tablet in six, selectable dialect languages and used by the trained interviewer when approaching participants.

Results: The study revealed positive data quality outcomes when using the smartphone, voice-based questionnaire survey compared with the paper-based questionnaire survey, both in terms of data completeness and time consumed in data collection process. Since the smartphone questionnaire survey was programmed to ask questions in sequence, no data was missing and there were no entry errors. Participants had positive attitudes toward answering the smartphone questionnaire; 69% (48/70) reported they understood the questions easily, 71% (50/70) found it convenient, and 66% (46/70) reported a reduced time in data collection. The smartphone data collection method was acceptable by both the interviewers and by the study participants of different ethnicities.

Conclusions: To our knowledge, this is the first study showing that the application of specific features of mobile devices like smartphone tablets (including dropdown choices, capturing pictures, and voiced questions) can be successfully used for data

collection. The mobile device can be effectively used for capturing photos of secondary data and collecting primary data with customized-language and voiced questionnaire survey. Using smartphone questionnaires can minimize or eliminate missing data and reduce the time consumed during the data collection process. Smartphone customized-language, voice-based questionnaires for data collection can be an alternative and better approach than standard translated paper-based questionnaires for public health surveys, especially when collecting data among ethnic and hard-to-reach groups residing in multilanguage-speaking settings.

(JMIR Mhealth Uhealth 2014;2(1):e7) doi:10.2196/mhealth.3058

KEYWORDS

expanded program on immunization; EPI; ethnicity; mobile technology; smartphone questionnaire survey; voiced question

Introduction

The paper-based questionnaire survey is the most frequent method used to collect health data, especially in low- and middle-income countries, where there is normally limited resources and technology [1,2]. Despite the fact that this has been the standard data collection method for decades, there are still extensively reported problems with paper-based questionnaires, including frequent errors, high storage costs, and high double-data entry costs. Currently, electronic data collection methods have been developed with the aim of merging the processes of data collection and data entry [2]. Many devices, such as personal digital assistants (PDAs) and smartphones, have been adapted to serve as electronic devices for data collection, and all of these are increasingly being used in place of paper-based questionnaires [1,3]. These PDAs and smartphones have limitations, however, particularly when it comes to downloading data, because they require telephone signals or wireless networks. In addition, all data can be corrupted if PDAs or smartphones are misplaced or stolen, and data can be lost if they are damaged [4-6]. However, electronic devices for data collection offer the advantages of improved data quality and consistency through the use of automated validation procedures and data range checks. They can integrate different kinds of formats (images, texts, voice) which can easily be transferred over long distances through wireless networks. Moreover, electronic devices for data collection have many advantages over paper-based questionnaires. There is no need for data entry or multiple printings, (making them budget-friendly), they avoid problems arising from illegible writing, and they can use media during interviews. The disadvantage is that all collected data is digitally stored and there are no hard copies available if problems occur during data collection. Thus, the electronic devices need to be designed and developed carefully in order to minimize problems and enhance data collection speed over paper-based questionnaires. Previous studies using PDAs, smartphones, and Internet-based devices [4,5,7-9] have reported high response rates and short data-collection times.

In the context of poor research infrastructure and of increasing demands for large-scale health surveys, the affordability and availability of mobile phones and wireless networks create a viable alternative to traditional paper and pencil methods. A study conducted in a peri-urban settlement in South Africa to evaluate the use of mobile phones in surveys by using lay community health workers, reported that using mobile technology via mobile phones offer benefits over PDAs in term of data loss and uploading difficulties [5]. In contrast, another study compared the completeness of data collection using the paper method and electronic method using handheld computers in an office-based patient interview survey [4]. A better return rate was found on paper- vs electronic-based methods. This was due to technical difficulties experienced with electronic data collection, and stolen or lost handheld computers. However, only 0.04% of total items were missing on electronic surveys, whereas 3.5% were missing on paper ones. Although handheld computers produced more complete data than the paper method for return rate, they were not superior because of the large amount of missing data due to technical difficulties with the handheld computers [4]. In Uganda, hundreds of health workers have used PDAs provided by the Ugandan Health Information Network to collect health data in the field. They revealed that health workers report increased job satisfaction due to the greater efficiency and flexibility provided by the technology [10]. Additionally, a study from India points to users who would not return to the paper reporting, since the mobile phone reporting saved time [11].

Besides the reported advantages of using smartphones and PDAs during surveys in terms of data completeness and timeliness, the mobile-technology device may also offer an advantage when collecting textual and picture data in different ethnic dialect settings. Several major technological innovations contributing to survey-data collection have been developed including graphic user interfaces and multimedia computing. There were reports on the effectiveness of using auditory communication and audio-visual communication techniques as part of the data collection method, particularly in the multilingual settings [12,13]. The mobile technology device can be customized to speak the specific language for each group, and thus standardize data collection in the field. This study was conducted to develop and test new electronic data capture tools using mobile devices (ie, smartphone tablets) with customized-language, voice-based questionnaires for data collection among 6 ethnic groups who speak different languages. The use of mobile-survey data capture was compared with the classic paper-based questionnaire method for data collection about the knowledge, attitude, and practice of hill-tribe mothers/caretakers toward immunization of their children. The main objective of this study was to evaluate differences in data completeness, time consumed, participant's satisfaction, and problems encountered during the two methods of data collection.

Methods

Study Sites

We conducted this study in 8 villages under the responsible areas of Wawi Sub-district Health Promoting Hospital (Mae Suai, Chiang Rai Province, Thailand). These areas are composed of 6 ethnic hill-tribal groups who speak different languages, have different cultures, beliefs, and lifestyles. These 6 hill tribes, include Akha, Karen, Mien/Yao, Lisu, Lahu, and Yunnan Chinese. Most of their spoken languages have no writing system. Figure 1a presents examples of study sites of these minority groups on the highland.

Figure 1. (a) Project setting and (b) data collection with smartphone questionnaire.

(a) Project setting on the high land

(b) Data collection by using smartphone questionnaire in the villages

Note: Pictures were taken as per permission of the study participants

Participants

A sample of 70 mothers with children older than 5 years in the study areas were recruited. The sampling frame was the names listed in the Wawi-database. The mothers registered in the Wawi database were selected by stratifying village locations and different ethnic groups. According to the routine activities for management of the Expanded Program on Immunization (EPI) as well as other health promotions under the Thailand Ministry of Public Health, each mother was approached (through a home visit) on a monthly basis by a designated Village Health Volunteer (VHV) to the approximately 10 allocated responsible households. Thus, the survey on EPI was conducted by 16 selected interviewers who are VHVs in the study areas. The interviewers were randomly selected and assigned to collect data from the randomly-selected hill-tribe mothers/caretakers.

Mobile-Technology Initiatives

The hardware requirement for the mobile device to be used in the field is that the mobile-device hardware must run on the Java programming language. In terms of technical information about the mobile technology, the programming was done with Eclipse (an open source development tool) on Android. Sixteen smartphone tablet devices were distributed to the 16 VHVs. The concept and workflow of the smartphone questionnaires are summarized in Figure 2. Three data collection functionalities were programmed and installed on the mobile devices, including dropdown choices, picture capturing, and voiced questions. Data/information was collected offline and could be synchronized onto a server database when data collection was complete, and when there were telephone signals or wireless networks available. It should be noted that the personal information was treated confidentially within the system applications during the study period.

Dropdown-choice functionality was developed and integrated into the mobile devices. The questions that were developed into dropdown-choice format, included sociodemographic parameters of hill-tribe mothers/caretakers and their children such as age, occupation, ethnicity, income and debt status, number of children in the family, type of house construction, drive time to the nearest hospital, vehicle and convenience for travelling to the responsible, district hospital in the area, child birth order, place of child birth, living with biological parents status, and source of vaccination. These questions with dropdown choices were asked at the beginning of the interview followed by other data collection techniques, specifically, picture capturing, and voiced questions. Respondents' answers were automatically

saved to the tablet's memory. Figure 3a presents the feature for dropdown choices on the VHV's smartphone questionnaire.

Picture-capturing functionality is one of the methods for secondary data collection. This study had to collect data from the Maternal and Child Health Handbook (MCHH) regarding immunization history, scheduled vaccination date, and actual vaccinated date. Thus, capturing a picture of the history of immunizations over the years as shown on the MCHH booklet was incorporated into the questionnaire set. Collecting such information by an individual, self-reported interview or manually extracting data from the book would be quite cumbersome; thus, capturing a picture from the book would make it easier for interviewers. This could also eliminate data missing during the data collection process. The immunization history page was captured as a picture on the smartphone data-collection device by VHVs and saved automatically to its memory. If the picture was not clear, the VHV would repeat the picture-capturing process. Figure 3b presents the picture-capturing functionality for secondary data on the VHV's smartphone. After all pictures were synchronized to the server, electronic forms were developed for data entry from the pictures. Immunization history data in the picture (scheduled and vaccinated date) was entered onto an electronic form. When all data was entered and submitted by the investigator, the immunization status (completely and incompletely immunized) and vaccine schedule compliance status (on time and out of schedule) were summarized and presented on the mobile device, which became a useful tool for VHVs to monitor the vaccine program of each child. Figure 4a-c presents the data entry from a captured picture and the summary statistics of individual immunization status, as well as their compliance to immunization schedule status.

Voiced-question functionality was purposively designed to collect data from 6 ethnicities who speak different languages, and where most of their languages have no writing system. The necessity of doing voiced questions on the mobile device arose from the fact that the VHVs cannot speak all six languages. This approach would also reduce the use of translators when performing data collection, and, in turn, lower mistranslations and standardize the question-asking process. The development of a voice questionnaire on smartphone tablets meant that the questionnaires were translated and incorporated onto the system screen into the 6 hill-tribe languages and Thai: Akha, Karen, Mien/Yao, Lisu, Lahu, Yunnan Chinese. This was done by local experts who are able to speak and read both Thai and his/her dialect languages. When performing data collection, the VHV would press the bullet button on screen for a question and the audio of the corresponding question would be spoken to the mothers/caretakers. The VHV then recorded the answers, all of which were multiple choice. In this study, the voiced questions in the smartphone tablet, included knowledge, attitude, and practice (KAP) of hill-tribe mothers/caretakers toward EPI. Figure 3c presents the feature for voice-question functionality regarding KAP toward EPI on VHV's smartphone questionnaire.

Figure 2. Concept and workflow of the smartphone questionnaire.

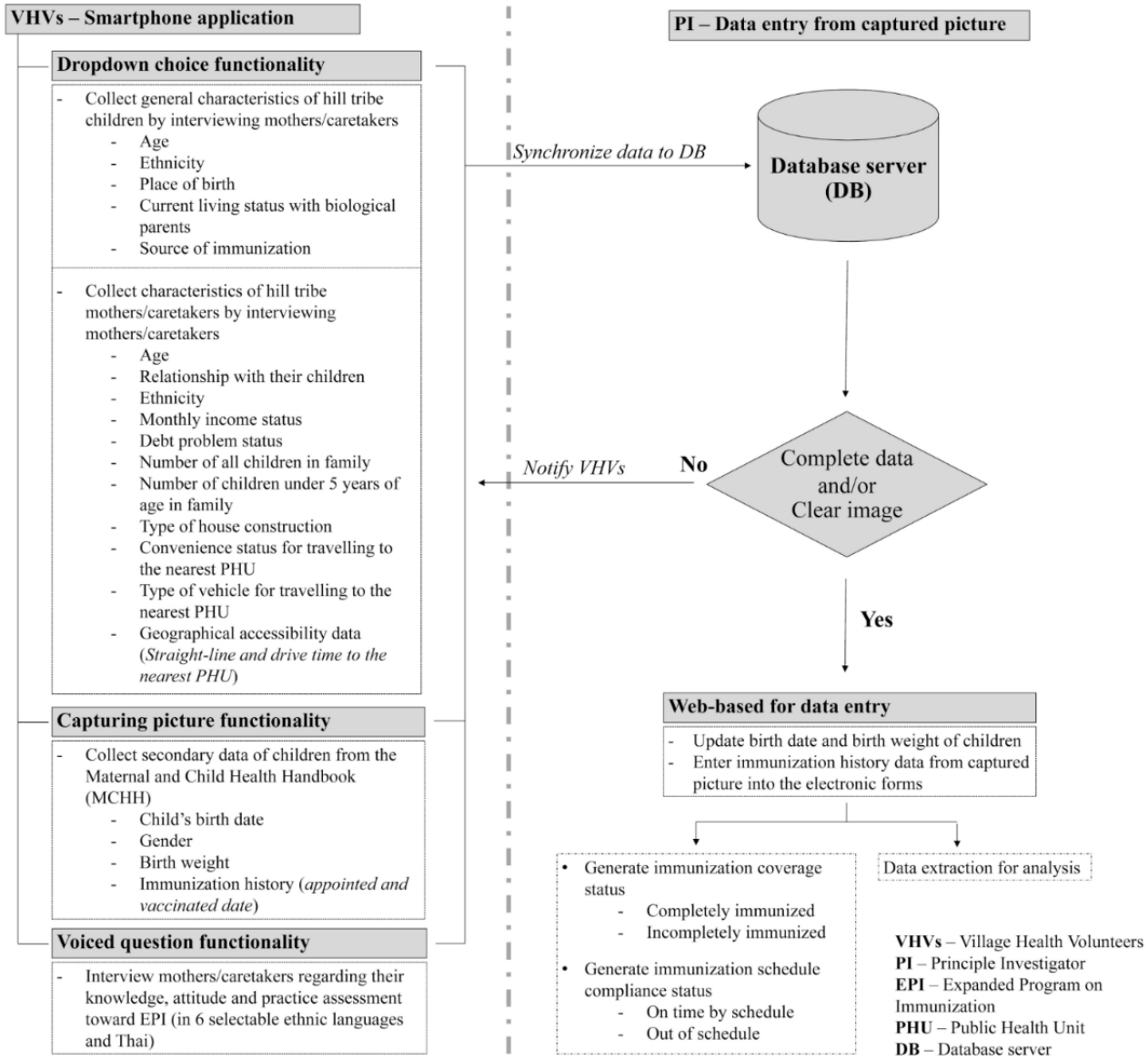


Figure 3. Feature of 3 functionalities on smartphone questionnaire: (a) dropdown choice, (b) picture capturing, and (c) voiced question.

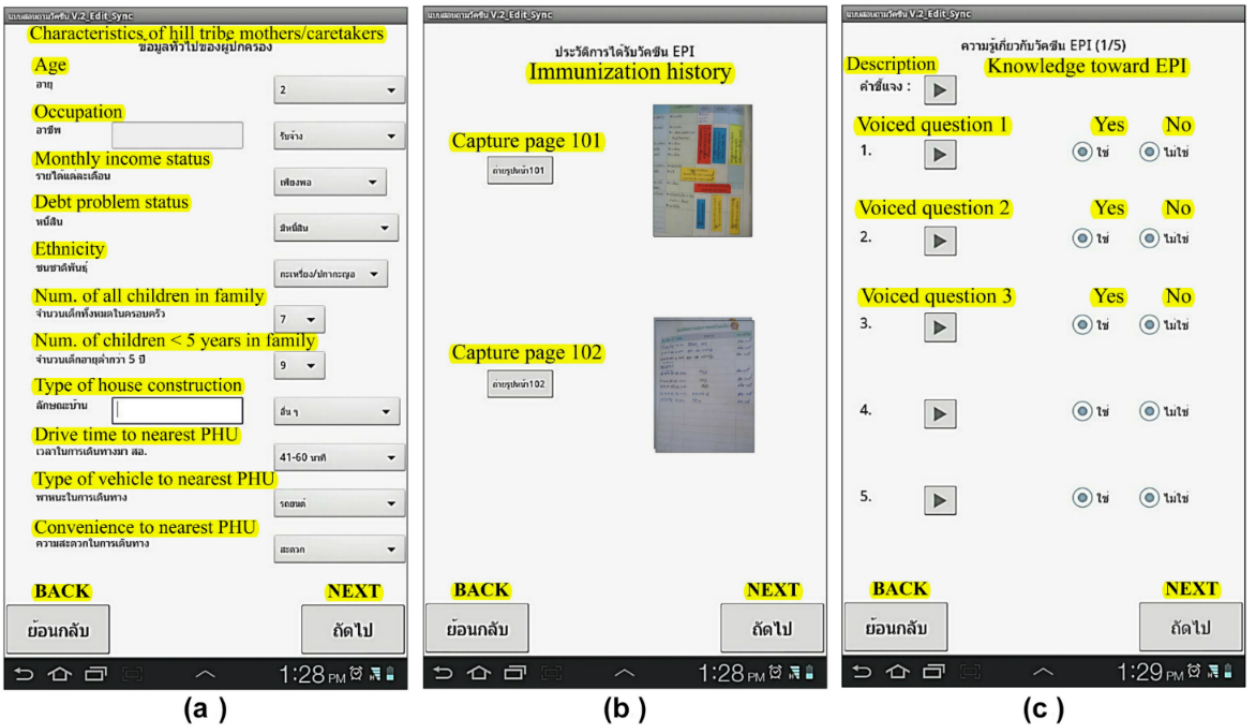
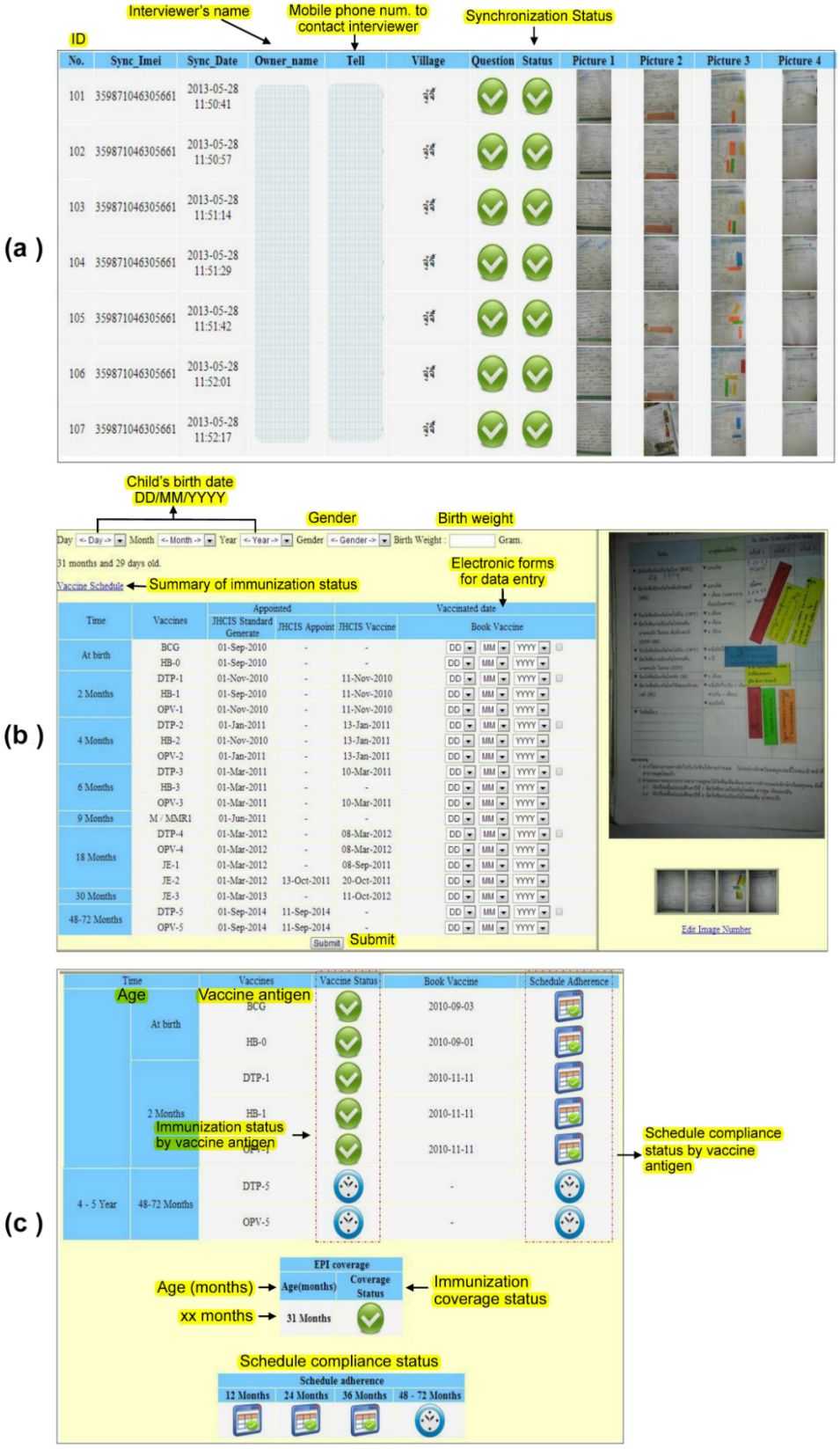


Figure 4. (a) Data monitoring on web-based, (b) immunization history data entry from captured picture, and (c) summary of individual immunization coverage and schedule compliance status.



Training of Interviewers

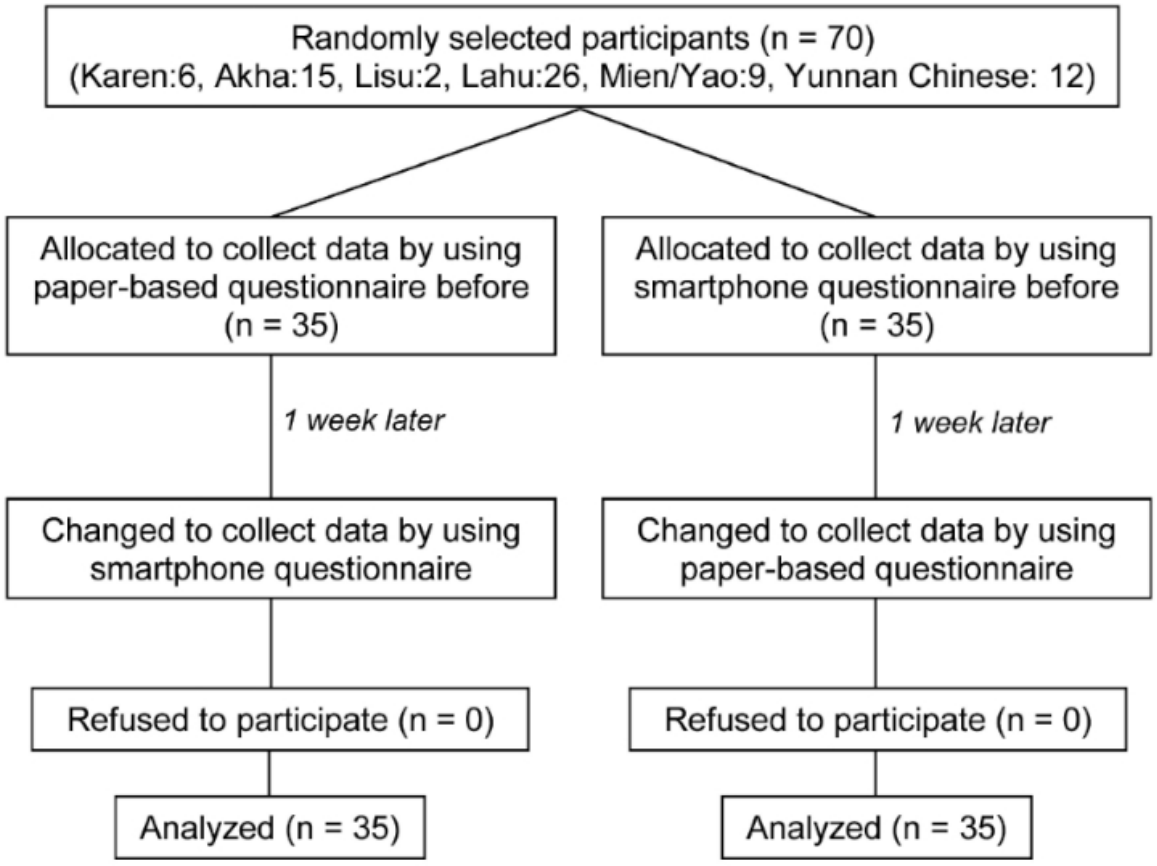
All interviewers had experience using mobile technology (smartphone tablet) from the StatelessVac project, which was funded by a grant from the Bill & Melinda Gates Foundation through the Grand Challenges Explorations initiative [14]. The StatelessVac project was conducted in Chiang Rai Province from April, 2012 to April, 2013, and aimed to use mobile

technology for enhancing routine EPI schedule reminders and behavioral change communication among ethnicity groups. Although the VHVs had practiced using mobile phone technology before, the use of mobile technology in this study was different from the StatelessVac. In this case, its purpose was data collection in surveys. Therefore, the 16 selected VHVs in this study received additional training on using smartphone, voice-based surveys and also to reinforce their data collection skills. They were trained for 2 days on the use of both smartphone tablets with voiced questions and paper-based questionnaire methods. Not only was training on using the mobile device provided, but the training also included communication skills and a real-life pilot practice interviews with hill-tribe mothers/caretakers using both data collection methods, explanation of questionnaires, translation of questions in each dialect languages, and practice to ask permission with informed consent from hill-tribe mothers/caretakers. All interviewers were trained individually to ensure that the two data collection methods were conducted correctly.

Data Collection

For the purpose of comparing the two data collection methods, customized-language, voice-based survey and the standard paper-based questionnaire regarding KAP, a cross-over design was adopted. The two groups of hill-tribe mothers/caretakers participants in this study were: (1) those surveyed by using a smartphone, voice-based then paper-based sequence, and (2) those using a paper-based then smartphone, voice-based sequence. The mothers/caretakers were randomly selected to the study groups with different sequences. The washout period between the two data collection methods was set at 1 week after the initial data collection method. Most studies with a time interval of the questionnaire administration for health-status instruments have ranged from 2 days to 2 weeks; however, a study investigating the 2-day and 2-week time durations reported no statistically significant differences in the test-retest reliabilities of the administered tests [15]. As it is generally recognized that a very short time interval might lead to the carryover effects, and with respect to the study population, a 1-week interval was selected to compromise the recollection bias in this study. The 16 VHVs who were interviewers in this study visited hill-tribe mothers/caretakers one by one in their routine job until the sample size of 70 was reached. Work flow for data collection is summarized in Figure 5. Figure 1b presents data collection using smartphone customized-language voice-based survey in the villages of the study area (note that all pictures presented in the figure were taken with permission from the villagers).

Figure 5. Workflow for data collection.



Study Variables

The survey was composed of 16 sociodemographic items in typical multiple-choice fashion on the paper-based questionnaires, and with dropdown choices on the electronic questionnaires on smartphone, customized-language, voice-based applications. The picture capturing was on mobile devices only. There were 55 voiced questions, including 25

items on knowledge toward EPI vaccines, 15 items on attitude toward vaccination, and 15 items on practice for preparing or activities to vaccination. The outcomes for this particular study were not about analysis of vaccine coverage or on KAP issues (which will be described in another study) but on the comparisons of methodology outcomes from the two data collection methods. The main outcomes of interest were data quality composing of data completeness, time consumed, and participants' satisfaction with the data collection methods. Data completeness and time consumed were based on repeated surveys with different methods from the same participant. The participants' satisfaction toward the mobile technology survey was assessed using a simple Technology Acceptance Model (TAM) [16,17] in terms of perceived ease of use and perceived usefulness. Questions included how easy the survey had been to answer, whether the participant understood the questions clearly, their convenience during answering, and whether the electronic data collection had saved time. The satisfaction data toward using the smartphone, voice-based questionnaire survey method was collected from mothers/caretakers after the data collection process was finished.

Ethical Considerations

This study was a part of the project "Assessment of Expanded Program on Immunization Coverage and its Determinants among Hill Tribe Children, Wawi Sub-District, Mae Suai, Chiang Rai Province, Thailand" (awaiting publication). The project was reviewed and approved by the ethics committee of the Faculty of Tropical Medicine, Mahidol University (Thailand). This study involves vulnerable research participants belonging to ethnic groups in Chiang Rai province, Thailand. All participants were informed about all details regarding the study, and asked to sign an informed consent form for participating by using their dialect language. The document was translated by VHVs.

There was no identification of name and family name of the respondents on the case record forms. The individual information was kept completely confidential to the researcher during data collection and analysis. The respondents were able to stop giving an interview at any time and did not need to give reason for the withdrawal of their consent.

Results

Picture Capturing of Data

During the study period, 70 hill-tribe mothers/caretakers were randomly selected from 363 mothers in the EPI-coverage assessment project. As part of the initiative of data collection on smartphone survey, the function of picture capturing was developed and used to collect the history of immunizations over the years in the MCHH booklet. Pictures of all pages with EPI recorded on the booklet of each child were taken and then directly transcribed into database. The data entry screen was designed corresponding to all data fields on the booklet pages, and thus all data were manually entered onto the system for further analysis on EPI coverage. The results of EPI coverage were beyond the purpose of this study.

Completeness of Data

To assess the effectiveness of the two data collection methods, 35 study participants were randomly assigned to one of the two study arms in the cross-over of the standard paper-based questionnaire survey and smartphone, voice-based survey methods. The questions captured on smartphone tablets were programmed to collect and store answers in a sequential manner with no skip pattern, and thus no data entry errors occurred after data synchronization. Hence, the use of smartphones with the voiced-question method produced complete answers significantly different from the answers obtained from the use of the paper-based questionnaire method. In the paper-based questionnaire method, 69% (48/70) of hill-tribe mothers/caretakers answered all questions completely (as opposed to the 70/70, 100% of smartphone voice-based method). Out of the 55 items on KAP, the number of questions that had incomplete answers on the paper-based survey method ranged from one item (among 17/70, 24% of respondents) to six Items (1/70, 1% of respondents). As shown in Table 1, the separate group analysis reveals that the sequence of data collection method (Group 1: paper before voice, and Group 2: voice before paper) had certain effect on data completeness. The incomplete answers of the paper-based method of Group 1 still ranged from one item (10/35, 29% of respondents) to six items (1/35, 3% of respondents), but for Group 2 only one item (7/35, 20% of respondents) was incomplete.

Table 1. Data completeness between paper-based and smartphone voiced questionnaire survey methods.

Variables	Paper QNN		Voiced QNN		*P*
	n	%	n	%	
Groups 1 and 2 (n=70)					
Complete answer	48	69	70	100	
Incomplete answer	22	32	-	-	
1	17	24			
4	2	3			
5	2	3			
6	1	1			<.001[a]
Range (minimum–maximum)	6(49-55)		-		
Group 1: Paper-voiced (n=35)					
Complete answer	20	57	35	100	
Incomplete answer	15	43	-	-	
1	10	29			
4	2	6			
5	2	6			
6	1	3			<.001[a]
Group 2: Voiced-paper (n=35)					
Complete answer	28	80	35	100	
Incomplete answer	7	20	-	-	
1	7	20			.016[a]

[a]McNemar Test used

Time Consumed During Data Collection

During the data collection process with both the smartphone, voice-based and paper-based questionnaire methods, the time consumed was measured. Time consumed was calculated in minutes from the time the first question was asked until the last KAP question was answered. Table 2 shows the mean duration of time consumed for data collection and the frequency of participants who spent different time slots to answer all questions. The mean duration of time spent on paper-based data collection was 32.39 minutes, compared with 22.51 minutes for a smartphone, voice-based survey. Of all participants, 37% (26/70) and 49% (34/70) spent 0-15 and 16-30 minutes, respectively, for data collection with the smartphone, voice-based method while 23% (16/70) and 43% (30/70) for the paper-based questionnaire method. The time consumed was significantly different between the two methods; the smartphone, voice-based questionnaire method was significantly faster than the paper-based method ($P<.001$). When analyzed separately, for the two sequences of data collection methods, (paper–voice and voice–paper groups), significantly shorter times for the smartphone, voice-based method were still observed.

Table 2. Time consumed between paper-based and smartphone voiced questionnaire survey methods.

Variables	Paper QNN		Voiced QNN		*P*
	n	%	n	%	
Groups 1 and 2 (n=70)					
Time consumed (minutes)					<.001[a]
0-15	16	23	26	37	
16-30	30	43	34	49	
31-45	7	10	-	-	
46-60	14	20	10	14	
61 minutes over	3	4	-	-	
Mean	32.39		22.51		
Range (minimum–maximum)	84(6-90)		56(4-60)		
Group 1: Paper-voiced (n=35)					
Time consumed (minutes)					<.001[a]
0-15	8	23	14	40	
16-30	11	31	16	46	
31-45	4	11	-	-	
46-60	9	26	5	14	
61 minutes over	3	9	-	-	
Group 2: Voiced-paper (n=35)					
Time consumed (minutes)					.001[a]
0-15	8	23	12	34	
16-30	19	54	18	51	
31-45	3	9	-	-	
46-60	5	14	5	14	
61 minutes over	-	-	-	-	

[a]Pearson chi-square

Participants' Satisfaction

All of the 70 hill-tribe mothers/caretakers were assessed for their satisfaction with being interviewed by a smartphone, customized-language, voice-based questionnaire survey after they finished the data collection process. The percentages of those who scored ≥80% in each term of satisfaction were: 57% (40/70) for ease of answering using the voiced questionnaire, 69% (48/70) for understanding questions clearly, 71% (50/70) for convenience of responding to questions, and 66% (46/70) for reduced time for data collection (Table 3). Many of the hill-tribe mothers/caretakers had a high level of satisfaction toward the voice-based, questionnaire survey method; they expressed their approval for mobile technology being used for surveys. This was despite a few minor problems during data collection (eg, the system halted for a few seconds, or a poor quality picture was captured by the VHVs).

Table 3. Participant's satisfaction toward the smartphone questionnaire survey (N=70).

Satisfaction toward voice QNN survey	n (%)
Ease of answering using the voiced questionnaire	
≥80% (4-5 score)	40 (57)
≥50% (2-3 score)	28 (40)
<50% (1-2 score)	1 (1)
Missing	1 (1)
Understanding questions clearly	
≥80% (4-5 score)	48 (69)
≥50% (2-3 score)	20 (29)
<50% (1-2 score)	1 (1)
Missing	1 (1)
Convenience of responding to questions	
≥80% (4-5 score)	50 (71)
≥50% (2-3 score)	19 (27)
<50% (1-2 score)	-
Missing	1 (1)
Reduce time for data collection	
≥80% (4-5 score)	46 (66)
≥50% (2-3 score)	22 (31)
<50% (1-2 score)	1 (1)
Missing	1 (1)

Discussion

Principal Findings

The technical challenge of applying novel ideas to develop customized-language, voice-based questionnaire functionalities on smartphones for data collection was manageable. Using a smartphone tablet for surveys in the field does not require a telephone signal or wireless network to synchronize data onto a server database. In this study, signals varied, as villages were located in remote highland areas, thus survey activities were conducted off-line and the data were synchronized when the telephone signals or wireless networks became available. This study confirms that data collection via smartphone can be an alternative method to paper-based questionnaires, even in remote/rural areas without the constraint of signal availability [5,9,18]. In this study, though the survey data were transmitted directly from the study tablets to the secured database server at the central office, there was no data encryption mechanism while transferring information to the server. This feature will be implemented in future design.

The results of this study suggest that novel functionalities of picture capturing, and voiced-questions on smartphones can produce data quality, in terms of data completeness, which affect the validity and reliability of the study outcomes. This supports the findings of other data-management studies [19,20]. The same result was found in another study in Thailand [21], in which mobile-phone devices were used to improve antenatal care (ANC) and EPI services in border areas. It was suggested that cell phones developed and integrated into the health care system could be used successfully, especially in low-resource settings [21]. Many previous studies reported the use of handheld computers (PDAs) for data collection [1,4,18,22], but a few revealed that they encountered numerous instances of missing data caused by technical difficulties, or from problems with loss or theft of the devices. Despite such problems, mobile technology use in data collection remains a feasible, acceptable, and preferred method, because it can produce more complete data than the classic paper-based method. Many researchers conducting studies using PDAs [4,22] suggested the use of other hardware solutions, such as tablet smartphones or cell phones, similar to what was done in this study. However, generalizing the result of this study in terms of data completeness could be limited by the cross-over design and small sample size. Even though there was a washout period between the two data-collection methods, the participants may still remember the 55 KAP questions asked using the first method; thus, the comparison of the methods measured data completeness rather than correct answers of the KAP. The focus of this study was to compare data quality between the two methods for the completeness, rather than correctness, of the answers.

Picture capturing for secondary data entry functionality on smartphones in this study demonstrates the successful application of new technology to collect data, especially when collecting data from ethnic minorities who speak different languages. If the data were to be collected on paper-based

questionnaire, there could be two chances of transcription errors, from the mothers' interview or booklet extraction to paper questionnaire and then from paper questionnaire to computer database. In contrast, there should be fewer data transcription errors when using picture-capturing secondary data due to cutting out one step of the data collection process; data are entered directly from the picture of data to the computer database. With the purpose to prove the concept of using picture capturing for secondary data, the current system has not yet designed for the feature of double-data entry to cross-checking data validity. The double-data entry function should be considered in future electronic questionnaire survey design. These features represent how technology can be used as a support tool to facilitate or enhance the work of interviewers and to increase efficiency of survey data collection with the complexity of automated interviewing systems and instruments [12,13].

In this study the use of the smartphone, voice-based questionnaire to collect data on KAP regarding EPI, compared with the paper-based questionnaire, has shown that the data collected was more complete, as the program was designed to ask the questions in sequence automatically. As found in this study, there were incomplete answers when using the paper-based data collection method, but none when using the smartphone, voiced-questionnaire survey method. This may be due to the fact that when performing data collection on paper questionnaires some respondents and/or the interviewers unintentionally skipped a required question, and a few respondents decided not to answer some questions. In contrast, the programming on smartphone survey does not allow the respondents to skip any required question(s). This finding suggests for future design of electronic questionnaires to be more flexible allowing respondents who may want to skip some questions. Thus, the result was similar to the findings of household surveys in South Africa that use mobile phones as data-collection instruments [4,5,23]. Furthermore, previous studies showed that data recording, transferring, and entry mistakes were not found when electronic devices (PDAs, mobile phones, tablets) were used for data collection [8,24,25].

Not only was the benefit of data completeness with the smartphone, voice-based questionnaire confirmed, but the results of this study also suggest that using the smartphone, voice-based questionnaire surveys reduced the time consumed for data collection. This study's results were similar to the findings of other studies that reported time spent in data collection using mobile technology [3,26-28]. Moreover, the study showed the time consumed during the KAP survey in using the smartphone, voice-based questionnaires that customized to the participant's own dialect resulted in substantial time saving over paper-based questionnaires. However, the limitation for the use of smartphone, voice-based questionnaires in this study was that none of the voiced-questions were open-ended. With existing technology, collecting open-ended voice answering for the voiced-questions can be done, but that will require programming and adapting the voice recognition solution. If open-ended voice questions are needed, one should plan their data-collection tool with such system functionality. However, as stated in previous studies, when planning to collect data electronically one should consider the appropriateness of methods to be used in accordance with study design, types of data collection, and characteristics of study participants [7,29].

A previous study was conducted in clinical research to compare users' satisfaction in using two devices for electronic data collection, laptops and handheld computers [25]. It was reported that users found the laptops easier, faster, and more satisfying to use than the handheld computers. This is similar to the findings of a study in China on using handheld data collection tools [22]. Though some technical problems occurred during the data collection process, it remained a feasible, acceptable, and preferred method by Chinese interviewers. In previous studies conducted to assess the acceptability and feasibility of using a mobile phone application for health care delivery among health care workers, conflicting results were reported. The health care workers expressed their positive perceptions toward mHealth, but poor uptake in their actual practice was demonstrated [30]. The survey in this study was conducted as part of the routine home visit by the community health providers (VHVs) who work closely with the village, thus they reported that the use of smartphones could enhance their routine work for health care service in EPI coverage assessment and can be used to educate hill-tribe mothers/caretakers when data collection was finished toward EPI vaccines. Besides interviewer's satisfaction, this study also assessed satisfaction among participants for data collection with smartphone questionnaires. The results on users' satisfaction of smartphone-voiced questionnaire surveys in this study confirmed that the underserved, hard to reach, and mostly illiterate users in the remote areas accepted the technology. The questions about technology acceptance used in this study suggest that high percentages of hill-tribe villagers thought that the customized-language, voice-based questionnaire method for data collection made them understand the question more and enabled them to answer accordingly. The survey of VHVs' satisfaction and their overall opinions could be used for improving the design of future electronic questionnaire survey.

One of the limitations of this study was that it was a small-scale survey, thus the costs for conducting the smartphone-questionnaire surveys were higher than the paper-based questionnaires. However, the costs of both data-collection methods would be similar if the study would be conducted on a larger scale. Both methods have different costs according to study scale; however, smartphone questionnaires would still be a feasible alternative for collecting field data even in a low-resource setting. [11,18].

The strength of this study was the data-collection tool, which was developed into a smartphone questionnaire using voiced questions to ask all participants in their dialect languages. As participants of this study speak different languages, and have varied beliefs and cultures, developing and implementing the tool was a challenge. Many languages do not have writing systems, thus most studies conducted among hill-tribe people often used structured, paper-based questionnaires with interviewers and/or translators to collect data [31-34]. This classic method might affect the validity and reliability of data because the way that interviewers/translators pose or translate the questions might induce all participants to answer in a certain

direction, and even when asking the same question to different participants the interviewers/translators may use different words/meanings. In developing the smartphone, voice-based questionnaire survey in this study, all questions were first translated and recorded as electronic files in the 6 hill-tribe languages (Karen, Akha, Mien/Yao, Lisu, Lahu, and Yunnan Chinese, as well as Thai), then the translated questions were cross-checked for clear and correct definitions of translation before piloting the tool for the actual local people who speak that language in the field. The final version was used in the study after a few revisions. The results of this study suggest that mobile devices with customized-language, voice-based feasibility would have a potential benefit in minimizing information bias.

Conclusions

This is the first study to present novel features on using smartphones for survey questionnaires with image-capture and voiced-interrogation functionality. The mobile device can be effectively used for photographing secondary data and collecting primary data with a customized-language and voiced-questionnaire survey. This study has been conducted as a proof-of-concept that smartphone, customized-language, voice-based questionnaire surveys can be successfully used for data collection, especially for the study involving people speaking multiple languages in the study setting. The benefit of using mobile technology to collect data can be observed in terms of reduced time spent in data collection and data entry processes, and minimizing or eliminating missing data when collecting data in the field. Moreover, this study suggests that both interviewers and participants accepted and preferred the technology being used in terms of its ease-of-use and usefulness of the device functionalities (dropdown choices, picture capturing, and voiced questions). There has been an increasing trend in using mobile technology in health care services and health research in the past decade, and further studies can be done, including, but not limited to, the use of several potential beneficial features of mobile technology applications in survey research, including character/voice recognition, geospacing/temporal data management, and animation questions.

Acknowledgments

This study is a part of the “StatelessVac” Project that was funded by a grant from the Bill & Melinda Gates Foundation through the Grand Challenges Explorations initiative; we would like to thank the Foundation for funding and supporting us throughout the duration of the project. This study was also partially funded by Faculty of Tropical Medicine and Faculty of Graduated Studies, Mahidol University. We would like to acknowledge Ms. Rattana Rakpanalee, and all health care personnel and village health volunteers at Wawi Sub-district Health Promoting Hospital in Chiang Rai Province for their assistance in project implementation. Also, thank you to all translators in Chiang Rai Province for their expert assistance in translating questionnaires from the Thai language to the six hill tribe languages. Thank you for all study participants who were willing to take part of the study. Special thanks to Mr. Paul Adams of the Office of Research Services, Faculty of Tropical Medicine, Mahidol University, for editing the language of the manuscript.

Authors' Contributions

Authors' Contributions: KJ, JK designed and planned the study, drafted the first version of the paper, submitted the paper, and approved the final version. KJ, PW designed and programmed the survey on smartphone. SL, PT, AK assisted in designing and planning the study, collected data, monitored activities at study sites, wrote the submitted paper, and approved the final version.

Conflicts of Interest

Conflicts of Interest: None declared.

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Abbreviations

ANC: antenatal care
EPI: expanded program on immunization
KAP: knowledge attitude practice
MCHH: Maternal and Child Health Handbook
PDAs: personal digital assistants
TAM: Technology Acceptance Model
VHVs: village health volunteers

Edited by G Eysenbach; submitted 29.10.13; peer-reviewed by WC Su, D Capurro; comments to author 09.01.14; revised version received 21.01.14; accepted 07.02.14; published 06.03.14.

Please cite as:
Jandee K, Lawpoolsri S, Taechaboonsermsak P, Khamsiriwatchara A, Wansatid P, Kaewkungwal J
Customized-Language Voice Survey on Mobile Devices for Text and Image Data Collection Among Ethnic Groups in Thailand: A Proof-of-Concept Study
JMIR Mhealth Uhealth 2014;2(1):e7
URL: http://mhealth.jmir.org/2014/1/e7/
doi:10.2196/mhealth.3058
PMID:25098776

Original Paper

Evaluating User Perceptions of Mobile Medication Management Applications With Older Adults: A Usability Study

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Abstract

Background: Medication nonadherence has a significant impact on the health and wellbeing of individuals with chronic disease. Several mobile medication management applications are available to help users track, remember, and read about their medication therapy.

Objective: The objective of this study was to explore the usability and usefulness of existing medication management applications for older adults.

Methods: We recruited 35 participants aged 50 and over to participate in a 2-hour usability session. The average age ranged from 52-78 years (mean 67 years) and 71% (25/35) of participants were female. Each participant was provided with an iPad loaded with four medication management applications: MyMedRec, DrugHub, Pillboxie, and PocketPharmacist. These applications were evaluated using the 10 item System Usability Scale (SUS) and visual analog scale. An investigator-moderated 30-minute discussion followed, and was recorded. We used a grounded theory (GT) approach to analyze qualitative data.

Results: When assessing mobile medication management applications, participants struggled to think of a need for the applications in their own lives. Many were satisfied with their current management system and proposed future use only if cognition and health declined. Most participants felt capable of using the applications after a period of time and training, but were frustrated by their initial experiences with the applications. The early experiences of participants highlighted the benefits of linear navigation and clear wording (eg, “undo” vs “cancel”) when designing for older users. While there was no order effect, participants attributed their poor performance to the order in which they tried the applications. They also described being a part of a technology generation that did not encounter the computer until adulthood. Of the four applications, PocketPharmacist was found to be the least usable with a score of 42/100 (P<.0001) though it offered a drug interaction feature that was among the favorite features of participants. The usability scores for MyMedRec (56/100), DrugHub (57/100), and Pillboxie (52/100) were not significantly different and participants preferred MyMedRec and DrugHub for their simple, linear interfaces.

Conclusions: With training, adults aged 50 and over can be capable and interested in using mHealth applications for their medication management. However, in order to adopt such technology, they must find a need that their current medication management system cannot fill. Interface diversity and multimodal reminder methods should be considered to increase usability for older adults. Lastly, regulation or the involvement of older adults in development may help to alleviate generation bias and mistrust for applications.

(JMIR Mhealth Uhealth 2014;2(1):e11) doi:10.2196/mhealth.3048

KEYWORDS

medication therapy management; medication adherence; mHealth; mobile health

Introduction

Medication Adherence

As many as half of all prescriptions are not taken as prescribed, costing the US health system over US $100 billion per year [1-8]. A decade ago, the World Health Organization declared medication nonadherence to be "a worldwide problem of striking magnitude" and anticipated that "increasing the effectiveness of adherence interventions may have a far greater impact on the health of the population than any improvement in specific medical treatments" [7].

For chronic conditions such as diabetes, hypertension, and dyslipidemia, up to one-half of individuals will stop taking a medication as prescribed within the first year [8-10]. For psychiatric conditions, such as depression or bipolar disorder, one-half are nonadherent by 3 to 6 months [11,12]. The ability or desire to adhere is dependent on the duration of illness, the perceived benefit of therapy, adverse effects (real or potential), and the complexity of the regimen [13]. Effective interventions for nonadherence can be as simple as blister packing medications [13]. However, more intensive interventions are often needed to improve clinical outcomes, including patient education [11,13], team-based case management [13], patient self-management [14], telephone follow-ups [11], motivational interviewing, and provider support through pharmacist medication reviews or telephone reminders [11].

The language of adherence is complex and evolving. Adherence generally refers to how a patient takes a medication in relation to the prescribed timing, dose, frequency, and duration of therapy [13,15]. True adherence is difficult to measure but is often assessed through pill counting, prescription refills rates, and patient questionnaires [16]. Medication persistence is more specific and refers to how long a patient continues to take their prescribed therapy after it is first written [9].

The term "compliance" is often used interchangeably with adherence, but has fallen out of favor in recent years for its paternalistic implication that a good patient passively follows physician instructions [16]. "Concordance" has emerged as a more patient-centered term for adherence in the setting of shared decision-making, though a recent review found little agreement on the definition and scope of concordance and little evidence to support the value of concordant relationships [17]. For the purposes of this paper, we have chosen the term medication adherence to refer to the product of collaboration between a patient and a health care provider, wherein both collectively identify the goals of therapy and the therapeutic regimen [18].

mHealth and Medication Therapy

Mobile health, or mHealth, applications offer one potential solution to help patients adhere to prescribed therapy. Over one-half of American adults own a smartphone and over one-third own a tablet [19,20]. One in 5 smartphone owners have downloaded at least one mHealth application [21]. Adults over age 50 are also accessing mHealth in increasing numbers. A 2010 survey by the American Association of Retired Persons showed that 89% of individuals over age 50 use a mobile device with the most common device being a cellphone and 7% using a smartphone [22]. Though 1 in 10 respondents are using an mHealth application to track health measures (eg, weight, blood pressure, blood glucose), 4 in 10 are interested in using one in the future [22].

For mHealth interventions to be both effective and accepted by end users, it is important to understand the differences between individuals who have, who will, and who will never adopt mHealth interventions. In the same way that there are barriers to medication adherence, there are also likely to be barriers to digital adherence. For example, user experience research has found users over age 50 can be easily frustrated by conceptual misunderstandings about the design of mobile devices [23,24]. They may also require training prior to use or may require devices tailored to their specific needs [25].

Among the thousands of mHealth applications commercially available, many are designed to help individuals organize and manage how they take their medications. Adults over age 50 make up the majority of medication users [26] and medication management applications need to consider this large target demographic. Our objective was to explore the usability and usefulness of existing medication management applications for adults over age 50.

Methods

Design and Setting

We used a mixed-methods approach to examine the usability and user perceptions of commercially available mobile medication management applications at the University of Waterloo School of Pharmacy. We included a qualitative assessment of user experiences using a grounded theory (GT) approach, which is reported according to the consolidated criteria for reporting qualitative research (COREQ) [27]. We also compared the usability of the test applications with the Systems Usability Scale (SUS), a validated measure of learnability and user satisfaction [28]. We did not develop any of the applications tested, and received ethics approval from the University of Waterloo Office of Research Ethics.

Medication Management Applications

We identified medication management applications by searching the Apples iTunes store using the terms "medication", "prescription", and "drug". After exploring the descriptions of over 100 mobile applications, two researchers identified and downloaded 22 applications focused on helping consumers manage general medication therapy rather than medications related to a specific illness. The researchers independently explored the functionality of each application by entering a list of prescription and nonprescription medications, setting reminders, and reviewing the applications with friends and family members over age 50. After 2 weeks, the research team reconvened and chose five applications for the final review,

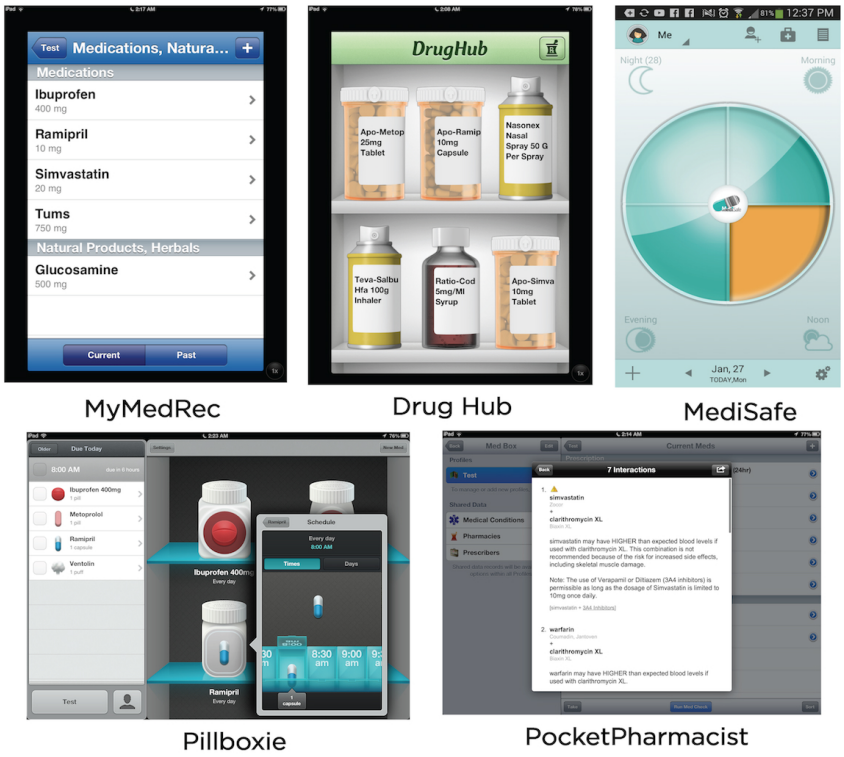
each highlighting a different feature, such as appearance, reminders, drug information, drug interactions, and connectivity (Table 1, Figure 1).

We chose MyMedRec (Version 1.0.4) for its simple features and linear data entry. MyMedRec was developed as a collaboration between the Institute of Safe Medication Practices Canada, Canada's Research Based Pharmaceutical Companies (Rx&D), and several health professional association across Canada. We chose Pillboxie (Version 2.6) for its graphical interface. A registered nurse in the United States developed Pillboxie to be a virtual medicine cabinet. We chose DrugHub (Version 1.3) for its drug information feature. The Great-West Life Assurance Company, a large provider of health insurance in Canada, developed DrugHub as a service to the general public. We chose PocketPharmacist (Version 3.1.8, Danike, Inc.) for its drug interaction feature. A pharmacist in the United States designed PocketPharmacist to provide users with medication information and the ability to check multiple drugs for any interaction. Finally, we chose MediSafe (Version 2.3.2, MediSafe Project) for its cloud-synced, family-centered profile sharing features. MediSafe was designed in Israel. At the time of the study, MyMedRec, Pillboxie, DrugHub, and Pocket Pharmacist were available for the iOS system, and Pocket Pharmacist and MediSafe were available for the Android OS.

Table 1. Features of the mobile medication management applications selected for review.

Full name	MyMedRec	Pillboxie	DrugHub	Pocket Pharmacist	MediSafe
Medication list	✓	✓	✓	✓	✓
Reminder alarms	✓	✓	✓	✓	✓
Drug information			✓	✓	
Drug interactions				✓	
Multiple user profiles	✓	✓		✓	✓
Profile sharing via email	✓	✓	✓	✓	✓
Sharing across multiple devices					✓

Figure 1. Screenshots of the mobile medication management applications included in the assessment.



User Testing

Participants and Sampling Frame

We included participants aged 50 years of age and over, who could speak and read English and who took some form of chronic medication. We did not require participants to have previous experience using a touchscreen device. We recruited participants by posting flyers and attending events at community centers and medical clinics. Our sampling strategy reflected a GT approach to qualitative analysis [29]. As we did not have any preconceived theories about the usability or usefulness of the applications for older adults, we began by purposively recruiting a sample of 13 participants who had a range of experience using medications and touchscreen devices [29]. We then recruited a theoretical sample of 22 participants to expand on the theories framed from the purposive sample [29]. According to Glaser [30] for the theoretical sample, "the analyst jointly collects, codes, and analyzes his data and decides what data to collect next and where to find them, in order to develop his theory as it emerges." As described by Draucker et al [31], we used several strategies for identifying the theoretical sample, including intensity sampling of individuals who would have "a lot to say" (eg, information technology experts), typical sampling of average users, extreme case sampling (eg, individuals with complex health conditions), and purposeful sampling to represent subgroups (eg, married couples). We continued sampling until data saturation was reached.

Our final sample included 35 participants aged 52-78 years (mean 67 years), 71% (25/35) of whom were female (Table 2). All but 2 participants reported at least one chronic medical condition and all participants were taking at least one medication, including prescription products, vitamins, and natural health products. Our sample included a range of low- to high-income participants, almost one-half of whom had a post-secondary degree. Most participants used a computer daily and over one-third used a tablet or smartphone daily.

Procedure

We used a group-based assessment model to meet our objectives as it allowed us to test multiple participants at once while capturing moments of consensus, censoring, and dissonance among new, novice, and experienced mobile device users (Figure 2) [32]. The number of study devices we had access to limited our group size to a maximum of 8 participants. Our final groups included between 3 and 7 participants.

We began each session with a meal or light refreshments and a 10-minute discussion of what medication management meant to participants. Each participant was provided with a third generation Apple iPad and given a series of ordered tasks. Participants in the purposive sample worked from the simplest application to the most complex (MyMedRec, Pillboxie, DrugHub, PocketPharmacist). For the theoretical sample, we randomized the order of the applications to assess order effect. We also introduced styluses and gave participants access to smaller devices such as the Apple iPhone 4, Apple iPod Touch, and the Samsung Galaxy S3. We introduced the fifth application, MediSafe (Medisafe Project LTD), because it had a unique pillbox graphical interface and had more connectivity than the other study applications, but excluded it after one session because participants complained of several system errors.

For each application, we asked participants to complete a series of application-specific tasks that could include the following: (1) adding prescription, nonprescription, and natural medicines, (2) scheduling reminders, (3) recording when a dose was taken, (4) emailing profiles, (5) reading drug information, and (6) scanning for drug interactions. We provided each participant with a set of standardized medication bottles that represented a clinically significant drug-drug interaction: warfarin, aspirin, and St. John's Wort; clarithromycin and atorvastatin; ramipril and ibuprofen; furosemide and ibuprofen; and levothyroxine and calcium carbonate [33]. We provided limited assistance to users who failed to complete a task after several attempts.

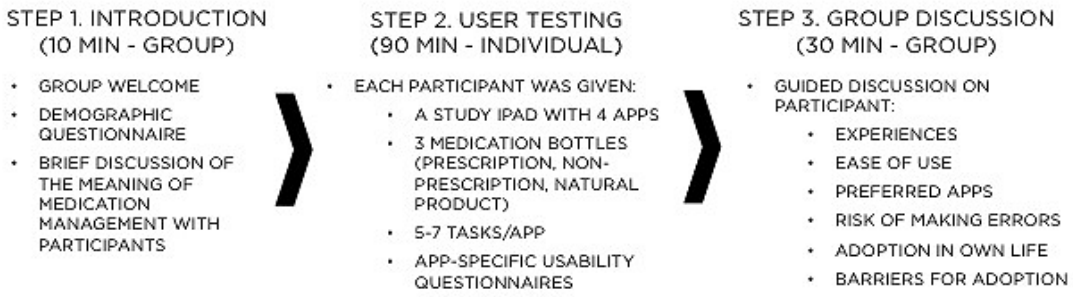
We concluded each session with a 30-minute focus-group discussion. The guided discussion included questions on overall user experiences, ease of use, concerns over the potential for data input errors, perceived quality of the information provided, preferences for different features, and expected adoption by adults over age 50. On completion, participants were given a $10 gift card in appreciation for their time.

Table 2. Participant characteristics (N=35).

Characteristic	Category	n (%)
Age	Median (range)	67 (52-78)
Gender		
	Male	10 (29)
	Female	25 (71)
Medical Condition(s)		
	None	4 (11)
	Heart disease	7 (20)
	Cholesterol	14 (40)
	High blood pressure	15 (43)
	Thyroid disease	5 (14)
	Bone and joint problems	6 (17)
	Cancer	2 (6)
	Diabetes	7 (20)
	Kidney disease	4 (11)
	Liver disease	0 (0)
	Lung disease	2 (6)
	Other	10 (29)
Medications		
	Prescription medications	30 (86)
	Vitamins	28 (80)
	Natural health products	16 (46)
	Manage medications for others	14 (40)
Highest level of education		
	High school	9 (26)
	College	13 (37)
	University	7 (20)
	Graduate degree	6 (17)
Annual household income		
	< $20,000	2 (6)
	$20,000 - $49,999	10 (29)
	$50,000 - $79,999	10 (29)
	>$80,000	6 (17)
	Prefer not to say	7 (20)
Use a computer		
	Daily	27 (77)
	Weekly	3 (9)
	Monthly	0 (0)
	Rarely	1 (3)
Use a tablet		
	Daily	10 (20)
	Weekly	1 (3)
	Monthly	0 (0)

Characteristic	Category	n (%)
Use a smartphone	Rarely	0 (0)
	Daily	5 (14)
	Weekly	3 (9)
	Monthly	0 (0)
	Rarely	0 (0)

Figure 2. Study design.



Data Collection and Analysis

Participant demographics and experiences were gathered using paper-based questionnaires and summarized using descriptive statistics. Participants were encouraged to write comments about their experience as they tried each application. Two researchers also recorded their observations of participant experiences, including questions asked, errors observed, and tasks users could not complete. Focus-group discussions were audio recorded. All data, including audio recordings, field notes, and participant comments, were transcribed and de-identified by a researcher and double-checked by a second researcher.

After each application, participants rated usability on a visual analogue scale (easy/difficult) and the 10-item SUS (Multimedia Appendix 1) [28]. The SUS is a validated tool that uses a 5-point Likert scale to provide a quantitative measure of the usability and learnability of a system and provide an overall score between 0 and 100 [28]. SUS scores were analyzed in SPSS using a repeated-measures analysis with post hoc tests to determine where usability differences occurred.

Grounded Theory Analysis

We used a GT approach as it allowed us to develop a theoretical interpretation of the meanings we observed older users attaching to mobile medication management applications without defining the phenomenon a priori [34]. For GT, data are systematically collected from many sources, including participant experiences, both written and voiced, and researcher observations. GT is a constant analysis method where data and emergent theories are continuously compared to ensure resulting theories are grounded in raw data. We based our analysis on the descriptions of GT by Patton [29], Glaser [30], Strauss and Corbin [35], and Suddaby [36].

Our data analysis, which began after the third session, followed three levels. For the first level of analysis (microanalysis), two independent researchers coded data by briefly summarizing each line of data. In the second level of analysis (axial coding), the two researchers organized the summaries into categories (Table 3). To assess interrater reliability, a third researcher compared the codes and categorizations for the first three sessions and any disagreements were resolved by discussion. For the third level of analysis (theory development), the emergent theories were formulated into a “logical, systematic and explanatory scheme” by the three researchers [35]. To minimize our own biases, we reflexively reviewed the transcripts a final time to identify any supporting quotations and contradictory data [37].

Table 3. Categories and labels used to organize grounded theory analysis.

Category	Examples of descriptive summaries
What does “medication management” mean?	-Remembering medications -Understanding medications -Drug–drug, drug–food interactions -Relationship with physician -Pill boxes -Renewing prescription
How did it feel to try the applications?	-Feelings: frustrating, challenging -Positive learning -Uncertainty of future adoption -Information overload -Shift from frustrating to doable
What was the easiest/most difficult application to use?	-Training would help make it easier -Prior experience required -Gender distinctions -MyMedRec, because it was easier to find way around -PocketPharmacist had too many submenus
What was the most/least preferred application?	-Not qualified to evaluate -Lack of experience with technology -Liked different features from each -Drug information applications -Application glitches
What features were liked?	-Graphics easier to understand than words -High value for listing supplements -Drug interactions -The simpler the better
What features were disliked?	-Ambiguous use of symbols -Requires previous knowledge of device -Not intuitive to look at corners -Unreliable reminders -Lack of food–drug interaction -Microscopic keyboard
What features were most surprising?	-Missing allergy–drug alerts -Untrustworthy drug interaction feature for PocketPharmacist -Lack of features on many apps -Surprised there was an email feature
How can/will the applications be used in real life?	-Uncertain if would ever use -Younger person associated with technology -Possible user: elderly relative, someone with 8 medications/day -Way of the future -Current management system works
What is the willingness to pay for the applications?	-Willing to use more a difficult application if free -Uncertain -Need a trial period -Surprised by the price, seems low -$100 for PocketPharmacist

Category	Examples of descriptive summaries
How long would someone spend learning the applications?	-Willingness to spend time everyday -It would take a week to learn with daily use -Overall it was not intuitive -Might spend a couple hours -I would give it 15 minutes
Should physicians or pharmacists recommend the applications?	-All younger persons already own technology -Not applicable to current older adults -Older generation is adopting new technology -Pharmacist job to educate patients on drugs -Variable levels of pharmacists -Providers are intolerant of nonadherent patients
Should the applications connect with physician or pharmacist computer systems?	-Future connection “so cool” -Useless if increased workload -Intolerance to uncooperative providers -No, my doctor will not accept email -Prefer to talk to the pharmacist or doctor in person
Should the applications be backed up?	-Expect backing up -Assume data is retrievable -Expect it to be saving something -Fact that it’s not backed up takes away from the usefulness -Thought the iPad could be backed up to the laptop

Results

User Testing

Based on the SUS scores (Table 4), the *F* test indicates PocketPharmacist had a significantly lower usability score compared with all other applications ($P<.0001$), whereas MyMedRec, Pillboxie, and DrugHub were not significantly different from each other. Order of use did not affect SUS scores when added to the model ($P=.44$).

Table 4. Overall Systems Usability Scale scores for each application assessed.

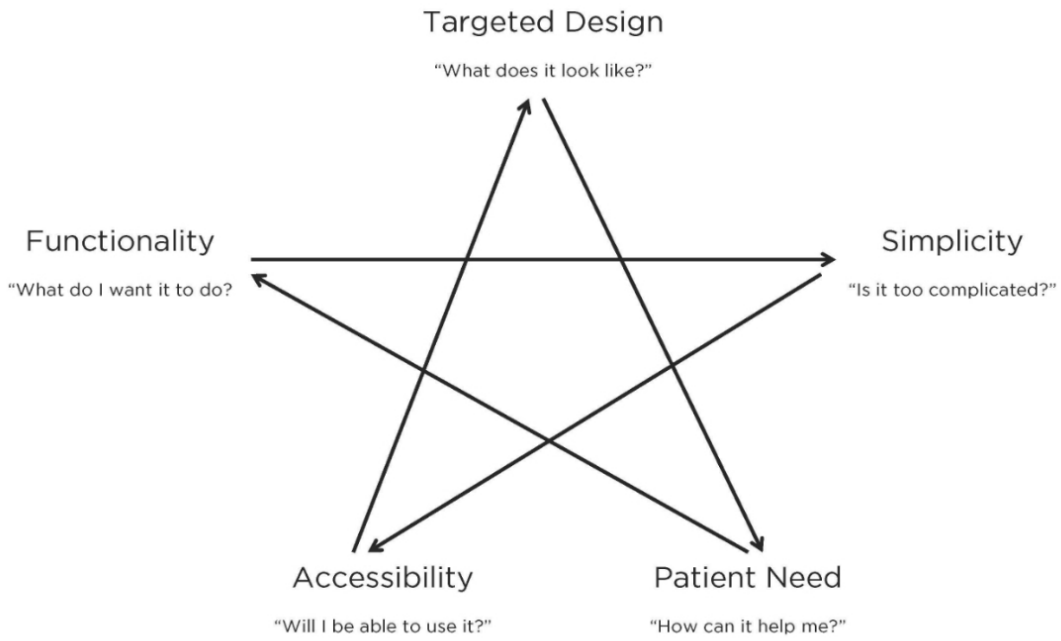
Application	Mean SUS score (SD)[a]
DrugHub (N=35)	57.1 (22.2)
MyMedRec (N=35)	55.6 (22.4)
Pillboxie (n=31)	52.2 (18.1)
PocketPharmacist (N=35)	42.1 (18.7)
MediSafe (n=4)	40.0 (15.1)

[a]Significant difference between applications $f=2.95$, $P<.0001$

Grounded Theory Analysis

Figure 3 describes the theoretical construct that emerged in our analysis, including the interplay between usability, accessibility, design, and need.

Figure 3. Model depicting first time experiences of older adults using mobile medication management applications.



Targeted Design

For participants, the early experience of learning to use a mobile medication management application was frustrating, overwhelming, and challenging but it was also fascinating, fun, and enlightening (Table 5). As one participant noted,

> *With a little bit of practice, with all of them, [it] would become a lot easier to like anything. You know, the first try at any of these, regardless whether you're familiar with an iPod or an iPad, it does not go smoothly. They're not terribly intuitive.* [Male, Group 8]

Early on, we observed that many participants were reluctant to learn by trial and error. They appeared to feel vulnerable or lost and often worried about making a mistake. Many spoke of trying not to break the device. We learned to start each session saying, "Don't worry, you won't break it" to encourage learning by trial and error. In describing the need for support, one participant explained,

> *there are a few steps missing I think in each of these [applications]…I didn't know how to get from a certain screen to another, it wasn't very evident, but once I was shown, I think it's easy to use.* [Female, Group 3]

Eventually, within the 2-hour timeframe of each session, almost all participants became comfortable inputting information. The experience of learning the applications can be compared with the implementation of new technologies in other areas of life, including banking and transportation:

> *I guess while I was doing it, I kept thinking about ok, when I was first ordering airline tickets on the computer, or bus tickets on the computer, the difference after you've done it a few times as opposed to the first time, trying to figure out which buttons to hit.* [Female, Group 1]

However, some individuals had more difficulty than others, and would likely need significant support, both technical and emotional, to adopt the application into their lives. One participant who found the applications extremely difficult to use highlighted this challenge when he concluded,

> *I don't want an app, I don't ever want to see one in my house or anything because to me they're just frustrating. Frustration devices.* [Male, Group 5]

When asked if they were willing to persist in using the applications, the opinion was divided between willingness to persevere until comfortable given a perceivable benefit, or only for 15 minutes due to impatience and lack of time.

> *I'd spend a bit of time, half an hour to an hour, not even an hour, half an hour to learn something like this, yes.*" [Female, Group 6]

Patient Need

The perceived usefulness of a mobile medication management application is closely related to the needs of the end user. Users who believed their current adherence strategies are sufficient are likely to consider the applications as less useful. One participant highlighted the importance of perceived usefulness by saying,

> *I like things fast and dirty, I would just give up. Say forget it, I'll just do it my old fashioned way.* [Male, Group 6]

Strategies for remembering to take medications included scheduling all medication doses at once, using a physical pillbox, wearing a digital watch with an alarm, and/or having a pharmacist who provides telephone refill reminders. Many also carried a written or printed list of medications in a wallet or

purse. Participants would only speculate future use under the assumption of declining health, declining memory, or the need to manage medications for a relative.

> *I'm looking at it from the point of view of my mother when she was elderly. She was confined to a wheelchair and okay, she wasn't computer literate. But had she been, you know, if she'd had it with her, in her chair, she could've looked at it and said 'yeah hey I need to take this pill' or there's a reminder, or 'no I can't', somebody's making lunch for her, 'no I can't have grapefruit because I've taken Lipitor' or something like that. I'm sure that kind of information would have been good. If you're not terribly mobile, I think something like that, and in this day and age, as time goes on, people are much more computer literate and can handle these things much more easily and how do you say, you know, that would be much more useful, if you're concerned, if you're taking a lot of medications. Because I know some people who are taking seven or eight a day.* [Female, Group 1]

Most also felt it was only appropriate for health care professionals to recommend an mHealth application if they had used it themselves and if the patient was willing, needed it, and was technologically literate.

Table 5. Participants summarize the experience of trying mobile medication management applications in one word.

Negative Words (Count)	Neutral Words (Count)	Positive Words (Count)
Frustrating (5)	Different (1)	Fascinating (2)
Challenging (3)	Perplexing (1)	Fun (2)
Overwhelming (2)		Enlightening (1)
Stressful/nerve-wracking (2)		Doable (1)
Confusing (1)		Interesting (1)
Exhausting (1)		Useful (1)
Complicated (1)		Informative (1)

Functionality

Mobile medication management applications can be conceptually separated into two categories: adherence (MyMedRec, Pillboxie) and information (DrugHub, PocketPharmacist). An "ideal" application was described as including both features:

> *I found MyMedRec covers everything, it's ordered properly. But it did miss the other little features, the little pillbox [in Pillboxie] and then the [drug interaction] check [in Pocket Pharmacist] and then [DrugHub]. I guess it's the access to the information and whether you could check interactions and things like that. If somehow you could incorporate that into the [MyMedRec] then it would be perfect.* [Female, Group 3]

In their daily lives, all participants sought information about their medications in order to stay aware and avoid adverse events. The drug information features were seen as providing background information on a new prescription, supplementing the information given by a health care professional, and satisfying curiosity.

> *For me, personally, I take a lot of pills everyday…I've got it so down and whenever I take a prescription, well the pharmacist is very good to go over things, but I always, always make a point of reading the literature when I get it.* [Female, Group 2]

While the most popular source of drug information was the pharmacist, some participants worried that too much information was dangerous and that the applications were replacing the expertise of the pharmacist. Given the choice, participants preferred an in-person conversation for important information:

> *Something like drug interactions? I don't want to be bothered by anything like that. I mean I know I should, but I want my pharmacist to say to me when I go in, don't take this or do take that. You know what I mean? I didn't go to school, I don't want to have the responsibility of worrying about that...* [Female, Group 1]

When asked to estimate the cost of applications, most participants valued drug information applications over adherence applications. Participants who had purchased applications expected to pay less than Can $5 (or often nothing at all), but those who had never purchased an application expected to pay up to Can $100 or a monthly fee. Most did not take into consideration the cost of the device itself.

Simplicity

There was a competing relationship between functionality and complexity. The "ideal" application may actually be two applications, one for adherence and another for information. Separating the features into two applications would maximize the functionality of both features rather than trying to do both incompletely.

> *I think there's two parts of it. There's reminding people to take the medication but then there's the whole information side with what's working with what. So it almost seems like you should have two apps.* [Female, Group 7]

For many participants, linear navigation was preferred. Participants commonly struggled with going "back and forth", essentially, moving forward to enter a medication into their profile and once completed, going back to enter a new medication (Table 6). Moving backwards also referred to fixing

a mistake. Participants moved from one main menu and followed single pathways to perform or correct a task. As such, most found MyMedRec and DrugHub to be easier and more logical. In contrast, Pillboxie and PocketPharmacist did not flow because, rather than advancing through different screens, navigation was broken into submenus or different windows on a single screen. Inconsistencies also caused confusion. To return to a previous screen or menu, MyMedRec and DrugHub used the standard iOS arrow pointing to the left corner. To back out of a task in Pillboxie, users had to tap outside the task window.

> *I'm impatient as hell. So when it comes to an app, it's got to be simple. See…it wasn't easy for me to find the prompts, you know, partly from [my] glasses, but also I'm impatient and I quit looking. And I said 'Oh I've spent all this time entering the stuff but if I put CANCEL, does that mean it's gone?* [Male, Group 5]

Similarly, the first screen a user saw with PocketPharmacist contained both a menu and submenu. Participants expressed feeling overwhelmed by the amount of information being presented all at once. Many first time users struggled with basic touchscreen features, such as accessing and using the keyboard and employing application-specific gestures. One participant felt this should be standardized,

> *So ultimately, you'd want a universal language, and a universal kind of, you know, this is where the back button is, this is where the forward button is. But if that doesn't happen, then every app has its own unique way.* [Female, Group 2]

Table 6. Application actions and features identified by participants as being nonintuitive or difficult to interpret.

Action/feature	Description of challenge
A "+" to add a new item	Though typically used to add a new item, the symbol had little meaning for first time users. Also, because it is often found in the top corners it is easily missed.
Go back	The back arrow is used to return the user to the previous screen but instead of testing the button, the research team was often asked, "How do I go back without losing my information?"
Cancel	The word "cancel" typically means "undo" but many participants felt it implied finality and described how they "cancel" social or service contracts such as memberships, subscriptions, and appointments.
Scrolling	Without a scrollbar, participants rarely looked for additional information.
Audio reminders	The audio alarms were inaudible to many participants, especially males.
Autocorrect	When typing, many participants focused on the keyboard and missed the autocorrect feature that would change drug names or dosage units (eg, "mcg" to "mg").
Inconsistent terminology	Inconsistent terminology led participants miss features. For example, reminder features were called "schedule," "dose reminder," or "first dose" in each application.
Sample text	Greyed text was used to provide examples of data that could be entered into a field, but participants typically misinterpreted the grey text to be the information of another user.
Peripheral buttons	Participants associated a black frame as being outside of the application and noninteractive, thus overlooking peripheral buttons completely.

Accessibility

One of the challenges faced by participants was that the adherence features we examined (dose reminders, refill reminders) made assumptions about the end user. For example, the reminder strategies (alarms, notification boxes) assumed users were "attached" to mobile devices. Participants said, for example,

> *Like, [young people] live with their cell, live with their Blackberry, and that becomes, you know what I mean. Like, I could see, even obviously, when those kids get to be 50, they will still be attached to the hip with those Blackberries.* [Female, Group 1]

Comparing the use of the applications on the tablet to the smartphone, one participant noted,

> *Reminders would probably be the best [feature] but it would be inconvenient unless I had one of the other devices that you could carry in your pocket or your shirt pocket or a woman could carry in her purse. (Male, Group 4).*

This is an important distinction because though the tablets are less portable, they are more accessible to individuals with age-related vision loss. In one case, a participant with severe low vision noted that touchscreen devices were surprisingly accessible,

> *I was always afraid to even look at them or try them, because I just thought that I wouldn't be able to see, so why even bother. But I was surprised…yeah.* [Female, Group 4, low vision]

The participants, as older adults, also described how they power off devices between use to conserve battery power or save it for emergencies.

> *These tablet things, they're not plugged in, so, most of the time…you tend to turn them off to conserve the battery and maybe they could be designed so that they automatically turn themselves on, give a signal, and then go back to rest.* [Male, Group 8]

The reminder strategies also assumed users were physically able to hear alerts. In every session, we observed at least 1

participant, often male, who could not hear the alarms going off in the room.

> *But some people may be hearing impaired and you know, maybe that could be accommodated, I'm not sure how. [Male, Group 8].*

Finally, participants worried that adherence strategies that required users to maintain a medication administration record were easily fallible.

> *With your daily plastic, you can see that you took it, with this thing, you may have put in that you took two pills…but you got distracted, so how do you know you took two?…It's not physical, you can't see it, as you get older. I mean, there's two sides. You forget to take things or you know, things like that, I don't know, it's too easy to screw up.* [Female, Group 6]

Discussion

Overview

We asked 35 adults aged 50 and over to spend 2 hours trying popular medication management applications on mobile devices. Most were new and novice users and we found that the currently available applications were not designed with older users in mind. Without simple and targeted design, the current applications are unlikely to be considered useful, usable, or accessible for a large proportion of individuals who need to take chronic medications.

Acceptance of Mobile Medication Management Applications

Dr Everett Koop famously said, "Drugs don't work in patients who don't take them". Similarly, mobile medication management applications will not work for users who do not use them. Reminders offered the clearest example of the gap between design and the older end user. One-half of prescriptions are not taken as directed [2,6], and dose reminders have the potential to help individuals remember doses that would have otherwise been missed. Most reminder systems also provide a record of adherence that could be used to help participants or clinicians understand the impact of nonadherence on their disease. However, in our study, reminders were widely considered to be of little use to older adults, many of whom have age-related hearing loss or who prefer to either leave their mobile devices at home or power devices off between use.

The Technology Acceptance Model, which was introduced by Davis in 1986 [38], suggests that acceptance depends on a user's perception of the usefulness and ease of use of a system. Similarly, the diffusion of innovation model emphasizes that a new technology needs to offer a "relative advantage" over the status quo [39]. The lack of perceived usefulness or relative advantage appeared to be the greatest barrier to acceptance or adoption in our study. Our participants felt capable of, and interested in, using mobile applications to manage medications, but they searched for a need that their current medication management system was not filling.

In a study of the factors that impact patient acceptance of online self-management technology, Or et al [40] concluded that the first step in designing a system that patients will accept is to focus on their needs. Barriers to medication adherence are complex and interwoven and not easily addressed by mobile applications [7-12]. In addition to age, barriers include health literacy, the health care provider-patient relationship, poor memory, care team size, medication efficacy, and the complexity of medication regimen [41]. Future mobile applications should be designed with the awareness that multimodal methods for nonadherence are more successful than interventions focusing on one aspect of nonadherence [11,13]. For example, the next generation of applications could provide users with access to plain language information on medications both before and after a prescription is filled, include accessible reminders for doses and refills, and offer strategies to simplify a dosing regimen. More advanced iterations could also help the consumer alert clinicians when they have a question, experience a side effect, or are unable to afford the cost of their prescribed therapy.

Application Development for Older Adults

We were able to speak with 3 of the 5 creators of the medication management applications tested. None had conducted usability testing in adults 50 and older. A tendency to target designs toward younger adults perpetuates the notion of the "digital divide" or "digital disengagement", where developers assume older adults lack the technological access and literacy of younger generation [42]. Loos [43] has cautioned against using age as the ultimate explanatory variable when examining the digital divide. By overlooking older users, developers may be failing to reach a major target demographic.

While we need to recognize that many older users are technologically savvy, Hawthorn [44] notes that we still need to make accommodations for "age-restricted users" with age-related changes in hearing, vision, cognition, and mobility. Application designers can consider the impact of age on usability and include large font, clear buttons, and high-contrast text. However, before developing an application for medication adherence for a specific operating system, the design team should consider the suitability of the mobile device for the target population. Most existing mobile devices should work well for addressing barriers such as lack of information. For younger people, they may also be useful for the day-to-day barriers to compliance such as forgetfulness. However, for older populations, forgetfulness and treatment complexity may be better suited to multimodal mobile interventions that include companion pillbox devices, for example.

To improve usability, it would be helpful for developers to provide clear instructions and describe important buttons or features for first time users (eg, "The area where you list all the medications you take is called the *Med Box*. Use this area to enter the names and doses of your medications"). Although some applications did provide examples, they were often small, low contrast, and easily misinterpreted as pre-entered information. The Nielsen Norman Group refers to the inability of identifying a touchable area as low discoverability [45]. To improve developers and designers should consider working with health organizations to identify target users who can participate in early- and late-stage usability testing.

Often, mHealth applications do not follow guidelines or include features considered essential for prevention and public health [46,47]. The lack of standardization and regulation may limit adoption by users over age 50 and their health care providers. For example, participants were suspicious of an application put forth by an insurance company. They were afraid personal information could be collected and used against their claims. On the other hand, when we spoke with the developers, no data were collected from the applications. Sentiments of use and privacy as barriers for adoption match with those from respondents in the 2010 AARP survey [22]. To promote consumer trust, one possibility is to develop a systematic self-certification model similar to the Health On the Net Foundation [48].

Strengths and Limitations

A strength of our study is that it reflects the experiences of first-time users. The rationale was that, in the real-world setting, many new users would try several medication management applications before choosing one to use or would be prescribed a mobile application that they had not used previously. However, the 2-hour format meant some features of each application could not be explored. In some cases, participants assumed certain features were missing. In each case, we demonstrated the feature in question to gather any additional feedback. During the discussions, application names and features were often confused with one another so we tried to ensure we regularly revisited each application to clarify which application was being discussed.

In future studies, participants should be given a device for a longer time period to examine the effects of daily use. Previous studies have found SUS scores to increase with the degree of experience with a program prior to usability testing [49]. Longitudinal usability testing may help uncover long-term benefits and drawbacks that first-time experiences cannot. Alternatively, usability testing of medication management applications with health care professionals may provide a deeper understanding of their acceptance and willingness to provide additional services in relation to application use by patients. Another potential solution that should be further explored is the combination of an application with a wearable device such as a smartwatch or wristband.

Conclusions

Though older adults make up the majority of medication users, mobile medication management applications are often designed for younger populations. The result is that age-related physical changes, such as hearing or vision loss, and the use of nonintuitive design features limit the usefulness of the applications for older users. When developing mobile interventions to improve medication use and adherence, designers, programmers, and developers need to consider older adults as potential high-impact end users and include this population in the design process. For older adults, standard features such as reminders may be poorly suited to most mobile devices, whereas applications that provide high quality information on side effects or drug interactions may be more desirable. Considering that the industry is not currently regulated, the focus also needs to be on building applications that limit the risk of errors and omissions.

Acknowledgments

Thank you to Mrs Erin Harvey, the statistics consultant at the University of Waterloo, and to the cities of Kitchener and Waterloo for providing recruitment support.

Conflicts of Interest

Conflicts of Interest: None declared.

Multimedia Appendix 1

Systems Usability Scale used to compare selected medication management applications.

[PDF File (Adobe PDF File), 22KB - mhealth_v2i1e11_app1.pdf]

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Abbreviations

COREQ: consolidated criteria for reporting qualitative research
GT: grounded theory
SUS: Systems Usability Scale

Edited by G Eysenbach; submitted 24.10.13; peer-reviewed by T van Mierlo, S Ong, L Dayer; comments to author 23.12.13; revised version received 30.01.14; accepted 17.02.14; published 14.03.14.

Please cite as:
Grindrod KA, Li M, Gates A
Evaluating User Perceptions of Mobile Medication Management Applications With Older Adults: A Usability Study
JMIR Mhealth Uhealth 2014;2(1):e11
URL: http://mhealth.jmir.org/2014/1/e11/
doi:10.2196/mhealth.3048
PMID:25099993

Original Paper

Mobile Phone Intervention Reduces Perinatal Mortality in Zanzibar: Secondary Outcomes of a Cluster Randomized Controlled Trial

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Abstract

Background: Mobile phones are increasingly used in health systems in developing countries and innovative technical solutions have great potential to overcome barriers of access to reproductive and child health care. However, despite widespread support for the use of mobile health technologies, evidence for its role in health care is sparse.

Objective: We aimed to evaluate the association between a mobile phone intervention and perinatal mortality in a resource-limited setting.

Methods: This study was a pragmatic, cluster-randomized, controlled trial with primary health care facilities in Zanzibar as the unit of randomization. At their first antenatal care visit, 2550 pregnant women (1311 interventions and 1239 controls) who attended antenatal care at selected primary health care facilities were included in this study and followed until 42 days after delivery. Twenty-four primary health care facilities in six districts were randomized to either mobile phone intervention or standard care. The intervention consisted of a mobile phone text message and voucher component. Secondary outcome measures included stillbirth, perinatal mortality, and death of a child within 42 days after birth as a proxy of neonatal mortality.

Results: Within the first 42 days of life, 2482 children were born alive, 54 were stillborn, and 36 died. The overall perinatal mortality rate in the study was 27 per 1000 total births. The rate was lower in the intervention clusters, 19 per 1000 births, than in the control clusters, 36 per 1000 births. The intervention was associated with a significant reduction in perinatal mortality with an odds ratio (OR) of 0.50 (95% CI 0.27-0.93). Other secondary outcomes showed an insignificant reduction in stillbirth (OR 0.65, 95% CI 0.34-1.24) and an insignificant reduction in death within the first 42 days of life (OR 0.79, 95% CI 0.36-1.74).

Conclusions: Mobile phone applications may contribute to improved health of the newborn and should be considered by policy makers in resource-limited settings.

Trial Registration: ClinicalTrials.gov NCT01821222; http://www.clinicaltrials.gov/ct2/show/NCT01821222 (Archived by WebCite at http://www.webcitation.org/6NqxnxYn0).

(JMIR Mhealth Uhealth 2014;2(1):e15) doi:10.2196/mhealth.2941

KEYWORDS

perinatal mortality; text messaging (SMS); mobile phones; developing countries

Introduction

With an increase in the number of mobile phone subscribers from 17 million in 2000 to 650 million in 2011, sub-Saharan Africa is experiencing a technological revolution [1]. The benefits of using mobile phone technology in health care systems in developing countries are diverse, and include improved reporting in health information systems, telemedicine providing care to populations otherwise deprived, and texting to improve adherence to treatment therapy [2,3]. Mobile health has great potential for sexual and reproductive health care and is seen as a key area in achieving the goals of the United Nations and the World Health Organization's (WHO) Global Strategy for Women's and Children's Health [4]. Despite widespread support for the use of mobile health technologies, evidence for its role in health care is sparse [5]. We are unaware of any other cluster-randomized controlled trial that has assessed the use of a mobile phone intervention to improve perinatal survival in a resource-limited setting.

Perinatal death is among the most devastating adverse outcome of pregnancy. Over 2.65 million stillbirths and 3 million early neonatal deaths occur each year worldwide [6,7]. Of these deaths, 99% take place in low- and middle-income countries [8,9]. Although under-five mortality has declined over the past 25 years, there has been little progress in reduction of neonatal mortality and it is an increasingly prominent component of the overall rate of under-five mortality [10]. Therefore, to achieve Millennium Development Goal 4 (reducing child mortality), reducing perinatal mortality remains a challenge.

Perinatal mortality is closely linked to maternal mortality and causes of death are similar, often obstetric in origin, including prolonged labor, preeclampsia, infection, and obstetric hemorrhage [8,9]. The three major causes of neonatal death are infections, intrapartum related causes, and preterm birth complications, contributing approximately one-third each [10,11]. Stillbirth accounts for approximately one-half of all perinatal deaths. Antepartum stillbirths are associated with maternal infection, hypertension, and fetal growth restriction, while intrapartum stillbirth is associated with obstetric emergencies and lack of skilled care [8,12]. Perinatal mortality is a sensitive indicator of the quality of antenatal, obstetric, and early neonatal care available to women and newborns in any setting. Unfortunately, those women at greatest risk are least likely to have access to life-saving interventions and in low-income countries where resources are limited, antenatal care coverage is poor, and many women deliver at home without skilled attendance and newborn care is inadequate [13,14]. Zanzibar is similar to many other developing countries where little is known about perinatal mortality. According to the 2010 Demographic and Health Survey the perinatal mortality rate in Zanzibar is 50 per 1000, and 36 per 1000 in mainland Tanzania [15].

This report presents the detailed effect of a mobile phone intervention named *Wired Mothers* on the secondary outcomes stillbirth, perinatal death, and death of a child within the first 42 days of life. *Wired Mothers* links women to the health system throughout their pregnancy, childbirth, and postpartum period using a text message and free call voucher system. A cluster randomization with the primary health care facility as the unit of randomization was carried out to evaluate the intervention. The design was chosen to prevent contamination between women cared for at the same facility.

Methods

Design

The *Wired Mothers* study is a pragmatic, randomized, controlled trial with the primary health care facility as the unit of randomization. The study took place from 2009 to 2010 on the island of Unguja in Zanzibar, a semi-autonomous part of the United Republic of Tanzania. We followed the Consolidated Standards of Reporting Trials guidelines for reporting cluster-randomized trials [16].

Participants

The study comprised 24 primary health care facilities and pregnant women attending antenatal care at these facilities. Clusters eligible for randomization were the four primary health care facilities in each of the six districts of Unguja Island with the most antenatal care visits in the previous year and a midwife among the staff. There were no major differences between included facilities. They were all primary health care facilities staffed with 1 or 2 midwives and access to basic infrastructure and equipment. The distribution of facilities in relation to hospitals providing Emergency Obstetric and Neonatal care was the same in intervention and control clusters (Figure 1). The eligibility criteria for participants was pregnant women who attended their first antenatal care visit at 1 of the 24 primary health care facilities regardless of gestational age or mobile phone ownership. A total of 2550 women were included in the study (Figure 2). Twenty-two women miscarried and 82 women withdrew or were not contactable during follow-up. Of these, 15 were known to have travelled outside the study area and three were not pregnant. During the study period 5 women died as a result of direct obstetric complications.

Figure 1. Research districts and location of intervention and control health facilities.

Figure 2. Procedures for the selection of the study population.

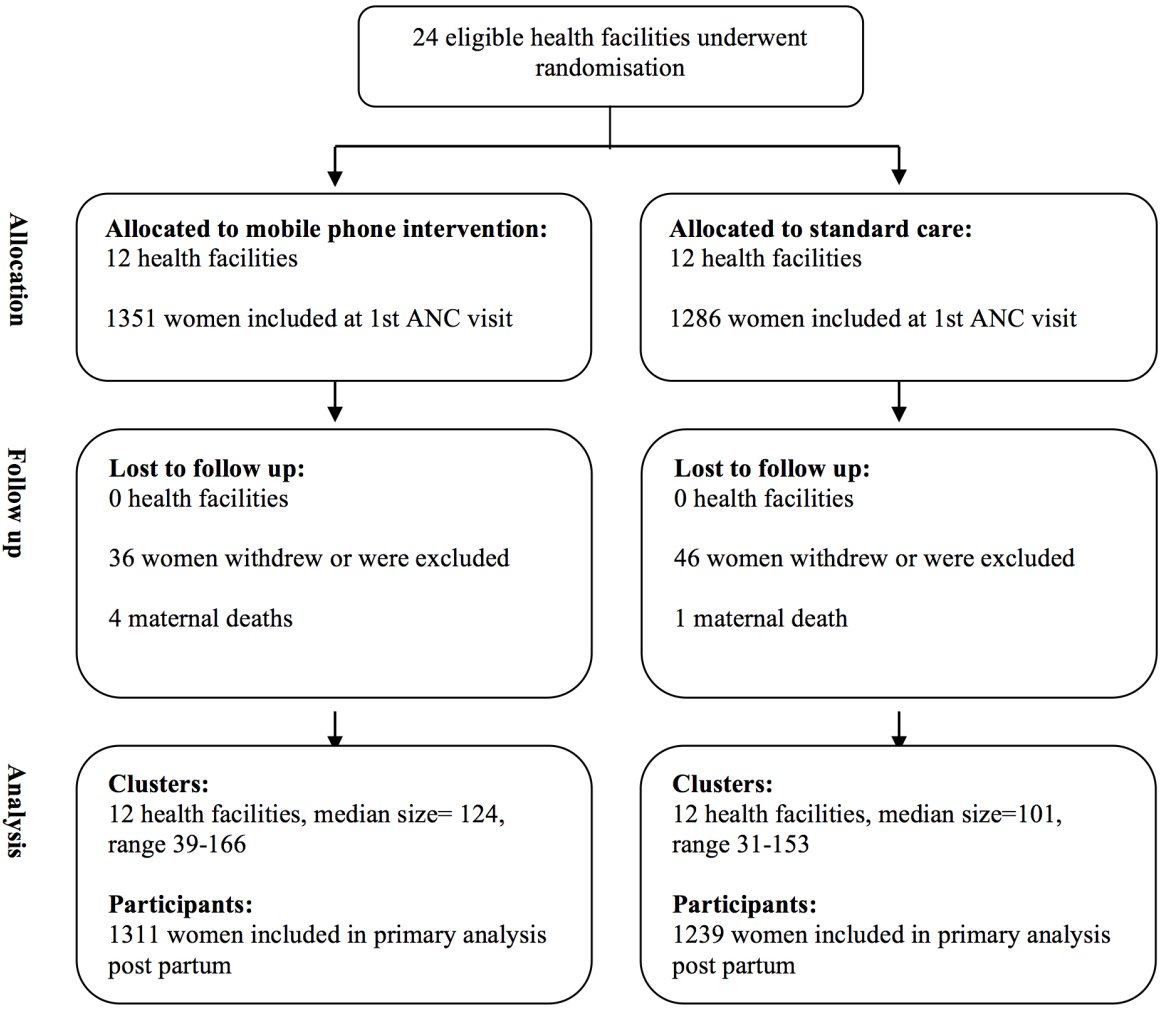

Figure 3. A Wired Mother with her child.

Ethics

The Research Council of Zanzibar approved the study protocol on January 27th, 2009. The trial is registered with ClinicalTrials.gov, NCT01821222. All women were informed about the nature and purposes of the study as summarized in the consent form written in the local language, Swahili. All women provided their consent either by signature or fingerprint prior to their inclusion in the study. Women were free to drop out of the study at any time without a change in the quality of care provided. All study results and completed questionnaires were kept confidential and were not accessible to people outside of the research team. The trial is registered after enrollment of participants, due to researchers not being aware of this International Committee of Medical Journal Editors publication demand for relatively benign interventions without individual randomization such as the *Wired Mothers*.

Intervention

The *Wired Mothers* mobile phone intervention was designed with the aim to link pregnant women to their primary health care provider throughout their pregnancy, childbirth, and postpartum period. The intervention was developed in Tanzania using simple technology and at low cost. It consists of two components: an automated short message service (SMS) system providing wired mothers with unidirectional text messaging and a mobile phone voucher system providing the possibility of direct two-way communication between wired mothers and their primary health care providers.

Women in the intervention group were registered at their first antenatal care visit with date, a phone number, and gestational age. The phone number was either their own or an access phone number of a husband/relative/friend. A specially-designed software that creates an individual pregnancy timeline for each woman and automatically sends text messages to the registered phone number was developed. The content and the frequency of the messages varied throughout the pregnancy and were intensified to weekly messages during the 4 weeks before delivery. The content of the messages focused on health education on topics, such as danger signs in pregnancy and the importance of skilled delivery attendance as well as appointment reminders for the next antenatal care visit. A total of 29,000 SMS were sent during the intervention period. Because the wired mothers intervention was developed in the context of the Ministry of Health in Zanzibar prioritizing to reduce maternal mortality, a voucher system was added to improve access to emergency obstetric care and improve referral mechanisms. Each intervention woman received the phone number of her local midwife and a small voucher of 500 TSH (Tanzanian shilling) allowing to call her. The women were not provided with mobile phones but a referral link was created in the health system through provision of mobile phones to midwives in primary health care facilities, and to midwives/doctors/drivers at the hospital level.

Implementation

Twenty-four primary health care facilities were eligible for the study and the Ministry of Health agreed to let the facilities be included in the trial (cluster level consent). Meetings were held with staff in participating primary health care facilities to explain the nature and purpose of the trial. The enrolled primary health care facility staff also functioned as research assistants recording an inclusion questionnaire with demographic and covariate information, registering each contact with the women and completing an end-of-study questionnaire 6 weeks after delivery. Research assistants were assigned to the 3 hospitals providing emergency obstetric care and all contact with the enrolled women were similarly recorded. All pregnant women attending their first antenatal care visit in one of the participating primary health care facilities, if willing to participate, were included in the study. All enrolled women received an individual identity number and card. Pregnancy outcome was recorded at delivery for facility-based deliveries and for all included women in a follow-up interview 42 days after delivery. If the women did not return for the end-of-study interview, the research assistant contacted them either directly or by phone. Women attending the standard care received the protocols recommended in Zanzibar in the best format offered in these facilities. Double entry of data was performed in Epidata, transferred, and validated in SPSS.

Outcomes

We evaluated the effect of a mobile phone intervention on the primary outcomes antenatal care (four or more visits) and skilled delivery attendance. These are presented in other papers [17,18]. Here, we present the interventions association with secondary outcomes stillbirth, perinatal death, and death of a child within the first 42 days of life. The intervention association with antenatal care and skilled delivery attendance is presented in other manuscripts. A perinatal death was defined as a composite of either a stillbirth or early neonatal death. We used the WHO agreed definition of stillbirth as any delivery in the third trimester (≥1000 g birth weight or ≥28 weeks of gestation) in which no signs of life (breathing, crying, heartbeat, movement) were evident [9]. An early neonatal death was defined as all babies born alive in the third trimester who die on or prior to day 7 after birth. The perinatal mortality rate is perinatal death per 1000 total births (live births and stillbirths). We included death of a child within 42 days (where end-of-study questionnaire was conducted) as a proxy of neonatal mortality.

Sample Size

Power calculations were made on the primary outcomes skilled birth attendance and antenatal care attendance and did not take into account the clustering effect. Based on the number of antenatal care attendees from the previous year, the expected of size of the study population during a 3-month enrolment period was estimated to be 1100 women in the intervention group and 1375 women in the control group. Subsequently, a power calculation, based on data on antenatal care visits and skilled delivery attendance from the Tanzanian Demographic Health Survey (DHS 2005), was performed to document if the expected study population would be sufficient to document a true difference between the intervention and the control group [19]. To estimate whether this sample size was sufficient for detection of public health relevant effects of the intervention, we used data from the DHS 2005. For instance, with a 95% probability and a power of 90%, 894 women (447 in each group)

were necessary for showing an increase of a relevant size (10% increase in the number of women delivering with a skilled birth attendant). Hence, according to our power calculations, our proposed sample size was sufficient to document an effect of our intervention on antenatal care and skilled delivery attendance.

Randomization and Blinding

Primary health care facilities, stratified by district, were assigned by simple random allocation to either the mobile phone intervention or control group (Figure 1). Clusters and study participants were not masked due to the nature of the intervention requiring overt participation.

Statistical Analysis

Analyses were performed based on the "intention to treat" principle and all available data were included in the analysis. We adjusted for the clustering of our data using generalized estimating equations in all logistic regression analyses. We specified an exchangeable working correlation to allow for within cluster correlation and standard errors were based on the robust covariance matrix. We used the traditional logit link, which resulted in odds ratios (ORs) as an effect measure. However, for small values of the risk these can approximately be interpreted as relative risks. For our binary outcome measure, perinatal death yes/no, logistic multilevel analysis was used to analyze if there was a difference in perinatal deaths between the intervention and control groups. In this model, we included all socioeconomic and obstetric confounding variables and eliminated them using backward elimination (age, occupation, education, mobile phone status, residence, parity, previous caesarean section, multiple-gestation pregnancy). Variables with statistical significance were included in the final model. These were age and multiple-gestation pregnancy. Premature delivery, mode of delivery, four or more antenatal care visits, and delivery attendant were considered intermediate variables and not included in the model. We found no interaction between the intervention and explanatory variables. For other secondary outcomes we used a similar approach. Results were expressed as OR for perinatal deaths with 95% CI. Because perinatal mortality is a rare event this can be interpreted as a relative risk. For all models the criterion for significance was set at $P<.05$ and all analyses were performed using SPSS (version 20).

Results

Socioeconomic characteristics of the study population were similar in intervention and control clusters. On average, mobile phones were owned by 37% of women, and 58% resided in rural areas (Table 1). Obstetric risk factors were also similar in the intervention and control clusters. On average, 7% of the women had previously had a caesarean section, 20% were pregnant for the first time, and 25% were in their fifth or more pregnancy (Table 2). Twin pregnancies accounted for 1%. Of these 15 pairs of twins, 2 were stillborn, and 4 were early neonatal deaths. In the studied pregnancies, 13.9% (182/1311) of intervention women and 16.1% (199/1239) of control women had a complication (Table 2). There was a difference in mode of delivery with more control women (29/1202, 2.4%) delivering with fundal pressure versus intervention women (3/1284, 0.2%). The cesarean section frequency was approximately the same with 3.5% (45/1284) of intervention and 3.8% (46/1202) of control women (Table 2). More women in the intervention group (574/1311, 43.8%) received the recommended four or more antenatal care visits than in the control group (385/1239, 31.1%). More intervention women delivered with skilled delivery attendance (766/1284, 59.7% vs 560/1201, 46.6%), and as previously described this difference was only statistically significant for urban women [17].

Overall, 2482 children were live born, 54 were stillborn, and 36 died within the first 42 days of life (Table 3). Of these, 69 children were perinatal deaths. Nine children were reported dead, but had an unknown time of death and they were, therefore, not included as perinatal deaths. The stillbirth rate was 17 per 1000 births in the intervention group versus 26 per 1000 births in the control group (Table 3). The overall perinatal mortality rate was 27 per 1000 total births. The rate was lower in the intervention clusters, 19 per 1000 births, than in the control clusters, 36 per 1000 births (Table 3). The intervention was associated with a significant reduction in the outcome perinatal mortality with an OR 0.50 (95% CI 0.27-0.93) (Table 4). Other secondary outcomes showed an insignificant reduction in stillbirths (OR 0.65, 95% CI 0.34-1.24) and an insignificant reduction in death of a child within 42 days (OR 0.79, 95% CI 0.36-1.74) (Table 4).

Table 1. Socioeconomic characteristics of study population.

Variable	Intervention n (%)	Control n (%)
Health facilities		
Number	12	12
Participants		
Number of women	1311 (51.4)	1239 (48.6)
Age [a]		
<19	107 (8.5)	118 (9.9)
20-24	310 (24.6)	307 (25.6)
25-29	371 (29.5)	309 (25.8)
30-34	248 (19.7)	259 (21.6)
35+	222 (17.6)	204 (17.0)
Occupation [b]		
Housewife	691 (53.0)	691 (55.8)
Farmer	286 (21.9)	241 (19.5)
Sales women	133 (10.2)	117 (9.4)
Government	51 (3.9)	46 (3.7)
Student	22 (1.7)	19 (1.5)
Other	121 (9.3)	112 (9.0)
Education [c]		
No	204 (16.0)	220 (18.3)
Primary	464 (36.3)	440 (36.7)
Secondary and above	569 (44.5)	503 (41.9)
Other (religious education)	41 (3.2)	37 (3.1)
Mobile phone status [d]		
Owns	494 (37.8)	439 (35.5)
Does not own	813 (62.2)	796 (64.5)
Residence status		
Rural	743 (56.7)	730 (58.9)
Urban	568 (43.3)	509 (41.1)

[a]Missing cases 95
[b]Missing cases 20
[c]Missing cases 72
[d]Missing cases 8

Table 2. Obstetric characteristics of study population.

Variable	Intervention	Control
	n (%)	n (%)
Parity [a]		
Prime	264 (20.5)	233 (19.4)
1-2	428 (33.2)	356 (29.6)
3-4	292 (22.6)	297 (24.7)
5+	306 (23.7)	315 (26.2)
Previous caesarean section [b]		
Yes	72 (7)	69 (7)
No	926 (93)	872 (93)
Multiple-gestation pregnancy [c]		
Multiple gestation	9 (0.7)	6 (0.5)
Single gestation	1297 (99.3)	1231 (99.5)
Premature delivery [d]		
<37 gestation weeks	600 (46.3)	550 (45.9)
At term	697 (53.7)	649 (54.1)
Severe complication		
Yes	182 (13.9)	199 (16.1)
No	1129 (86.8)	1040 (83.9)
Mode of delivery [e]		
Spontaneous vaginal	1231 (95.9)	1122 (93.3)
Fundus pressure	3 (0.2)	29 (2.4)
Assisted vaginal delivery	5 (0.4)	5 (0.4)
Cesarean section	45 (3.5)	46 (3.8)
Antenatal care		
Four or more visit	574 (43.8)	385 (31.1)
Less than three visits	737 (56.2)	854 (68.9)
Delivery attendant [f,g]		
Skilled	766 (59.7)	560 (46.6)
Unskilled	518 (40.3)	641 (53.4)

[a]Missing cases 59

[b]Missing cases 611

[c]Missing cases 7

[d]Missing cases 54

[e]Missing cases 62

[f]Missing cases 65

[g]We used the WHO definition, whereby skilled delivery attendants are midwifes, doctors, or nurses who have been educated and trained in the skills needed to manage pregnancies, childbirth, and the immediate postnatal period, including the identification, management, and referral of complications in women and newborns. We also included home deliveries assisted by skilled birth attendants, although international consensus has not been reached on this issue.

Table 3. Number of births, deaths, and mortality rates.

Variable	Intervention	Control	Total
	n	n	n
Total births	1300	1236	2536
Live birth	1278	1204	2482
Still birth	22	32	54
Fresh	17	24	41
Macerated	5	8	13
Perinatal mortality	25	44	69
Neonatal mortality[a]	18	18	36
Still birth rate (per 1000 births)	17	26	21
Perinatal mortality rate (per 1000 births)	19	36	27
Neonatal mortality rate[b] (per 1000 live births)	14	15	15

[a]Missing cases 7

[b]Death<42 days

Table 4. . Intervention association with secondary outcomes.

Variable	Unadjusted OR[a,b] (95% CI)	Adjusted OR[a,c] (95% CI)
Stillbirth		
Intervention vs control	0.62 (0.31-1.22)	0.65 (0.34-1.24)
Perinatal mortality		
Intervention vs control	0.49 (0.27-0.90)	0.50 (0.27-0.93)
Neonatal mortality [d]		
Intervention vs control	0.85 (0.37-1.95)	0.79 (0.36-1.74)

[a]Odds ratio

[b]Adjusted for within-cluster effect

[c]Adjusted for within-cluster effect and significant variables associated with perinatal mortality

[d]Death<42 days

Discussion

Principal Findings

Our findings showed an association between the *Wired Mothers* mobile phone intervention and a reduction in perinatal mortality. Children born by women in the intervention group had a 50% reduction in perinatal mortality compared with children born by women in the control group. There was an insignificant reduction in death of children within the first 42 days, indicating that the beneficiary implications of the *Wired Mothers* intervention was centered on improving women's choices of care and access to care during pregnancy and in the time surrounding the delivery.

Strengths and Limitations

The principal strength of our study is that it met the requirement of systematic reviews calling for trials of mobile phone interventions in developing countries [2,3]. The intervention was developed at low cost in Tanzania using locally-based software development expertise to promote sustainability of the program. We used a robust study design with a relatively large sample of health facilities and participants. Others have used similar design for trailing complex interventions in low-resource settings [20]. Intervention and control clusters were similar in socioeconomic and obstetric background characteristics, and it is reassuring that after adjustment for identifiable potential risk factors, the crude and adjusted results are similar. Blinding was impossible due to the nature of the intervention increasing the chance of a selection or information bias. Because 9 children had an uncertain time of death there is a risk that we may have underreported perinatal deaths in either intervention or control clusters. It is a limitation that the number of women with miscarriages (22) or who withdrew from the study (82) exceeds those with the outcome perinatal death (69), particularly because there is a high likelihood of worse outcomes in those women lost to follow up. We therefore caution that other studies with perinatal mortality as a primary outcome should confirm our findings.

Comparison With Other Studies

Because this is the first trial assessing the association between a mobile phone intervention and perinatal mortality we cannot compare with other results. Free et al [2,3] found that while mHealth studies have been conducted many are of poor quality, few have a low risk of bias, and very few have found clinically significant benefits of the interventions. The 2012 Lancet report of technologies for global health identified only nine randomized controlled trials for mHealth in low-income countries [21].

Our results are in line with other studies of perinatal mortality in sub-Saharan Africa, although the perinatal mortality rate for our study (27 per 1000 births) was below the estimates for Tanzania [6,9,22]. Our study confirms results from others indicating that stillbirths may constitute up to 70%-80% of perinatal deaths and underlines the importance of access to good quality antenatal and delivery care [22]. Being one of the main causes of early neonatal death it is a concern that we found higher incidences of prematurity than otherwise reported from the region [23,24]. The gestational age at delivery is however based on provider estimates and should be interpreted with caution. It is apparent that with access to adequate medical care, especially in the intrapartum and early neonatal periods, many perinatal deaths might be prevented [25]. For instance, a study from Tanzania assessed a basic neonatal resuscitation training at hospital level and demonstrated a remarkable sustained 47% reduction in early neonatal mortality (within 24 hours) and a 24% reduction in fresh stillbirths [26]. The authors suggest that the most plausible explanation for this reduction in fresh stillbirths was that most nonbreathing infants are in primary apnea with a heart rate and will initiate spontaneous respiration in response to drying and stimulation only if implemented in a timely manner [26]. We found an association between the *Wired Mothers* intervention and a reduction in perinatal mortality. However, we cannot explain the exact factors that contributed to this. There was an increase of antenatal care and skilled delivery attendance in the intervention clusters but, for instance, a low rate of caesarean section in both groups [17,18]. Hence, an increased level of caesarean section in the intervention group did not contribute to the reduction.

A major part of the evidence for sexual and reproductive mHealth comes from the use of text reminders. Studies primarily indicate potential to improve knowledge and awareness [5,27,28]. Another area where mHealth is widely used is text-based appointment reminders. Two recent reviews have found moderate quality evidence that mobile phone text message reminders for health care appointments are more effective than no reminders and that such interventions may be appropriate for implementation [2,29]. Similarly, our study has produced evidence of increased skilled delivery attendance among urban women benefiting from a mobile phone intervention (OR 5.73, 95% CI 1.51-21.81) and an overall increase in women attending antenatal care four or more times as recommended by the WHO (OR 2.39, 95% CI 1.03-5.55) [17,18]. There is, to our knowledge, only one other trial from a developing country that has attempted to use a health outcome as a primary outcome. In Kenya, a high quality trial used text messages to improve adherence to antiretroviral therapy among HIV-positive patients. This intervention significantly reduced the patients' viral load but did not significantly reduce mortality [30]. Our results and the study from Kenya are in accordance with the limited existing literature on mHealth as a moderate tool for behavioral change, and indicate that positive behavioral effects can be reached in developing countries [2,3,31]. It is not possible to determine which component (eg, the SMS reminders or the vouchers) had the most significant impact on perinatal mortality. The *Wired Mothers* intervention sought to influence and improve all stages in receiving adequate care as proposed in the "Three Delays" model, and most notably the decision making to seek care and reaching an appropriate obstetric facility [32]. The SMS text messages aimed to empower women to make informed decision about attending regular antenatal care and delivery with a skilled attendant. The level of voucher contacts between the women and their primary health care providers were higher than expected. It served to improve emergency referrals, but it also served to increase linkages and trust on a more general basis.

Policy Implications

The policy implications for this study are that text-based mobile phone interventions such as *Wired Mothers* should be considered to reduce perinatal mortality and to achieve Millennium Development Goal 4. An increasing number of developing countries have a framework in place with national mHealth policies and there are a number of mHealth solutions being piloted in developing countries. Few are being scaled up and the real test for mHealth is scalability and integration into existing systems [33]. Despite the global progress in reducing deaths of children younger than 5 years, there is little reduction in the global perinatal mortality rates. The causality of maternal deaths, stillbirths, and early neonatal deaths are interlinked. Therefore, monitoring and policies should be integrated. We suggest to include reduction of perinatal mortality in the post 2015 agenda to further reduce child mortality in developing countries.

Conclusions

In conclusion, the *Wired Mothers* mobile phone intervention was associated with a reduction in perinatal mortality. Mobile phone applications may contribute to improved health of the newborn and should be considered by policy makers in resource-limited settings. Overall, there is limited evidence on the effects of mobile phone interventions and further high-quality research is required to draw more robust conclusions, particularly for developing countries within the field of reproductive and child health.

Acknowledgments

Funding for this study was provided by the Danish International Development Cooperation. The funding institution had no role in the study design, data collection, data analysis, data interpretation, or writing of the report. The corresponding author had full access to all the data in the study and had final responsibility for the decision to submit for publication. The research team would

like to thank Drs Mohammed Jiddawi and Boudewijn Peters for their enthusiastic and persistent concern for the wellbeing of women and children in Zanzibar. The study would not have been possible without them. We would also like to thank all the health workers and pregnant women for their time and input to the study.

Authors' Contributions

Authors' Contributions: All authors were involved in the development of the study design and implementation plan. SL was the principal investigator for the study and SL and BBN are the guarantors. SL, MH, IMB, AS, KS, MHM were responsible for implementation of the study and VR and BBN for overall supervision. SL and BBN did the quantitative analysis. SL wrote the initial draft of the paper. All authors critically reviewed the manuscript and approved the final version.

Conflicts of Interest

Conflicts of Interest: None declared.

Multimedia Appendix 1

The story of Jina - a wired mother.

[WMV File (Windows Media Video), 53MB - mhealth_v2i1e15_app1.wmv]

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Abbreviations

DHS: Demographic Health Survey
OR: odds ratio
SMS: short message service
TSH: Tanzanian shilling
WHO: World Health Organization

Edited by G Eysenbach; submitted 04.09.13; peer-reviewed by E Liechty, W Carlo; comments to author 15.11.13; revised version received 17.01.14; accepted 05.02.14; published 26.03.14.

Please cite as:
Lund S, Rasch V, Hemed M, Boas IM, Said A, Said K, Makundu MH, Nielsen BB
Mobile Phone Intervention Reduces Perinatal Mortality in Zanzibar: Secondary Outcomes of a Cluster Randomized Controlled Trial
JMIR Mhealth Uhealth 2014;2(1):e15
URL: http://mhealth.jmir.org/2014/1/e15/
doi:10.2196/mhealth.2941
PMID:25098184

Original Paper

Integrating Mobile Phones into Medical Abortion Provision: Intervention Development, Use, and Lessons Learned From a Randomized Controlled Trial

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Abstract

Background: Medical abortion is legal in South Africa but access and acceptability are hampered by the current protocol requiring a follow-up visit to assess abortion completion.

Objective: To assess the feasibility and efficacy of information and follow-up provided via mobile phone after medical abortion in a randomized controlled trial (RCT).

Methods: Mobile phones were used in three ways in the study: (1) coaching women through medical abortion using short message service (SMS; text messages); (2) a questionnaire to assess abortion completion via unstructured supplementary service data (USSD, a protocol used by GSM mobile telephones that allows the user to interact with a server via text-based menus) and the South African mobile instant message and social networking application Mxit; and (3) family planning information via SMS, mobisite and Mxit. A needs and context assessment was done to learn about women's experiences undergoing medical abortion and their use of mobile phones. After development, the mobile interventions were piloted. Recruitment was done by field workers at the clinics. In the RCT, women were interviewed at baseline and exit. Computer logs were also analyzed. All study participants received standard of care at the clinics.

Results: In the RCT, 234 women were randomized to the intervention group. Eight did not receive the intervention due to invalid numbers, mis-registration, system failure, or opt-out, leaving 226 participants receiving the full intervention. Of the 226, 190 returned and were interviewed at their clinic follow-up visit. The SMSs were highly acceptable, with 97.9% (186/190) saying that the SMSs helped them through the medical abortion. In terms of mobile phone privacy, 86.3% (202/234) said that it was not likely or possible that someone would see SMSs on their phone, although at exit, 20% (38/190) indicated that they had worried about phone privacy. Having been given training at baseline and subsequently asked via SMS to complete the self-assessment questionnaire, 90.3% (204/226) attempted it, and of those, 86.3% (176/204) reached an endpoint of the questionnaire. For the family planning information, a preference for SMS was indicated by study clients, although the publicly available Mxit/mobisite was heavily used (813,375 pages were viewed) over the study duration.

Conclusions: SMS provided a good medium for timed, "push" information that guided and supported women through medical abortion. Women were able to perform a self-assessment questionnaire via mobile phones if provided training and prompted by SMS. Phone privacy needs to be protected in similar settings. This study may contribute to the successful expansion of medical abortion provision aided by mobile phones.

Trial Registration: Pan African Clinical Trials Registry (PACTR): PACTR201302000427144; http://www.pactr.org/ATMWeb/appmanager/atm/atmregistry?dar=true&tNo=PACTR201302000427144 (Archived by WebCite at http://www.webcitation.org/6N0fnZfzm).

(JMIR Mhealth Uhealth 2014;2(1):e5) doi:10.2196/mhealth.3165

KEYWORDS

mHealth; telemedicine; SMS; medical abortion; USSD; mobisite

Introduction

Background Information

Medical abortion is legal in South Africa, and services have recently been expanding in the public sector. Medical abortion has support from both clients and providers [1-4]. Reasons given by clients included privacy, control of the process by the client, and avoidance of surgical procedures. Providers of surgical abortion in the public sector felt that medical abortion could help relieve the burden on current services [3] because medical abortion is more acceptable to nursing staff with ambivalent feelings about abortion.

The current protocol requires a follow-up appointment to assess abortion completion, and in practice the regimen of clinic visits required for medical abortion is higher than that for surgical abortion [2,5], and substantial staff time can be spent tracing clients who have defaulted on their follow-up appointments ([6]; personal communication by Deborah Constant with medical abortion provider, 2010). From a client perspective, each additional clinic visit can be a burden to those who have difficulty accessing abortion services due to time and/or economic constraints (eg, working women, women at school, or women living far from clinics). Previous research has shown that this visit can be replaced with a telephone assessment [7-9].

Mobile Phones in South Africa

South Africa has a very high level of mobile phone ownership. International Telecommunications Union (ITU) [10] statistics indicated that there were 134.8 pre- and post-paid mobile subscriptions for every 100 people in 2012. South Africa's All Media and Products Survey (AMPS) reported in 2011 that 80% of adults personally own, rent, or use a mobile phone, while only 15% have a landline telephone at home [11]. In terms of gender, there is only a 5% difference in favor of men in terms of mobile ownership [12].

There is little published research for South Africa on shared versus private use of mobile phones. One study of 411 low-income urban youth in Cape Town found that more than three-fourths (77%) of respondents reported that they owned a personal handset rather than using or sharing someone else's phone (18%) [13]. A small minority used someone else's phone but owned a personal SIM card (4%). The ITU's and AMPS' high rates of mobile penetration in South Africa tally with the findings of Kreutzer's study: the majority of South Africans have their own mobile phone.

Use of Mobile Phones in Health

mHealth literature can provide evidence for efficacy from similar interventions and suggestions for good practice. Particularly relevant is a review of research evaluations of mobile phone voice and text message interventions that provided care and disease management support, which looked at outcomes of care and processes of care [14]. The authors reported, "[s]ignificant improvements were noted in compliance with medicine taking, asthma symptoms, HbA1C, stress levels, smoking quit rates, and self-efficacy. Process improvements were reported in lower failed appointments, quicker diagnosis and treatment, and improved teaching and training." Importantly, they stated that enhancing current standards of care with reminders, disease monitoring and management, and information provision through mobile phones can help improve health outcomes and care processes, and that this has implications for both patients and providers.

The recent review of mHealth behavior change communications interventions in developing countries [15] emphasized the importance of formative research to design interventions that are appropriate for the audience from a cultural perspective and in terms of health needs and telephone use. The review also recommended pretesting of messages to test these elements.

While the number of studies on the use of mobile phones in health has grown rapidly in the past few years, there are significant gaps in the mHealth body of evidence [16], and investigation into the use of telephones in medical abortion was limited to the use of voice calls in verbal consultative follow-up [7,8]. To our knowledge, no studies into the use of text-based mobile phone interventions for medical abortion follow-up were known at the time of designing this study.

Purpose

To explore the use of mobile phones to simplify medical abortion provision, a study was done in South Africa to assess the feasibility and efficacy of a package of information, self-assessment of abortion completion, and support provided via mobile phones to reduce the need for a follow-up visit by clients, enhance the experience of medical abortion for clients, reduce demands on medical abortion providers; and strengthen post-abortion knowledge and uptake of family planning.

This paper describes the process of developing the various mobile interventions used in the randomized controlled trial (RCT), reports on findings of the study related to mobile phone use in this context, and reflects on lessons learned. It is anticipated that this will contribute to the growing body of knowledge around the use of mobile phones in health, and in particular the use of mobile phones to make a medical procedure easier.

Methods

Study Phases

The study involved three phases: a needs and context assessment (NCA), a pilot, and an RCT (PACTR201302000427144). Development of the mobile interventions was done after the NCA.

Needs and Context Assessment

The NCA was designed to learn about the experiences of South African women undergoing medical abortion to inform the content of text messaging (short message service, SMS). We also wanted to understand women's use of their mobile phones to design the mobile interventions suitably. Twenty consenting clients were asked at their medical abortion follow-up appointment about their experience of their medical abortion, current use of their mobile phones, the privacy of their mobile phone, their language preference for texting, and their feedback on draft text messages was solicited. Feedback on the draft text messages was sought by sending participants one text message, and showing them other text messages in mobile phone mock-ups.

Six medical abortion providers were also interviewed to learn more about issues they faced in medical abortion provision and their impressions of challenges faced by clients, so that these could be addressed in the mobile interventions. The NCA was done in May and June 2011 at a nongovernmental clinic in Cape Town's city center and a public sector clinic in Khayelitsha, a disadvantaged township area 20 km outside the city.

Development of the Mobile Interventions

Rationale

The development of the mobile interventions used the information gleaned from the NCA. Mobile was used in three ways in the study: (1) text messages coaching women through the medical abortion process; (2) self-assessment of abortion completion; and (3) provision of family planning information and encouragement via a mobisite (website optimized for mobile phones), Mxit (a popular South African mobile instant message chat and social network with over 7.5 million active users) [17], and text messaging.

These mobile-based interventions were all text-based and automated so that no additional burden was placed on health care providers, and the interventions could be easily scaled if effective or useful.

Text Messaging

Text messages were chosen for coaching because they can be timed (ie, sent at a particular time and date), and are a private means of communication if recipients have their own phones (which is largely the case in South Africa).

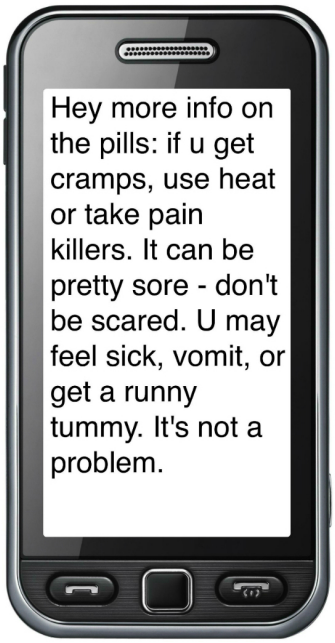
The text messages were sent via Cell-Life's online system Communicate, which allows for text messaging campaigns to be preloaded on the system and triggered by registering a new study participant on the system. (Hence, text messages did not need to be sent manually for each participant; she just needed to be subscribed to the relevant Communicate SMS campaign, and her text messages were automatically sent by the system.) Text messages were set to be sent at particular times (at 9 am and 6 pm), and participants had been told what time to expect the text messages in a welcome-SMS.

SMS text messaging content was developed based on a literature review that covered how women experience the medical abortion process (eg, timing of bleeding and pain, and potential danger signs like excessive bleeding and fever), and issues raised by women and providers in the NCA (Figure 1). The text messages were provided in English only in the pilot, and an additional two South African languages in the RCT (Xhosa and Afrikaans).

In the pilot and RCT, each participant received 23 text messages over approximately 3 weeks. Nineteen of these were double SMSs; that is, two concatenated into one to allow for a longer text message.

Participants could opt out of receiving text messages at any point by sending a free please-call-me text message to a number that had been provided in the first text message they received after consenting to the study. This is standard procedure in South Africa—when people subscribe to a text messaging service, they should be provided with a way to stop the text messages. This was particularly important in our study, in case women had privacy concerns arising from the SMSs.

Figure 1. Example of text message.



Self-Assessment

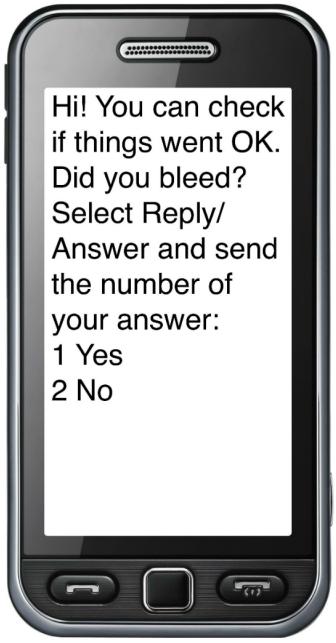
The self-assessment of abortion completion (SA) was a questionnaire designed to be self-administered by participants via mobile 10 days after they had taken the final medical abortion pills, following a text message to complete the questionnaire (Figure 2). Its content was developed based on a literature review and interviews with providers and key informants to understand how abortion completion could be assessed based on questions women would be able to understand and answer. The questionnaire routed users through up to five questions, to assess if the abortion was complete or incomplete, or if pregnancy was ongoing. If the SA concluded that the abortion was incomplete or pregnancy ongoing, the final screen urged users to go back to the clinic for further care.

We decided to provide the SA via mobile phone because a paper-based SA could raise privacy concerns or be lost if clients received it at the clinic on day 1 of the medical abortion process. We also thought that asking participants to do the SA via SMS would be a discreet way of prompting them to do it, and more

effective than a pamphlet, which could be lost or easily ignored. There were no privacy concerns with the SA because although its content concerned abortion, it was up to the user to decide when they completed it.

We implemented the SA to be available either via Mxit or via unstructured supplementary service data (USSD) for clients not able or willing to use MXit. USSD is a protocol used by GSM mobile telephones that allows the user to interact with a server via text-based menus. The offering of the SA via USSD meant that an airtime payment had to be made, as USSD costs most users 20 South African cents per 20 seconds. An R10 (approximately $1.10) airtime payment was made on the day they were sent the text message asking them to complete the SA. The SA was implemented in English, Xhosa, and Afrikaans.

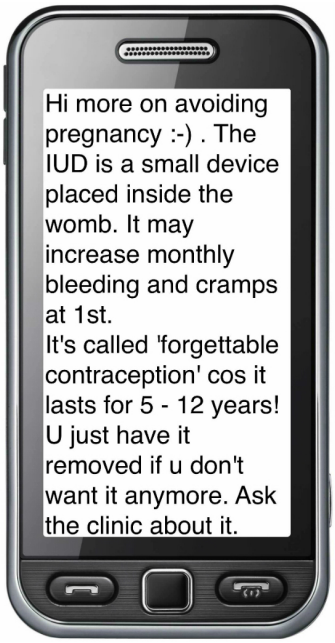
Figure 2. First screen of the self-assessment.



Family Planning Information

The family planning content was based on the World Health Organization's *Family Planning: A Global Handbook for Providers* [18] and study principal investigators' knowledge of appealing features of various family planning methods (Figure 3). The content was loaded on a mobisite [19], which was also viewable through Mxit. Participants were sent 2 text messages asking them to view the information. The mobisite was created using the free and open source content management system Joomla along with the personal device assistant extension to make the site render well in mobile browsers and Mxit. After the pilot, SMSs providing participants with tips for future choices of family planning methods were added.

Figure 3. Example of family planning text message.



Pilot Study

The pilot of the study was run as a small version of the RCT, and was done to test the mobile interventions and study processes. It did not involve a control arm, and was carried out at the same sites as the NCA from June to September 2011. The pilot was done in two phases due to very low use of the SA in the first pilot and technical problems. Phases 1 and 2 involved 20 and 10 women, respectively.

Randomized Controlled Trial

This was a two-arm trial in which participants were randomized into a control arm (N=235) and an intervention arm (N=234). Both arms received the standard medical abortion care from the clinics. It was conducted at two nongovernment and two government-run clinics. These were located in Cape Town's city center; a busy suburban transport terminus; and in Khayelitsha. To be eligible, participants were already signed up to undergo a medical abortion at the clinic, 18 years or older, willing to come to their clinic appointments and be accessible by phone for 7 weeks after consenting, and own a mobile phone on which they could get medical abortion -related information and messaging. A baseline questionnaire was administered after consent (before randomization), and an exit questionnaire was administered at the participant's follow-up appointment. A telephone interview 1 month after the text messages ended was attempted to probe use of the family planning content provided via mobile phone.

Results

Needs and Context Assessment

The NCA provided valuable information on mobile phone use among the study target population, as shown in Table 1.

In terms of mobile phone privacy, 65% (13/20) of clients indicated that no one else used their phone. These other people were most often family members or the client's boyfriend, while

2 clients said that friends had access to their phone. For text messaging privacy, 80% (16/20) said that no other people ever picked up their phone and read their SMSs. Eighty percent (16/20) indicated that their phone was private enough for them to feel comfortable receiving text messages related to abortion.

In terms of language, 80% of clients (16/20) indicated that they would prefer to receive the text messages in English, while 2 indicated a preference for text messages in Xhosa and 1 preferred Afrikaans. One client would not mind receiving the text messages in Xhosa or English.

Feedback on the text messages indicated that 85% (17/20) thought that they were useful, particularly as a reminder to take their pills; the text messages told them what to expect and provided support. Fifteen percent (3/20) thought that the text messages were not useful because the information was incorrect; the clients didn't want a reminder because the event was sad; and the client already had the information from the clinic.

Table 1. Activities on mobile phone (N=18).[a]

Activity	n (%)
Make/receive calls	18 (100)
Send/receive please-call-me's	15 (83)
Text messaging	18 (100)
Mxit	3 (17)
Facebook	9 (50)
Email	4 (22)
Browse the Internet	7 (39)

[a]Two missing responses

Pilot

The pilot showed that the processes and systems used for text messaging initiation and ongoing sending worked well, apart from a Communicate bug experienced in the first pilot that was fixed. The feedback on the text messages showed that most clients were happy with the quantity and content of the messages. All said unequivocally that text messaging helped them through the procedure and that they would recommend them to a friend having a medical abortion. A minority found the messages too long or had difficulties with privacy or problems understanding them.

One participant sent in a please-call-me text message to the designated opt-out number to stop the text messages, on the day that she had received her last text message.

The phase 1 pilot highlighted problems with SA use. Log files provided by the USSD service provider showed that only 65% (13/20) of participants tried the SA. We traced the problem to a bug in Communicate, which meant that the text messages giving participants their airtime on the day that they were to do the SA were not always sent successfully. This was remedied, and in the second pilot, 80% (8/10) of participants tried the SA.

Over both pilots, 70% (21/30) tried the SA and only 48% (10/21) of those who tried were able to complete it successfully. Many users tried the SA multiple times, sometimes with clear patterns of learning (for instance, initially managing to advance one or two screens, and after repeated attempts managing to finish the SA). Based on the pilot results, to maximize SA use, we instituted a short training session on the SA at the time of consent where the fieldworkers went through a simulated SA with the participant on their phones. We also added a manual reminder-text message: if a participant had not completed the SA after 2 text message requests, they were sent a third text message indicating that our logs showed that they had not yet attempted the SA.

Twenty-four clients completed the follow-up telephone interview. Eighty-three percent (20/24) said they had tried to access the family planning information via Mxit or mobisite and of these, 19 (95%) succeeded in reading the information. However, to ensure that everyone in the RCT intervention group received family planning information, we added 5 family planning-related text messages to the campaign of coaching text messages.

Randomized Controlled Trial

Description

This paper does not report on the outcomes of the RCT, which is to be reported elsewhere (paper under submission). Findings relevant to the acceptability and use of mobile phones in the RCT are reported here. In terms of participant numbers, of the 234 randomized to the intervention group at baseline, 8 did not receive the intervention due to invalid numbers, misregistration, system failure, or opt-out, leaving 226 participants receiving the full intervention. Of the 226, 190 (84%) returned and were interviewed at their clinic follow-up visit.

Mobile Phone Privacy

At baseline, 86.3% (202/234) said that it was not likely or not possible that someone would see text messages on their phone; 79.5% (186/234) said that others use their phone never or almost never.

However, the exit interviews showed that 20% (38/190) had worried about privacy and receipt of text messages about abortion. Most of those citing privacy concerns were worried about people, particularly family, seeing the text messages:

> *Because I did not tell anyone at home so I didn't want them to find out before I tell them.*
>
> *If somebody would have seen the SMSs then they would know what I was doing.*

No adverse events relating to mobile phone privacy were reported, however.

Text Messaging Language

Text messages were available in English, Afrikaans, and Xhosa in the RCT. No participants chose Afrikaans, and 6.8% (16/234) chose Xhosa.

Technical Issues With Text Messaging

A total of 5471 text messages were sent with a failure rate of 5% (that is text messages that could not be delivered due to a network problem or a problem with the user's phone). Participant comments on the text messages showed that delayed receipt of the text messages was an issue for some, as was repeated deliveries of text messages (the same text message being delivered more than once). Delayed receipt is an inevitable problem because mobile networks can be congested, and users' phones are sometimes switched off or out of network range. We do not know the reason for repeated deliveries, but assume that it must be an issue on the network.

Qualitative feedback from participants on whether the text messages had helped them through their abortion showed that overwhelmingly, women experienced the text messages as a guide:

> *It's almost like they are so informative, they came exactly when you need them and some of the things that SMS told me I was not told at the clinic—so it is like you have a nurse by you all the time.*
>
> *The SMSs were telling me what to expect like the one that told me that I might vomit and that did happen, but I was not worried because the SMSs had warned me.*
>
> *I felt that there was someone who knew and understood. They told me what was going to happen.*
>
> *I didn't have support as I was the only one who knew so the SMSs were there to support and to guide me through the process.*

Many also said that they felt supported and comforted, and less alone:

> *Felt someone was holding my hand through the whole process.*
>
> *Sometimes the SMSs comforted meI felt the SMSs understood what I was going throughFelt like a friend.*
>
> *It is a very good thing to have if it was not because of the SMSs, I would have freaked out and come to the clinic—it was like somebody was there looking out for me.*

For those who said that some of the text messages made them unhappy, one said that the text messages brought back bad memories, and another said that she was scared to know what was going to happen. Two said that the text messages that talked about blood made them unhappy:

> *I was expecting that somebody will tell me that I am not going to bleed too much but the SMS I received about bleeding disappointed me.*
>
> *The SMSs about bleeding and clots is the only one that made me unhappy. I was so scared to see blood.*

Comments on the text messages show that some participants shared the text messages. Because this was not an issue that we probed, we do not have statistics on the extent of sharing:

> *Really opened my eyes. Took me through process. Boyfriend also read SMSs. It made me feel at ease.*
>
> *They helped me because if I forgot something I will go to my SMSs to remind me. My mother even said: "These people really care about abortion, they even send you SMSs".*

For those who indicated that they did not feel comfortable with the timing of the text messages, comments indicate that daytime might not be the best time to send the text messages (due to the greater likelihood of others seeing the text messages during the day).

Only 1 participant opted out of getting the text messages, on the same day as she had consented to participate in the study. She was called to find out her reasons for opting out, and said that it was for personal reasons.

Participant Feedback on the Text Messages

Table 2 summarizes participant feedback on the text messages, which was sought in the exit interview.

Table 2. Participant feedback on text messages (N=190).

Question	Answer	n (%)
The text messages were too many	Agree	20 (10.5)
Some text messages were too long	Agree	14 (7.4)
I felt comfortable with the time the text messages were sent to me	Agree	179 (94.2)
The information in the text messages is clear and easy to understand	Agree	99 (52.1)
Some of the text messages made me unhappy	Agree	5 (2.6)
Some of the text messages confused me	Agree	9 (4.7)
I would recommend text messaging to a friend who was going through the same thing	Agree	188 (98.9)
I was always worried about privacy (that someone might see the text messages)	Agree	38 (20)
The text messages helped me through my abortion	Agree	186 (97.9)

Self-Assessment

In the exit interview, participants were asked about their use of the SA (Table 3) and most indicated that they had attempted to complete it. Reasons for not completing the SA included not understanding the instructions in the text message, someone else having the phone, and not feeling like it or forgetting. Of those who said they had attempted the SA, most said that the SA was easy or very easy to do. For those who found it hard, difficulties centered on network or system failures. A specific question was asked about failures experienced when attempting the SA, and almost one-fourth of participants reported failures. Participants were asked whether they reached the end of the questions (where it said that the questions were finished), and the vast majority thought that they had.

Computer-generated logs of actual SA use were also analyzed and are shown in Table 4.

Table 5 shows the number of text messages that had to be sent to try to get participants to attempt the SA.

Table 3. Self-reported data on self-assessment use.

Outcome	N	n (%)
Attempted the SA	190	175 (92.1)
Reached an endpoint	175	162 (92.6)
SA easy to do	173	161 (93.1)
Failures experienced	177	42 (23.7)

Table 4. Computer log data on self-assessment use.

Outcome	N	n (%)
Attempted the SA	226	204 (90.3)
Reached an endpoint	204	176 (86.3; 77.9% of 226)
Reached different endpoints on successive attempts	176	12 (6.9)
Number of attempts needed to reach endpoint	176	1.7 (1.6); 1 (1-2)[a]

[a]Data presented as mean (SD); median (IQR).

Table 5. Prompting needed for SA use.

Outcome	N	n (%)
Attempted SA before first text message	226	4 (1.8)
Attempted SA after first text message	226	150 (66.4)
Attempted SA only after second text message	226	29 (12.8)
Were reminded to do SA: third text message	226	38 (16.8)[a]
Responded to third text message and attempted SA	38	21 (55.3)

[a]Five participants were not sent reminders but should have been. Hence, 43/226 (19%) needed a third reminder.

Family Planning Information

Of the 234 clients in the intervention arm, 75.6% (177/234) completed telephone interviews 1 month after the text messages ended, although these yielded little useful information on women's accessing of family planning information via mobile phones. Fifty-two percent (92/177) of those contacted indicated that they had been able to access the family planning information via the mobisite or Mxit (67 did not; 18 had missing data). However, we doubt this self-reported figure because at baseline only 12.8% (30/234) indicated that they used Mxit (we did not ask about mobisite use). Participant comments reinforced what we knew about many of the women not having phones that could access the Internet or Mxit, and reference was made to preferring to access the information via text messaging. Use statistics for the period of the RCT (October 2011 to May 2012) indicate that 813,375 pages of the Mxit/mobisite were viewed, but we cannot match these figures with study participants because site statistics are anonymous.

Discussion

Principal Results

This paper focused specifically on findings related to the development and use of the mobile phone-based interventions provided in the study. Our main findings were that the extensive formative research process led to the development of text messages that were highly acceptable and a valued form of coaching through medical abortion; a mobile phone-based questionnaire to check abortion progress was viable in terms of use, given a short training session; and phone privacy in the study context was not perceived to be a major issue, although in practice more women worried about privacy than had indicated this at baseline.

While a three-stage study design added to study time and cost, it was essential to assess how people in our target population used their phones so that we could tailor what mobile technologies (eg, Mxit, USSD, and SMS) were appropriate for delivering the interventions. The pilot phase allowed us to do usability testing, particularly for the SA, and showed us the importance of a short training on how to do it.

It is of particular interest that the text messages were seen as supportive, like someone was there for the recipient. They were not written to be overtly supportive; the text messages did not deal with the decision to terminate, or say things that specifically indicated support. Rather, they focused on the practical aspects of medical abortion, and sought to reassure about what physical experiences are normal. Feeling supported could have arisen from the content and scheduling of the text messages matching the women's experiences and so they felt understood. The feature of text messages being a push technology was important for scheduling: Push means that the recipient does not have to do anything to receive the messages; they arrive on the phone without the recipient having to take an action other than consenting to receive the text messages. The push nature of text messages meant that we could time receipt of information according to the expected process of a medical abortion and deliver the messages in a medium that made it more likely that they would be read on or close to receipt.

Gurman [15] has indicated that timing of text messages is an area needing research; this study has indicated that morning and early evening were acceptable to the large majority (text messages were sent around 9 am and 6 pm). Given that a few participants raised timing-related privacy concerns (eg, receipt of text messages at work), it would be ideal to allow recipients to choose the time of receipt of text messages.

In terms of language choice for the text messages, a strong preference for English was indicated in the NCA. This was borne out in the RCT, even though 2 of the 4 study sites were in a predominantly Xhosa-speaking area. This preference among non-first language speakers for English texts is true of many of Cell-Life's other (unpublished) instances of text messaging use in health, although it is not always the case.

While most participants did not identify phone privacy as an issue, the RCT showed that having received the text messages, more participants had privacy concerns than had indicated this at signup. This is not surprising because receipt of text messages during abortion would have been unfamiliar to the participants. We suggest that similar interventions should consider two ways of mitigating privacy concerns. The first is showing potential recipients examples of text messages they will receive that may lead to privacy problems, to help them decide if they are comfortable receiving such text messages. Second, a way of allowing recipients to stop the text messages should be provided and recipients should be periodically reminded of this during the time that they receive the text messages.

There was high, successful use of the SA questionnaire, and most women completed their self-assessment in good time for them to take action on the result, if they needed to. This shows promise for other medical procedures where self-assessment via mobile by patients could relieve burden on them or health care providers. Women may have been motivated to complete the SA because they were aware that they were part of a study, although the fact that they followed standard-of-care (which includes a follow-up appointment to assess abortion completion) may have demotivated some of them. The airtime sent to women before they were asked to complete the SA should not have acted as an incentive to do it, because participants received the airtime whether they attempted the SA or not.

The fact that many more women thought they had finished the SA than actually had indicates that such a system should include a mechanism to feed back to the user whether they have completed the assessment.

Comparison With Prior Work

This study's findings on using text messages to drive SA use is in keeping with other studies that have shown that SMSs can be an effective spur to action in a health care context, such as getting women to perform breast self-examination [20] or take an HIV test [21].

Potential Reuse of the Mobile Interventions

The text messages used in this study can be used by medical abortion providers in other locations, although a localization process would be recommended (testing of text messages, and adaptation of content for local conditions). The SA questionnaire

could be used in different settings, although the questionnaire was not satisfactory in detecting ongoing pregnancy (these results will be reported elsewhere). The family planning information is available at [19]. The study protocol, instruments, SMS text messages, presentations, and other media are available at [22].

Conclusions

To explore the use of mobile phones to simplify medical abortion provision, a study was done in South Africa to assess the feasibility and efficacy of text messages to coach women through medical abortion, a questionnaire assessing medical abortion completion via mobile phone, and family planning information provided via mobile. This paper described the process of developing these mobile interventions, and showed the importance of assessing the context and piloting. It reported on findings of the study related to mobile phone use in this context. Text messages provided a good medium for timed, push information that guided and supported women through medical abortion. Women were able to complete a self-assessment questionnaire via mobile phone if given a short training session. Phone privacy was not as much of an issue as we thought it might be, although it concerned more women after they had received the intervention, than indicated that it would be an issue at baseline. It is hoped that this study may contribute to the successful expansion of medical abortion provision aided by a technology that is increasingly ubiquitous—mobile phones.

Acknowledgments

Funding for this study was received from the World Health Organization with supplementary funding from the Research Development Grant and Harry Crossley Senior Clinical Fellowship, University of Cape Town. We wish to thank Sarah Crede, Tembeka Fikizolo, Beverley Arendse, Ntombomzi Mcanjana, Joanna Romell, and Marijke Ablas.

Conflicts of Interest

Conflicts of Interest: None declared.

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Abbreviations

AMPS: All Media and Products Survey
ITU: International Telecommunications Union
NCA: needs and context assessment
RCT: randomized controlled trial
SA: self-assessment of abortion completion
SMS: short message service
USSD: unstructured supplementary service data

Edited by G Eysenbach; submitted 04.12.13; peer-reviewed by R Engel, J Blum; comments to author 31.12.13; revised version received 15.01.14; accepted 19.01.14; published 14.02.14.

Please cite as:
de Tolly KM, Constant D
Integrating Mobile Phones into Medical Abortion Provision: Intervention Development, Use, and Lessons Learned From a Randomized Controlled Trial
JMIR Mhealth Uhealth 2014;2(1):e5
URL: http://mhealth.jmir.org/2014/1/e5/
doi:10.2196/mhealth.3165
PMID:25098569

Viewpoint

Going Mobile: How Mobile Personal Health Records Can Improve Health Care During Emergencies

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Abstract

Personal health records (PHRs), in contrast to electronic health records (EHRs) or electronic medical records (EMRs), are health records in which data are accessible to patients and not just providers. In recent years, many systems have enabled PHRs to be available in a mobile format. Mobile PHRs (mPHRs) allow patients to access health information via the Internet or telecommunication devices, such as mobile phones, personal digital assistants, and tablet computers. mPHRs have the potential to help patients and providers identify medical conditions and prescriptions from numerous locations, which may minimize medical errors and identify improvements to health behaviors during emergencies, when patients present to a new provider, or EHRs are not accessible. Despite their benefits, numerous challenges inhibit the adoption and further development of mPHRs, including integration into overall health technology infrastructure and legal and security concerns. This paper identifies the benefits of mPHRs during emergencies and the remaining challenges impeding full adoption and use, and provides recommendations to federal agencies to enhance support and use of mPHRs.

(JMIR Mhealth Uhealth 2014;2(1):e8) doi:10.2196/mhealth.3017

KEYWORDS

electronic health record; personal health record; public health emergency; mobile health

Introduction

The use of electronic records has been widely recognized as an efficient way to improve the provision of health care and enable health care providers to access and share patient information. Health care providers may document a patient's medical history in a number of ways. Electronic medical records (EMRs), for instance, are digital copies of patient charts commonly used in physicians' offices to record patient data [1]. Electronic health records (EHRs) are more comprehensive in scope, including information from all the clinicians involved in a patient's treatment, such as immunizations, family medical histories, and previous providers [1]. Primary care physicians may even share EHRs with other health care professionals and institutions, including specialists, laboratories, and nursing homes [1]. The information documented in EHRs is also found in personal health records (PHRs). However, unlike EHRs, which are only accessibly to clinicians, patients can use PHRs to manage and update their own medical information [1]. PHRs can therefore empower individuals to improve their health status and improve clinical outcomes, as they are able to better monitor health conditions and more effectively communicate with health care providers. Patients typically use PHRs in one of three formats: a provider-maintained digital summary of clinical information accessible to patients; a patient-owned software program that allows users to view and update their own health information; or portable, interoperable digital files with which patients can manage and transfer information [2]. PHRs in mobile format (mPHRs) fall into the third category and allow patients to access health information via the Internet or telecommunication devices, such as cellular phones (specifically, smartphones, or cellular phones that includes an operating system capable of running general-purpose applications and performing many of the functions of a computer), personal digital assistants, and tablet computers. The increasing use of mPHRs among patients reflects a broader trend in health care digitization: the growing

popularity and utility of mobile medical applications [3]. Such applications operate on the aforementioned mobile devices, which have rapidly evolved into ubiquitous tools for sharing information and communicating with others. Mobile devices also possess the potential to withstand certain types of infrastructural failures during disasters. As such, they may be uniquely qualified to play important roles in responding to public health emergencies (PHEs).

To date, studies indicate that PHRs and their mobile counterparts have served patients well in their interactions with health care professionals, but these studies focus primarily on the applications of PHRs during non-emergencies [4-8]. Similarly, consumers and health care practitioners thus far have used PHRs largely in nonemergency settings. However, the incidence of PHEs—specifically, natural disasters—is increasing worldwide [9]. Correspondingly, the number of individuals who are injured or displaced by such events is also likely to rise, thereby generating major logistical challenges for health care delivery in post-disaster settings. In such situations, reliable sources of clinical information are invaluable to patients who cannot communicate or receive treatment from caregivers who are unfamiliar with their medical histories. Given the challenges associated with communicating during disasters, we suggest that integrating PHRs and mPHRs into emergency response plans could help ensure quality health care delivery if or when existing methods of information sharing (eg, paper- and/or computer-based records) fail. However, several critical challenges must first be addressed.

To support the analysis in this article, we conducted a literature review using the research databases PubMed and SCOPUS. We then identified scientific studies and peer-reviewed literature that address PHRs and their use in emergency and nonemergency settings, as well as legal and regulatory concerns relating to their use. We also reviewed literature from federal agencies, particularly the Department of Health and Human Services (HHS), regarding health information technology (HIT) and EHRs, and the potential integration of PHRs into these processes.

In this paper, we first provide an overview of state of the art research regarding PHRs and their various applications. Based on state of the art research and secondary sources (eg, reports from federal and private entities), we next consider the entities involved in mobile health innovation in the United States. Third, we explore the applications of mPHRs, along with their associated strengths and shortcomings, as well as the legal and regulatory frameworks for HIT in the United States. Finally, we conclude with policy recommendations to clarify the roles of PHR technologies in emergency response and improve post-emergency health care delivery.

PHR Applications

Overview

In recent years, scientific studies have documented the role of PHRs in improving self-care practices among patients and transforming health care delivery [10]. Studies have looked at the various formats of PHRs, including Web-based and mobile-based applications, as well as the use of PHRs among specific populations, such as patients with chronic health issues and children. Moreover, the growth of self-management tools for remote monitoring, particularly those available in Web and mobile application formats, contributes to the increased use of PHRs and mPHRs among consumers. Similarly, providers' perceptions that PHRs are useful self-monitoring and information-sharing tools can permit PHRs to play a key role in ensuring continuity of care [11-14].

Several studies indicate that PHR tools can improve clinical outcomes. For example, PHR use has been associated with improved self-monitoring and positive clinical outcomes for hypertension [15], adherence to immunizations and other practices supporting child wellness [16], and management of medications such as medication review and hypertension monitoring tools [17]. However, studies also indicate that the benefits of PHRs in improving clinical outcomes can be correlated with age, because younger patients are more likely to use PHRs frequently. Ethnic and racial minorities have also been reported to adopt PHRs less frequently than whites do, and patients from lower income groups are less likely to use PHRs as compared to those with higher incomes [18]. Previous studies have also addressed barriers and concerns to the use of PHRs and, more generally, personal health information. Such concerns include access to safeguarding patient privacy [19] and emergency access to patient-controlled online health data [20].

While the various uses of PHRs and factors influencing their development have been well documented in the scientific literature, there is limited literature assessing the unique role and challenges of mPHRs or the role of PHRs and mPHRs during emergencies. Furthermore, there are no documented uses of PHR technologies during disasters. Still, the positive clinical outcomes achieved through PHR use may be replicated in emergencies with the appropriate infrastructures and policies in place. Below, we explore the current state of PHR development, use, and regulation in the United States, highlighting areas requiring further attention.

Key Players

Overview

Several entities are involved in the collection, storage, and dissemination of personal health information. Of these, consumers, technology developers, health insurance companies, and federal agencies play particularly important roles. As HIT comes to play a greater role in emergency response and recovery, it is imperative that policies address the needs of stakeholders from each of these groups, particularly in matters of patient care. This is especially important, given the need for more information on the ways emerging technologies might address the unmet needs of special populations (eg, children, the homeless, disabled individuals, non-English speakers, etc). Below, we identify the various impacts that these groups have had on PHR and mPHR development and use, and remaining concerns to be addressed.

Consumers

A 2012 study from the Pew Research Center concluded that 85% of US adults own a cell phone, 53% of whom own smartphones [21]. Approximately one-third of cell phone owners (31%) have used their phones to look for health information, which is a 17% increase from a national-level comparable survey conducted in 2010 [21].The study also indicated that 52% of smartphone owners gather health information on their phones, compared to only 6% of non-smartphone owners [21]. Cell phone owners who identify themselves as Latino, African American, between the ages of 18 and 49 years, or hold a college degree are also more likely to gather health information using their cell phone [21]. Furthermore, approximately one-fifth of smartphone owners (19%) have at least one health application on their phone. Marketing forecasts indicate that by 2017, half of the world's 3.4 billion smartphone or tablet users will use mobile health apps [22]. As the use of mobile health applications continue to grow, particularly among specific demographic groups, many entities should consider how mPHRs could be developed to support emergency and post-disaster care, in addition to routine health management.

Consumers, health insurance companies, and mobile application developers have all generated support for PHRs, albeit inconsistently. A 2011 survey of 1200 respondents conducted by IDC Health Insights revealed that 7% (84) of consumers had created online PHRs, but fewer than half continued using them [23]. However, other providers report significantly higher rates of customer retention and PHR usage. In 2011, for example, Kaiser Permanente's PHR service, My Health Manager, saw 74 million logins, 10 million prescription refills, and 29.7 million lab results viewed, indicating frequent patient-provider interactions [24].

Similarly, certain populations—notably, disabled individuals—have expressed interest in portable PHR solutions such as smart cards or implantable microchips for medical emergencies [5]. One survey of 302 individuals (categorized as "well," "unwell," and "disabled") reported that several nondisabled respondents indicated they had thought about how their information would be accessed in an emergency. However, only disabled respondents described incidents where access to personal medical data rose to the level of a life-or-death issue, which is consistent with disabled individuals' overall higher level of emergency department (ED) utilization [5]. Interestingly, health-related computer use (ie, searching for medical information, communicating with providers, and filling prescriptions) among disabled populations is 19% higher than that among nondisabled individuals, signifying a potential niche for the expansion of PHR services [5]. Homeless individuals represent another population that could benefit greatly from increased PHR use. Recent research indicates that homeless patients make considerable use of ED services and are significantly more likely to solicit information on chronic health problems than patients with stable housing [25]. A study of more than 5700 ED visitors revealed that 70.7% (176/249) of homeless patients own cell phones (compared to 85.9% of patients with stable housing) [25]. Furthermore, there was no significant difference in the frequency of new media use between these two groups [25].

In light of the failure of now-defunct PHR services such as Google Health and Revolution Health, it follows that successful consumer technologies are those that "inform or entertain users, or enable social communication" [23]. Other groups—notably, Microsoft, Kaiser Permanente, and WebMD—have enjoyed greater popularity among consumers by partnering with insurance companies and other health care providers, a strategy that is successful because it integrates new technologies into existing platforms and business models [23]. Similarly, in a 2008 study conducted by User Centric in which subjects were asked to build their own PHRs, the majority of participants were interested in maintaining them after the study [26]. The move toward digitization, combined with growing numbers of smartphone and social media users, empowers consumers to more proactively monitor their health. As technologies that facilitate this shift, mPHRs could evolve into important elements of today's HIT infrastructure.

PHR Developers

Despite their status as emerging technologies, PHRs—both mobile and Web-based—already come in many varieties and address numerous medical conditions. Because they enable patients to track their health conditions outside of a medical facility, PHRs and mPHRs boast a variety of applications in chronic and noncommunicable disease management, particularly for ailments like diabetes mellitus, heart disease, cancer, and mental illness [8]. For example, BodyKom, a mobile application for cell phones, enables nonhospitalized cardiac patients to track and share their vital signs with physicians via their cell phones [27]. Dexcom has also developed a biosensor that monitors blood sugar levels, transmits data to patients' mobile devices, and automatically updates their mPHRs as well as their providers' EHRs [8]. Several mental health applications (eg, Mobile Therapy and CBT MobilWork) function as ad-hoc therapy tools, enabling patients to record symptoms between clinician visits and providing mental health professionals with a plethora of information on their patients' health statuses outside of medical settings [7]. Given the increasing use of EMRs and EHRs, electronic PHRs and mPHRs in particular represent an important development in HIT.

Insurance Companies

Given that insurance claims are an important source of medical information, health insurance providers represent another major stakeholder in the expansion of PHR services. Medical practitioners have also shown support for PHRs, particularly in situations involving patient transfer between caregivers [28]. A 2009 national survey reveals that 42% of doctors—especially those practicing in rural areas—are willing to start using electronic PHRs [29]. Companies like Blue Cross and Blue Shield, Aetna, and United Healthcare all offer PHR tools to their clientele; of these, Aetna also offers a mobile option for accessing personal health information.

During the aftermath of Hurricanes Katrina and Rita, medical professionals faced a major health care delivery challenge: obtaining accurate medical histories for the 7500-plus individuals who were ill, injured, or seeking consultation [30]. In response, Blue Cross and Blue Shield, which reported that over 300,000 customers and providers lost their medical records,

began offering claims-based health histories to evacuees receiving medical treatment from new caregivers [31]. Hurricane Katrina also prompted the Markle Foundation to implement a different solution to the problem of health care delivery: an online portal called KatrinaHealth, where patients, pharmacists, and doctors could easily access prescription and dosage records in the wake of the storm [32]. System users reported that ready access to this information helped evacuees renew their medications and assisted health care professionals in coordinating care and avoiding prescription errors [33]. The Markle Foundation further reported that electronic PHRs could one day eliminate the logistical barriers associated with maintaining decentralized sets of patient records, but "are not yet a viable solution in disasters…because too few people have them and they exist on multiple platforms that may not be compatible with one another" [32]. Furthermore, because authorities have granted little attention to the management of personal medical information in emergencies, concerns over privacy and security continue to dissuade American consumers from using PHRs [32].

Federal Agencies

Despite support from consumers, insurance companies, and health care professionals, the federal government has offered relatively little guidance and made limited progress in integrating PHRs into the nation's existing HIT infrastructure. However, a select few federal agencies, such as the Centers for Medicare & Medicaid Services, have recognized the potential of PHRs and support their use to improve patient-provider communication [34]. HHS has also released a privacy notice for PHRs supporting "individuals' use of PHRs as a mechanism to facilitate access to, and control over, their health information" [35]. The Centers for Disease Control & Prevention (CDC) have supported HHS' work on PHRs, calling for further research on confidentiality, security, interoperability, regulation, and evaluation [6]. The US Food and Drug Administration (FDA), meanwhile, which maintains regulatory responsibility for medical devices, has formulated policies pertaining to certain mobile health applications. These policies, however, do not extend explicitly to EHR or PHR applications [36]. In September 2013, the FDA released a guidance document stating that it would exercise "enforcement discretion for mobile apps that enable patients or providers to interact with Personal Health Record or Electronic Health Record systems" [37]. The document goes on to specify that in addressing these applications, the FDA will not enforce the mandates established by the Food, Drug, and Cosmetic Act [37].

Considering the roles that PHRs (including mPHRs) might play during PHEs, increased involvement from consumers, insurance companies, clinicians, and federal entities is necessary. Engaging other stakeholders—emergency responders, medical volunteers, and public health laboratories, for instance—is also critical to the successful integration of PHRs into emergency response efforts.

Benefits

Examples

Just as the shift from paper-based records to EHRs provides numerous benefits to providers and patients, mPHRs can also capitalize on the benefits of digital records. In fact, mPHRs arguably provide more benefits to patients than EHRs, as increasing and widespread Internet access and mobile device use allow patients to access their records from anywhere with an Internet connection. PHEs typically present emergency responders with immense logistical challenges with respect to exchanging information in a timely and accurate manner, particularly in health care settings [38]. In such situations, when the displacement of an affected community can impede access to routine providers, alternate modes of communication are necessary to ensure continuity of care. PHRs—and mPHRs in particular—may present a viable solution to this recurring problem. Although mobile-based information exchange systems themselves are not immune to failure, they nevertheless present patients and clinicians with a feasible backup strategy for sharing critical medical information. In fact, many health care practitioners who treated patients following Hurricane Katrina supported the use of standardized, interoperable, electronic PHRs as a means of enhancing emergency patient care [39].

Proven Benefits

mPHRs Allow Health Care Providers to Better Share Information With Patients

mPHRs give providers a mechanism to share information with patients, including clinical summaries, diagnoses, educational resources, and appointment reminders. They also enable patients to refill prescriptions, access lab results, track immunizations, and schedule appointments. Some of these features (eg, prescription refills) exist in applications developed by major retail outlets such as Walgreens and CVS, but do not comprise a holistic health record. However, other mobile services (eg, Group Health, Castlight Mobile, MyChart, myCigna, Coventry Mobile, MHBPSM Mobile, Evita Personal Health Record, and Capzule PHR) do serve as holistic records of health information. Still other applications—such as Health4Me and IBX—even enable patients to view their insurance claims, track health spending, and search for local health care professionals. As indicated in one study, the functions of PHRs have the potential to create a more comprehensive and balanced view of the patient, because patients control and manage the information in the record. Health care providers can therefore view records, as documented by patients, directly [11].

PHRs thus allow patients to reference pertinent medical information at any time and share such information with other providers, even during ED visits and other unscheduled visits. This feature of PHRs also facilitates continuity of care if a patient receives treatment from a new provider. The clinician in this case would have access to a thorough record of the patient's existing medical conditions, including previous medical tests, procedures, prescriptions, and conditions. Such information, in turn, would prevent duplication of tests and

treatments and minimize risk of administering medications that can complicate conditions or allergies.

There are several mPHRs that serve many of the aforementioned functions; some are even specially customized for emergencies. Microsoft HealthVault, for example, enables users to create medical records specifically for unexpected hospital visits or to inform first responders. Another application, Gazelle, allows smartphone users to receive and share lab results. Similarly, a Web-based PHR service called Synchart stores patients' health information and can grant clinicians emergency access to said information during a crisis.

Potential Benefits

mPHRs Provide Patient Medical Histories at the Point of Care

mPHRs, which may improve provision of care during PHEs, give health care providers instant access to a patient's medical history and recent medical events that can be beneficial in both emergency and nonemergency situations. However, PHEs, which may encompass events as diverse as infectious disease outbreaks, natural disasters, or manmade catastrophes, present logistical barriers that impede health care delivery and timely access to critical medical information. During PHEs, when many patients are displaced or health care facilities lose abilities to access EHRs, mPHRs may be one of the only ways of providing accurate, recent medical information. Patients will likely present to makeshift medical facilities or those with limited operational capabilities, receive care from an unknown provider, or be unable to communicate their medical histories.

When patients are unable to seek care from their primary care physician or a facility with access to their medical history, mPHRs can help providers determine essential information, such as medical conditions and drug allergies, needed to inform treatment options and better coordinate and direct care. Such information could be useful when health systems are strained and facilities may lack adequate numbers of staff. mPHRs can inform providers of important health information that can ultimately reduce medical error and improve triage. mPHRs may also particularly benefit specific populations during PHEs, including nonresponsive patients who cannot communicate with providers, those who seek care at an alternative care site, vulnerable and special populations, and children and young adults. For vulnerable and special populations, such as non-English-speaking persons, those belonging to ethnic minority groups, mentally unstable patients, and those who are deaf or blind, mPHRs may be the only communication method between patient and provider. Smartphone ownership and broadband Internet access among many of these populations is increasing. Nationally, between 2000 and 2011, rates of Internet access increased among Hispanic, Black, and Asian households by 34.7%, 33.3%, and 26.5%, respectively [40]. Similarly, as of 2013, 51.6% of Asians report owning a smartphone, along with 48% of African Americans and 45.4% of Hispanics [40]. Among Latino Internet users, 28% are predominantly Spanish speakers, suggesting that a Web-based PHR platform may be an effective way of reaching this target minority group [41].

Pediatric populations can also present unique challenges to providing health care in emergency settings, particularly when children either do not have or are separated from parents and guardians. In California, for example, there are more than 56,000 children in foster care, many of whom face barriers to health care access despite greater needs (50% of foster care children suffer from at least 1 chronic condition, while 25% suffer from 3 or more) [42]. These patterns also hold nationally, where 90% of children entering foster care have physical health problems and another 55% suffer from 2 or more chronic conditions; these individuals also make more frequent use of costly medical services such as group care, inpatient psychiatric treatment, and ED services [42]. mPHRs will likely benefit clinicians serving this particular population, given the increasing use of smartphones among teenagers and young children. In March 2013, a national survey estimated that 37% of American teens (ages 12-17 years) own a smartphone, signifying another major niche for PHR expansion [43]. Select groups, such as the Children's Partnership, have acknowledged that effective and accessible PHRs, when linked to a broader health information exchange system, could significantly increase the availability of accurate and timely information for young adults, especially those without guardians [44]. PHRs have the potential to facilitate better communication among providers, families, caseworkers, and others making care decisions on behalf of young people. Furthermore, PHRs also provide a mechanism for young people to become responsible for decisions regarding their own care and build self-sufficiency, particularly for those who lack access to regular medical care. Studies also indicate that PHRs also encourage parents to play more proactive roles in seeking out preventive medical care for their children; for example, parental PHR use is linked to improved immunization adherence [16].

In addition to mitigating the challenges associated with caring for pediatric populations, mPHRs may also be one of the only ways to quickly obtain patient information when medical facilities are struck by disaster and can no longer provide optimal care. As noted in one study, the value of PHRs "extends to contingency preparedness in all categories of events, from natural disasters to terrorist attacks, and infectious disease pandemics such as avian flu" [11]. As health care facilities move toward EHRs as their primary medical record systems, they rely more heavily on basic operational capabilities, such as electricity and functional emergency generators, to access the records stored on a facility's server. When these assets fail, the quality of patient care, in turn, deteriorates. During Hurricane Sandy, for example, power outages and computer failures forced New York University Hospital to evacuate more than 200 patients (including critically ill infants) and transfer them to neighboring facilities [45]. Recordkeeping challenges often accompany such major transitions of care. Employees at Staten Island University Hospital, for instance, resorted to using paper records to track evacuated patients during Hurricanes Sandy and Irene, a strategy that proved inefficient and burdensome [46]. In such situations, mPHRs could assist health care providers in accessing patient information in a timely manner, thereby enabling them to make informed decisions and diagnoses that can reduce medical error and relay critical information for new patients. Furthermore, many cloud computing data centers often retain redundant power

supplies, Internet connections, and hardware to ensure that consumers can still access their data even in the event of a power outage [47]. Providing more accurate and faster diagnoses is imperative when triaging patients and coordinating care during events that overwhelm health care facilities.

PHRs Have the Potential to Advance Telehealth

Telehealth, the delivery of health care via telecommunication technology, relies on methods such as real-time videoconferencing to facilitate teletriage and medical care in emergency scenarios. Telehealth strategies—videoconferencing, the use of smartphones and wireless networks, and email, for example—have already proven to be effective at sharing information between clinicians and medical facilities [48]. Select PHRs also enable information exchange between qualified clinicians, and can integrate transmission and virtual imaging capabilities. Thus, they offer a platform for "virtual visits," allowing office-based health care providers and home-based health care workers or patients to coordinate patient management. Even basic patient information, such as blood pressure readings, temperature, glucose levels, and other medical notes, can be transmitted from home providers to physicians via a PHR. These functionalities enable physicians to obtain patient histories remotely and instruct home providers of necessary changes to the patient's care regimen, which can be a key step toward building home telehealth capabilities. Integrating PHRs into a broader telehealth infrastructure could thus enhance emergency health care delivery by mitigating patient surges at health care facilities.

Challenges

Overview

Despite the potential benefits of integrating mPHRs into mainstream medical practice and disaster response efforts, some critical challenges remain. Because there are no documented cases of PHR usage in disaster response, it is difficult to identify the specific challenges associated with PHR implementation during PHEs, although several studies have explored the shifts in standards of care during disasters [48-51]. Furthermore, PHRs have yet to be widely adopted even in routine medical practice, suggesting that the barriers impeding increased use must be resolved first. These barriers, along with recurring, well-documented communication challenges during emergencies, are outlined below.

The United States Lacks a Unified Infrastructure for Managing and Verifying the Integrity of Data Stored in PHRs

The ability to access accurate medical information is essential to the success of disaster response activities. However, the loss of critical infrastructure and personnel during PHEs impedes data collection. PHRs certainly present a viable solution to this problem, but require solid software platforms to function effectively. Most available PHRs and mPHRs currently operate on different, noninteroperable platforms, and thereby complicate efforts to gather pertinent medical information. Many PHR systems are integrated with a specific EHR system so, if EHR systems are not interoperable with each other, providers can be limited as to what content they can view. Furthermore, if PHR systems are stand-alone, and not integrated to a larger EHR system, users must manually enter information. Without the ability to exchange data with other systems, PHRs will devolve into "information islands" that remain divorced from other repositories of patient information, and provide limited value to health care professionals [52]. Such a lack of interoperability between EHR and PHR systems impedes information flow, which could be vital during emergencies. Standardization is also critical to the successful integration of PHRs into the nation's HIT system.

Data integrity poses another critical challenge to clinicians relying on PHRs to access medical histories. Depending on the PHR service in question, clinicians may lack the ability to verify the accuracy of patient-entered data. Whereas PHRs provide useful patient information, consistent standards are needed to verify data integrity. For example, enabling consumer access, identifying who is entering the data, determining authenticity of data entered, and detailing how information flows from one PHR system to another or to an EHR system are necessary, minimum requirements to ensure overall interoperability of PHR systems.

Furthermore, in the event of emergencies, when electronic systems may fail or be vulnerable to external threats, EHR systems must be able to prevent unexpected loss of protected health information. If PHR systems become integrated into EHR systems, then PHR systems must also be able to manage potential threats. PHRs can provide necessary patient information when EHRs are unavailable, whether due to system hacking or power failures. PHRs are therefore the most viable "back up" option to provide individual patient information when original health records are destroyed or unavailable.

Costs Associated With Maintaining PHRs Are Unclear and May Present a Significant Barrier to Medical Institutions

Although consumers have expressed interest in adopting PHRs to manage their health information, it remains unclear whether the cost of PHRs would dissuade potential users. Many PHRs are free, although select smartphone applications charge a nominal download fee. However, medical institutions seeking to establish PHR systems may face significantly higher costs. For example, one study considered the costs associated with developing an mPHR application, building the software infrastructure to run the application, and handling user activity. Their PHR model, which accounts for numerous costs during application development and authentication, including personnel costs, data centers, user support, and record matching services, generated costs of $450,000 [53]. Such expenses may be beyond the means of certain medical institutions aiming to provide their patients with cohesive, interoperable PHR platforms. In a different study, authors note that "many of the putative financial benefits of PHRs only occur when PHRs are tightly integrated with EHRs, so that seed funding of PHRs in practices that operate an EHR might advance PHR adoption to the 'tipping point'" [52]. Similarly, another study points out that having "a common language with patients and readily available health information allows health care providers the potential to not

only save lives, but to reduce the impact of the financial burden on our health care system" [54].

Patient-Managed Health Records Present Consumers and Policymakers With Several Legal, Regulatory, and Privacy Challenges

As exemplified by the transition to EHRs, the health care industry in the United States is becoming increasingly reliant on technology. Consumers, too, are a major driving force behind the growing market for digital health care solutions. Despite these trends, however, legal and regulatory frameworks for governing mobile health care applications (as opposed to PHRs in non-mobile formats) remain conspicuously absent [6,35]. Given the continued expansion of mobile health, the current lack of regulation could impede health care delivery efforts in post-emergency settings. Previous PHR systems have encountered privacy and legal concerns, but the adaptation of PHRs into a mobile format, much like the adaptation of hospital records to EHRs, take on a new dimension of challenges regarding who can access and manipulate the data. PHEs, however, even those that complicate efforts to deliver timely, effective medical care, do not preclude the need for robust legal frameworks to protect patients. Resolving the challenges associated with maintaining protective legal standards would ensure patients' privacy and safety even during PHEs. So far, legal and regulatory frameworks have generally failed to meet the challenges emerging from new developments and applications of consumer-operated, digital health care technologies. Three specific areas of concern include ownership and control of information in a PHR, third party use of consumer data for secondary purposes, and the application of existing laws to PHR systems.

PHRs vary in the way that consumers "own" their health information and, consequently, privacy and legal concerns vary according to the system's design. Select PHRs give consumers access to their health information while others provide them exclusive access. Because of this difference in accessibility, insurance companies, health care providers, and others who administer PHRs must clarify the differences between legal control and ownership of the medical record. Moreover, relevant stakeholders must clarify how a consumer's ownership and control over their own PHR and relevant personal health information differs from a provider or institution's ownership and control over that same record. Such clarifications are needed to identify accountability for potential liabilities, rights to access, and obligations to act on data inputted into the PHR.

In addition to concerns surrounding control and ownership of PHR systems, privacy concerns also exist surrounding the use of third party vendors that may store or mine data for alternative uses. Several insurance companies and health care institutions may consider using, or already use third party systems for consumer data. However, it is unclear how these vendors use the consumer data in these systems. As PHR systems are designed and revised, consumers should be given the option to make their personal health information accessible to third party vendors for secondary uses.

Roadblocks to the Integration of Personal Health Records and Electronic Health Records

PHRs allow iterative communication between patients and providers, and the integration of PHRs and EHRs would permit exporting data among information systems. An underlying challenge is that PHRs alone do not have universal standards and there is no standardized way to design and maintain PHRs [55]. Even if such challenges were resolved, and despite the potential benefits of integrating PHRs and EHRs, several factors would still inhibit their integration. First, it remains unclear how health system roles and responsibilities will change if systems are integrated. For example, concerns about liability risk and adverse effects for providers, such as increased workload and inadequate reimbursement, remain unresolved. Second, there is an absence of standards to inform the process by which systems should be integrated. Furthermore, it is unclear if there are limitations to the current HIT infrastructure that would present technical challenges to integration. Third, related to limitations of current infrastructure, concerns about privacy, security, the use of information by third parties, and lack of oversight impede integration [10,56].

Recommendations

Overview

Although the majority of PHR development in the United States takes place in the private sector, we maintain that the federal government is best suited to design, implement, and regulate PHR use during PHEs, given its involvement in emergency preparedness and response efforts at the national, state, regional, and local levels. The federal government also oversees health care delivery and innovation in HIT and is therefore well positioned to implement the appropriate standards for PHR standardization and interoperability. The following recommendations outline initial steps that federal agencies can take to integrate PHRs into the nation's emergency response strategies and overall HIT infrastructure.

Meaningful Use

Congress should identify meaningful use criteria to govern the use of mPHRs and allow eligible providers to earn incentive payments, modeled on the standards set for EHRs. Legislation that calls for the establishment of meaningful use criteria for mPHRs would encourage widespread adoption and use of mPHRs during emergency and nonemergency settings. Just as the American Recovery and Reinvestment Act of 2009 authorized incentivized payments for providers to encourage adoption and use of EHRs, such legislation could authorize incentive payments to providers that meet criteria for the use of mPHRs. Similarly, HHS' Hospital Preparedness Program could help fund efforts to explore the role of public health records in augmenting surge responses during PHEs. Such criteria and incentives could help standardize how providers use mPHRs and direct relevant federal agencies to address challenges to their use.

Proposed legislation should specifically highlight the potential uses of mPHRs during emergencies. While many private companies develop and monitor mPHRs, establishing criteria

for how providers and health care systems use and access these records can maximize the benefits of mPHRs to clinical outcomes.

Integration Into Mainstream Health Care

Relevant federal entities, such as the Office of the National Coordinator for Health Information Technology (ONC), FDA, and HHS, should identify how to integrate PHRs and mobile portals into mainstream health care, especially for use during emergencies. Several challenges impede information flow among systems, such as difficulty integrating systems and monitoring how data from PHRs fit into EHRs. Aside from interoperability challenges, clear guidance may be needed to identify how and when health care providers should use data from mPHRs with routine clinical work. For example, it remains unclear if providers should receive payment for viewing data from mPHRs, if payment should be contingent on the situation in which an mPHR is used (ie, emergency versus nonemergency setting), and if providers will be held liable for actions determined according to the information in a PHR.

ONC and the Centers for Medicare & Medicaid Services have jointly developed meaningful use criteria for EHRs. These criteria would require EHRs to accept patient-generated data, which may include biometric data, blood pressure, information on chronic conditions and treatment, and other information in a patient's medical history. For example, the Health Information Technology for Economic and Clinical Health Act of 2009 includes language describing meaningful use with respect to EHR technology, but lacks provisions for information exchange via mobile media [57]. Federal agencies involved in determining meaningful use criteria should clearly identify how patient-generated data should be used in broader HIT systems, to address issues of interoperability of systems and liability for providers.

Finally, the Hospital Preparedness Program, managed by the Assistant Secretary for Preparedness and Response, is charged with enhancing "hospital and health care system planning and response at the state, local, and territorial levels," facilitating "the integration of public and private sector medical planning and assets to increase the preparedness, response, and surge capacity of hospitals and other health care facilities," and improving "state, local, and territorial infrastructures that help hospitals and health care systems prepare for public health emergencies" [58]. Thus, exploring new modes of emergency communication and implementing crisis standards for information exchange certainly fall under the purview of HHS. HHS should therefore encourage health care providers, both private and public, to expand disaster response planning to integrate new communications technologies, including PHRs.

Governance and Legislation

A federal agency, such as the ONC, should assume a regulatory role and establish a legal framework for mPHRs and related efforts. Many federal efforts have recognized the growth of the mobile health sector and identified the need for strategic leadership and guidance, yet critical gaps in existing legislation and governance remain. The absence of a dedicated regulatory body and legal framework for mobile health further exacerbates the challenges associated with expanding mPHR use. While the FDA has expanded guidance to include mobile apps that function as medical devices, guidance for managing patient information in post-emergency settings remains virtually nonexistent. Having these in place ensures that patients, clinicians, mobile application developers, and insurers are accountable for the management of mPHRs.

Protection of Privacy

The application of existing legal and privacy provisions should be continuously addressed as mPHRs develop. Because PHRs and mPHRs are emerging health information technologies, the legal and privacy concerns regarding their use may change as technologies and their roles in HIT more generally evolve. Select PHRs, offered by health care providers and health plans, are covered by the Health Insurance Portability and Accountability Act of 1996 (HIPAA) Privacy Rule. In the event that HIPAA applies to a PHR or mPHR, the information within these records is protected by the law. However, those systems that are not offered by HIPAA covered entities must adhere to the privacy policies and their respective vendors. A system that is not covered by HIPAA may be covered by other applicable laws; however, all PHR and mPHR system providers should identify how health information is protected and communicate such policies to consumers.

Marketplace Support

Congress should identify new ways to support HIT development. In 2012, Representative Mike Honda introduced the Healthcare Innovation and Marketplace Technologies Act (HIMTA), aimed at fostering further innovation and entrepreneurship in the HIT sector. Congress should support the legislation, and similar bills, that calls on the FDA to establish a marketplace for new technologies and advance training for health care workers to handle their implementation and use [26,59]. HIMTA specifically contains provisions for an FDA-run Office of Wireless Health that will create and maintain the necessary framework to regulate mobile health technologies, such as mPHRs. The office would also offer legal support to mobile developers, provide loans to physicians who adopt new technologies, and create educational materials to elucidate privacy guidelines [60]. Despite the potential benefits of enacting HIMTA, the FDA maintains that its forthcoming mobile medical application policies would not apply to mobile applications that perform the functions of an HER or PHR system [61]. Congress should therefore encourage the FDA and other relevant federal agencies to identify their respective roles in supporting the development of PHRs and similar forms of HIT. Congress should also develop crisis standards of operation for technologies that facilitate health information exchange during PHEs.

Acknowledgments

The authors thank Eric Toner, MD, for his help in shaping this analysis.

Conflicts of Interest

Conflicts of Interest: None declared.

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Abbreviations

CDC: Centers for Disease Control and Prevention
ED: emergency department
EHR: electronic health record
EMR: electronic medical record
FDA: US Food and Drug Administration

HHS: US Department of Health and Human Services
HIMTA: Health Innovation and Marketplace Technologies Act
HIPAA: Health Insurance Portability and Accountability Act
HIT: health information technology
mPHR: mobile personal health record
ONC: Office of the National Coordinator for Health Information Technology
PHE: public health emergency
PHR: personal health record

Edited by G Eysenbach; submitted 10.10.13; peer-reviewed by D Hanfling, L Seldon, M Kalz; comments to author 15.11.13; revised version received 16.12.13; accepted 07.02.14; published 05.03.14.

Please cite as:
Bouri N, Ravi S
Going Mobile: How Mobile Personal Health Records Can Improve Health Care During Emergencies
JMIR Mhealth Uhealth 2014;2(1):e8
URL: http://mhealth.jmir.org/2014/1/e8/
doi:10.2196/mhealth.3017
PMID:25098942

Original Paper

Using the iPod Touch for Patient Health Behavior Assessment and Health Promotion in Primary Care

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Abstract

Background: There is a growing recognition of the importance of lifestyle behavior change for health promotion and disease prevention, as well as the concomitant influence of patient–physician communication on effective behavior change. Mobile technology is increasingly being recognized as an important and efficient tool to collect patients' health behavior data and facilitate patient–physician communication.

Objective: The aim of this study was to assess the feasibility of an iPod touch-based health behavior assessment (HBA) tool in enhancing patient–physician collaborative goal-setting for health promotion in primary care.

Methods: A total of 109 patients from three primary care clinics in central Texas completed a brief HBA, which was programmed on an iPod touch device. An instant feedback report was generated for the patient and their physician simultaneously to facilitate collaborative goal-setting. Within approximately 7 days of the HBA, the patients were phoned for a follow-up survey for their feedback on the iPod touch–based HBA and resultant patient–physician communication.

Results: Patients were able to complete an HBA on the iPod touch with ease. Among those who completed the follow-up survey (n=83), 30% (25/83) reported that their physicians discussed the HBA report with them, while 29% (24/83) established behavior change goals with them. More than 90% (75/83) of the patients reported positive experiences with the iPod touch–based HBA.

Conclusions: It is feasible to use mobile tools for HBA in the primary care setting. The HBA also facilitated patient–physician communication on behavior change. However, more research is needed on the effectiveness of large scale dissemination of mobile-based HBA technology on health communication and behavior change for preventing or managing lifestyle-related chronic conditions, such as obesity, diabetes, cancer, or heart diseases.

(JMIR Mhealth Uhealth 2014;2(1):e14) doi:10.2196/mhealth.2927

KEYWORDS

iPod touch; behavior change; health behavior assessment; health promotion and disease prevention; patient-physician communication; mobile health technology; mHealth

Introduction

Unhealthy behaviors such as physical inactivity, smoking, and unhealthy diets are major contributors to costly chronic health conditions, for instance cancer and other chronic diseases, including diabetes, obesity, and heart diseases [1-3]. For example, despite decades of smoking cessation messages, about 20% of US adults are still current smokers [4]. A large

proportion of Americans also exhibit other unhealthy behaviors with less than one-half of adults meeting the US Center for Disease Control's 2008 physical activity guidelines and more than two-thirds of adults (68.8%) being overweight or obese (body mass index [BMI]>25) [5,6].

Planned health behavior changes are widely recognized as among the most cost-effective interventions for achieving positive health outcomes for prevention and control of chronic diseases [7,8]. For example, one large multicenter trial, the Diabetes Prevention Program, demonstrated that the cost per quality-adjusted life-year was US $1100 for a combined physical activity and nutrition intervention compared with US $31,000 for an intervention based on medication alone [9]. Additionally, the benefits were maintained over an extended period of time [9]. Research also suggests that cueing clinicians to discuss recommendations for behavior change during medical appointments improves physician adherence with health behavior guidelines and clinical outcomes [10]. Once cued, discussions about behavior change can be structured in ways that are most likely to encourage change. For example, smoking patients who were told by their doctors to quit smoking were more likely to take action than their counterparts without physicians' recommendations [11]. Furthermore, counseling to encourage behavior change may be most effective when the content is individualized to the person for whom the change is recommended [12].

While there are clearly health outcomes and care delivery benefits associated with systematically collecting health behavior data and initiating patient-physician conversation about behavior change, there are practical challenges. Many clinics are understaffed and underresourced and struggle to meet all of the current competing demands they face [13-15]. To meet the growing demands for care, health care systems must maximize the quality and quantity of time spent in patient-physician encounters by integrating innovative technologies to incorporate patient preferences and perspectives, and working within the context of patients' social networks, cultures, and communities [16].

Interactive behavior change technology (IBCT) has been recognized as a potential resource for improving the effectiveness of health behavior change in health care systems [17]. The past 2 decades have witnessed a rapid development and adoption of mobile health technologies in health promotion and health care [18]. As the penetration of mobile technologies (eg, iPod touch, smart phones, personal digital assistants) in the general population continue to deepen, mobile health technology is increasingly being used as an efficient tool for patient data collection, transport, and storage [19-21]. Additionally, there has been some initial international work in this emerging area of computer-administered health assessments, notably by Goodyear-Smith [22]. If well designed, the application of IBCTs in the primary care setting can be an effective approach to collect health behavior data, facilitate clinician review of patient status, and guide delivery of educational messages and behavioral counseling [18,23,24]. However, there may be potential data privacy issues as well as issues with the accuracy of data with mHealth that must be taken into consideration.

Therefore, the goal of the current study was to assess the feasibility, including usability, acceptability, uptake, and perceived value of using the iPod touch in a health behavior assessment (HBA) in the primary care setting. The reason for choosing the iPod touch was its perceived ease of use, relatively low cost, and adaptability with other mobile devices.

Methods

Study Design, Site, and Participants

We conducted a cross-sectional study with data collection at two time periods of approximately 7-days apart in 2011. The study setting was three conveniently selected primary care clinics of a large university-affiliated, multisite specialty health care system in central Texas. The participants were adult patients who had scheduled a routine office visit with their primary care provider in the participating clinics. The criteria for participation included: (1) being at least 18- years old, (2) the ability to speak and read English, (3) having scheduled an appointment for nonurgent care, and (4) arriving at the clinics at least 15 minutes before their scheduled appointments. The study protocol was reviewed and approved by the Scott & White Healthcare institutional review board with no written consent required from subjects.

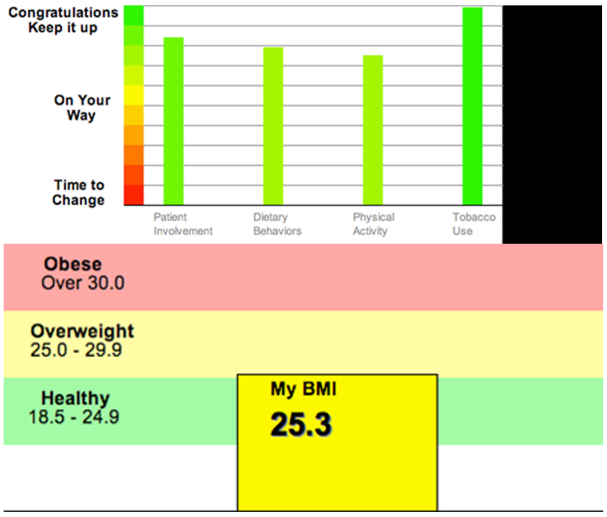
Data Collection Procedure

Our information technology specialists programmed the iPod touch device to collect participants' demographic, general health status, and anthropometric data, along with data on health beliefs and involvement with their health, as well as HBA drawn from North Carolina Health Partners "Starting the Conversation" Series [25] using an interactive, Web-based, touch-screen iPod assessment and report system. A random survey number was generated when the device was handed to each patient. To further protect participant privacy, no data were cached in the iPod touch software so as to prevent going back to prior answers from another patient. The software was tested for usefulness, security, completeness, and stability before being deployed for actual use. The software resided and was run from a Web server that was located in a managed, secure, Intranet data center that used enterprise level back-up and security practices standard for health care and clinical information systems. As an Intranet-based Web solution, the software and data collected were not accessible via the public Internet. Data from the participant responses and generated reports were stored in a secure, relational database that resided in the same data center and was managed using the same health care and clinical information systems practices.

Figure 1 displays sample screen shots of the HBA on the iPod touch. After patients checked in and waited for their appointments, a clinical research staff member approached and asked them to participate in the study. After verbal informed consent was given by the patient, the research staff gave them a quick training on how to use and navigate the iPod touch. The training included teaching participants how to make a selection from a choice of answers and how to use the wheel on the device to make a response. After a participant completed the HBA on the secure iPod touch, an HBA summary report was generated and simultaneously sent wirelessly to a research printer (see

Figure 2 for sample HBA summary reports). A copy of the HBA summary report was given to the participant and another copy was attached to their folder and given to their physician before encounter with the participant. The physician could use the summary report as a cue to start the conversation and provide appropriate recommendations on behavior change. The participant was provided a monetary compensation of US $20 for their time. Within 7 days of the clinic visit, the patients were contacted again by phone for a follow-up survey regarding their experiences with using the iPod touch and whether they discussed the report with their physician and established any behavior change goals during the clinic visit.

Figure 1. Sample screen shots of iPod Touch HBA.



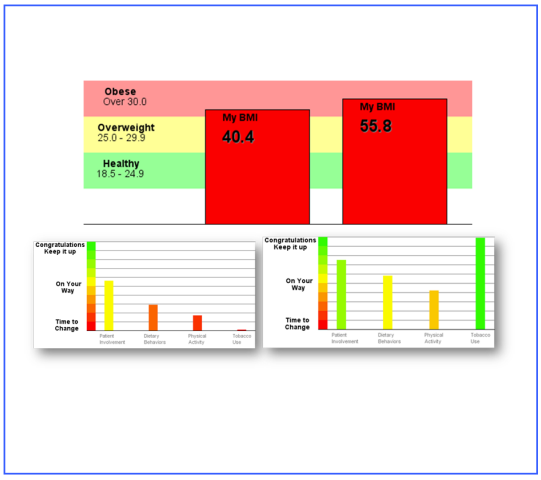


Figure 2. Sample generated HBA summary reports.

Measures

We collected the following information using the iPod touch device: (1) demographic data, including gender, age group, and race/ethnicity, (2) health status data, including general health, physical health, and mental health, (3) anthropometric data, including height and weight, (4) data on participant activation or involvement with their own health using 12 questions about health beliefs, such as taking responsibility for their health condition and understanding the nature and causes of their health conditions, and (5) data on health behaviors using seven questions about dietary behaviors, six questions about physical activity behaviors, and six questions about smoking behaviors.

Given our interest in a pragmatic set of measures to assess lifestyle behaviors in primary care settings, we chose to employ questions from the Starting the Conversation Toolkit developed by researchers at the University of North Carolina as a brief tool for rapid lifestyle assessment, behavioral counseling, and monitoring behavioral change in a variety of health care settings [25]. As indicated in prior work, having a set of brief items is critical for getting assessments integrated into clinical-care settings [26]. Focusing on the behavioral assessment questions from the Starting the Conversation ToolKit, we purposively selected three critical behaviors (tobacco use, eating behaviors, and physical activity) related to the onset and progression of many different chronic diseases [27]. Research in the dietary assessment arena confirms the utility of using this brief screening tool for evaluating intervention impact [28]. These types of Starting the Conversation questions are now part of a harmonized data set for behavioral assessment widely recommended for use in both community and clinical settings [24,29]. Our brief assessment also included items on patient

involvement, drawn from the short form of the Patient Activation Measure [30].

Table 1 summarizes the list of the HBA questions. The 12 questions on "participant involvement" required participants to make a choice from a 4-point Likert scale from strongly agree to strongly disagree. The 7 questions on "dietary behavior" required participants to make a choice from three answers (eg, "How many times a week do you eat food that is fried or high in fat?": 0 = Less than 1; 1 = 1-3; 2 = 4 or more), which were scored 0-2 for a possible total score ranging between 0 and 14, with 0 representing the healthiest eating behavior and 14 representing the unhealthiest. Similarly, physical activity had six questions with a possible score of 0-12 (eg, "How many times a week do you go out for a brisk walk?": 2 = 4 or more; 1 = 1-3; 0 = Less than 1), with higher mean scores meaning being more active; "tobacco use" also had 6 questions with possible score range of 0-12 with higher mean scores meaning more tobacco use.

The follow-up phone survey comprised 15 items, including 12 questions on their experiences with using the iPod touch on a 5-point Likert scale from strongly agree to strongly disagree, two "Yes-No" questions on their communication with their physicians, and one open-ended question on any other information or feedback they liked to share with us.

Table 1. Health behavior assessment questions on the iPod touch.

Patient involvement	Eating behavior	Physical activity	Tobacco use
1. I am responsible for managing my health condition	1. Eat food that is fried or high in fat	1. Go out or a brisk walk per week	1. To perk me up or give me a lift
2. Taking active role in my health is most important factor	2. Servings of fruits or vegetables eaten	2. Hours spent watching TV or on the computer	2. When I am with friends or drinking socially
3. I can take actions to prevent problems with my health	3. Regular sodas and glasses of sweet tea or juice drunk	3. Walk, ride a bike or bus vs. driving	3. Helps me feel comfortable and relaxed
4. I know what my prescribed medications do	4. Eat beans (eg, black beans) chicken or fish	4. Do gardening or intense housework	4. When I'm anxious, worried, depressed or angry
5. I can tell when I need medical care	5. Eat regular (not low-fat) chips or crackers	5. Participate in sports or exercise program per week	5. Within half an hour after I wake up
6. I can tell my provider concerns I have when not asked	6. Eat desserts or other sweets	6. Think of ways to move more vs. less	6. Without really thinking about it
7. I can follow through on medical Rx I need to do at home	7. Margarine, butter, or meat fat use on bread		
8. I understand nature and causes of my health conditions			
9. I know the medical treatment options available			
10. I know how to prevent further problems			
11. I can figure solutions when new problems arise			
12. I can maintain healthy lifestyle changes like diet and exercise			

Statistical Analysis

Data management, including data entry and coding, recoding, as well as analysis were done using SPSS. As a pilot study focused on feasibility and initial efficacy assessment, data analyses were limited to descriptive statistics. We first computed survey response and follow-up rates. We then performed descriptive statistics on the health behavior measures, participants' interactions with their physicians, and their experiences and perceptions of the iPod touch device as an assessment tool, including means and standard deviations. Exemplary quotes from participant feedback are included as illustrations.

Results

Survey Response and Follow-Up Rates

Of 293 subjects who were approached by the research staff for participation, 27.6% (81/293) were ineligible, 15.4% (45/293) were not interested, and 57.0% (167/293) expressed interest. Of these, 16.2% (27/293) refused verbal consent, while 83.8% (140/293) consented to participate. However, 31 subjects could not complete the HBA survey before being called to the exam room for their physician appointment resulting in a total of 109 subjects who completed the HBA. The mean time needed for participant instruction on navigating the iPod touch device was 43.5 (SD 29.9) seconds.

Of the 109 participants who completed the HBA survey in the clinic, 76.1% (83/109) were successfully contacted for the

follow-up phone survey within 7 days of their clinic visit after up to four phone call attempts.

Subject Characteristics

As shown in Table 2, participants were mostly female (75/109, 68.8%) and non-Hispanic White (69/109, 63.3%), with 15.6% (17/109) being African American and 16.5% (18/109) being Hispanic/Latino. Only 10.1% (11/109) were 65 years or older. The majority was overweight or obese (84/109, 77.1%), while a minority self-reported their general health as fair or poor (25/109, 23.9%). As further depicted in Table 3, the mean BMI of the participants was 30.9 (SD 6.6). Participants also reported approximately 1 week of poor physical or mental health days each month.

Participants generally reported a high involvement with their own health, with the vast majority of them reporting strong agreement or agreement with being responsible for managing their health conditions (107/109, 98.2%), taking an active role in their own health (109/109, 100%), being confident in taking actions that will help prevent or minimize some symptoms (106/109, 97.2%), and having the confidence to tell their health care provider concerns they have when not asked (105/109, 96.3%). While they reported less tobacco use (mean score 1.9, SD 3.7), they reported average behaviors regarding healthy eating (mean score 6.1, SD 2.4) and physical activity (mean score 7.6, SD 2.7).

Table 2. Demographics and general health information of participants (n=109).

Characteristic	n (%)
Age group (years)	
18-30	31 (28.4)
31-45	33 (30.3)
46-64	34 (31.2)
64+	11 (10.1)
Gender	
Male	34 (31.2)
Female	75 (68.8)
Race/ethnicity	
African American	17 (15.6)
Asian/Pacific Islander	4 (3.7)
Hispanic/Latino	18 (16.5)
White	69 (63.3)
Other	1 (0.9)
Body mass index (BMI)	
Underweight	1 (0.9)
Normal weight	24 (22.0)
Overweight	26 (23.9)
Obese	58 (53.2)
Self-reported general health	
Excellent	6 (5.5)
Very good	21 (19.3)
Good	56 (51.4)
Fair	22 (20.2)
Poor	4 (3.7)

Table 3. Health status and health behavior assessment of participants (n=109).

Characteristic	Mean (SD)
Body mass index	30.9 (6.6)
Number of days physical health not good in the past 1 month	6.3 (8.5)
Number of days mental health not good in the past 1 month	7.1 (8.8)
Number of days unable to do ADLs[a]	5.4 (8.6)
Dietary behavior (0-14)	6.1 (2.4)
Physical activity (0-12)	7.6 (2.7)
Tobacco use (0-12)	1.9 (3.7)

[a]Activities of daily living

Patient–Physician Communication and Collaborative Goal-Setting

Of the 83 participants who successfully completed the follow-up phone survey, 30% (25/83) reported that their physicians discussed the HBA report with them, while 29% (24/83) established behavior goals related to the HBA report with them.

Feedback of iPod Touch Device

Table 4 depicts participants' feedback on using the iPod touch for HBA. Participants generally accepted using iPod touch for HBA, with the vast majority reporting overall positive experiences (82/83, 99%) and acknowledging that the words were easy to see (83/83, 100%), it was easy to use (82/83, 99%), questions were easy to understand (81/83, 98%), they did not believe the iPod touch negatively affected their interaction with their doctor (79/83, 95%), the report was easy to understand (78/83, 94%), and they did not feel rushed to answer the questions (74/83, 89%). Exemplary quotes provided by the participants about their experiences with the iPod touch device corroborated the quantitative findings including comments such as,

> *Awesome, very easy to read, very quick. Good for people who haven't used iPod.*

Another participant suggested,

> *I wish they would do everything like that (iPod) because I think it is a lot better than reading and writing. I was able to see the text better on the iPod than on paper.*

Table 4. Participants' responses to the follow-up phone survey (n=83)[a].

Characteristic	Strongly agree/Agree (%)	Not sure (%)	Strongly disagree/Disagree (%)
1. iPod touch device was easy to use	99	1	-
2. Words on the iPod touch easy to see	100	-	-
3. Questions were easy to understand	98	1	1
4. Felt rushed to answer the questions	10	1	89
5. Report was easy to understand	94	4	2
6. Will use information to better health	94	5	1
7. Report makes me want to change	83	11	6
8. Will like to use device more in clinic	94	2	4
9. Report helped to talk to doctor	76	9	15
10. iPod touch negatively affected interaction	4	1	95
11. iPod touch positively contributed to health	86	7	7
12. Overall experience with iPod positive	99	1	-

[a]$P<.001$ in all cases using the binomial sign test

Discussion

Principal Findings

This pilot study assessed the feasibility of using a common mobile tool for HBA and counseling in a primary care setting. Our data suggest that the iPod touch device may be a feasible device to assess lifestyle behaviors. Nearly all participants reported a positive experience overall, finding the words on the iPod touch screen easy to see. The vast majority of patients found the device very easy to use and the questions easy to understand. In addition to its user-friendliness from a participant perspective, as seen in other studies, the iPod touch also offers ease from researchers' perspective. For example, it minimizes survey response error, it is reliable in eliciting sensitive data in

a private and confidential manner, and it is advantageous in terms of easy data storage and transportation.

In addition to being an easy-to-use HBA tool, we also found that the iPod touch was a promising device to assist behavior change in a diverse population of varying age groups, genders, ethnicities, and health status. The generated HBA reports triggered patient-physician collaborative goal-setting for one-third of our patients. This finding corroborates a call to use mobile health technologies or IBCT to promote health behavior change in the primary care setting [18,31].

Limitations

Several limitations of the study should be noted. First, we had a small and convenient sample recruited from one health care system from one geographical region. Thus, the findings may not be generalizable to other patients in primary care setting. In addition, we did not include children or non-English speaking patients. While promising, further research with a larger sample is needed for better understanding on how different populations may use mobile technology for both HBA and health communication messaging. Second, our follow-up rate was 76.1% (83/109) and we had a short follow-up time (7 days) in the study. Given that this was a pilot study to assess feasibility of using mobile tool for HBA in primary care setting, such a response rate was expected. However, better compliance may have resulted if participants had been compensated after completing all phases of the study instead of only after the iPod touch survey. Further studies are needed to enhance follow-up and better observe how mobile technology might impact long-term behavior change in patients. Third, our study was focused on using the iPod touch device for HBA. Training on how to use the printed HBA reports for better patient–physician communication and goal-setting for behavior change was not included as part of this study. We also did not collect any data on participant technological expertise, or physician's feedback on using printed HBA reports in their communication with patients, which is needed in future studies. Future research must also include such training for both patients and physicians, so the proportion of patients receiving counseling on behavior change can be increased as well as the assumed effectiveness of such behavioral counseling. Fourth, we used an iPod touch platform for conducting the HBA. In future studies, a comparison of the benefits and costs of iPod touch devices with other mobile devices would be instructive.

Conclusions

Despite these limitations, the current study suggests that it is highly feasible to use mobile tools for HBA and counseling in primary care settings for the prevention or management of obesity, diabetes, cancer, or heart disease, which are heavily influenced by lifestyle behaviors. Recognizing the magnitude of the prevalence of unhealthy behaviors in Americans, but limited health care resources, Congress passed the Health Information Technology for Economic and Clinical Health Act, which emphasizes the use of electronic health records [32]. Mobile health technologies can be integrated into the increasingly popular electronic health records. Recent studies are also documenting the value of standardizing questionnaires of HBAs and use for patient counseling [24,31]. As the mobile health research accelerates and adoption of electronic health records in health care settings continues, mobile devices such as the iPod touch HBA are promising health communication tools that can be easily integrated into the daily operation of primary care clinics.

Acknowledgments

The study was supported by a Scott & White Healthcare Institutional Research Fund (#08182, PI: SNF). Publication support was provided by the Central Texas Cancer Awareness Research Education and Services (CTxCARES) funded by the Centers for Disease Control and Prevention (CDC) and the National Cancer Institute (NCI) through cooperative agreement number 1U48DP0010924. The opinions are the sole responsibilities of the authors and do not represent those of the funding agencies. We thank Dawn Begaye for study coordination, Bradley Bartels and Kristin Hamilton for data collection, and Phyllis Davis for administrative assistance. We also thank Tom Peck and Anita DuBose for the design of the iPod touch software system.

Conflicts of Interest

Conflicts of Interest: None declared.

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Abbreviations

BMI: body mass index
HBA: health behavior assessment
IBCT: interactive behavior change technology

Edited by G Eysenbach; submitted 29.08.13; peer-reviewed by S Langrial, J Cartreine, T Cheng, A Holzinger; comments to author 30.10.13; revised version received 29.01.14; accepted 27.02.14; published 21.03.14.

Please cite as:
Forjuoh SN, Ory MG, Wang S, des Bordes JKA, Hong Y
Using the iPod Touch for Patient Health Behavior Assessment and Health Promotion in Primary Care
JMIR Mhealth Uhealth 2014;2(1):e14
URL: http://mhealth.jmir.org/2014/1/e14/
doi:10.2196/mhealth.2927
PMID:25100308

Original Paper

Smartphone Ownership and Interest in Mobile Applications to Monitor Symptoms of Mental Health Conditions

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Related Article:

This is a corrected version. See correction statement: http://mhealth.jmir.org/2014/3/e34/

Abstract

Background: Patient retrospective recollection is a mainstay of assessing symptoms in mental health and psychiatry. However, evidence suggests that these retrospective recollections may not be as accurate as data collection though the experience sampling method (ESM), which captures patient data in “real time” and “real life.” However, the difficulties in practical implementation of ESM data collection have limited its impact in psychiatry and mental health. Smartphones with the capability to run mobile applications may offer a novel method of collecting ESM data that may represent a practical and feasible tool for mental health and psychiatry.

Objective: This paper aims to provide data on psychiatric patients’ prevalence of smartphone ownership, patterns of use, and interest in utilizing mobile applications to monitor their mental health conditions.

Methods: One hundred psychiatric outpatients at a large urban teaching hospital completed a paper-and-pencil survey regarding smartphone ownership, use, and interest in utilizing mobile applications to monitor their mental health condition.

Results: Ninety-seven percent of patients reported owning a phone and 72% reported that their phone was a smartphone. Patients in all age groups indicated greater than 50% interest in using a mobile application on a daily basis to monitor their mental health condition.

Conclusions: Smartphone and mobile applications represent a practical opportunity to explore new modalities of monitoring, treatment, and research of psychiatric and mental health conditions.

(JMIR mHealth uHealth 2014;2(1):e2) doi:10.2196/mhealth.2994

KEYWORDS

psychiatry; mobile; smartphone; depression; technology; applications

Introduction

Self-report scales are a mainstay of assessing symptoms and their change in patients with mental health disorders. A frequent limitation of such scales is that they typically gather retrospective rather than real-time reports. Experience sampling method (ESM), also known as ecological momentary assessment, is a data collection method used in mental health that allows patients to record their current state and context in a structured manner. Reports, often in diary format, are completed several times per day usually at random intervals with the goal of capturing a patient’s state in “their natural setting” [1,2]. ESM offers several advantages over retrospective recollections of patient symptoms. First, it reduces the need to

rely on episodic memory, which can be unreliable. Second, it creates the potential to capture transient, randomly occurring symptomatic experiences. Third, it allows a better understanding of daily fluctuations and patterns of change anchored in time to activities, social contexts, and time [3].

While psychiatric and mental health research has focused on macro-scale cross-sectional differences and longitudinal changes, examining mental illness from the micro-level perspective offers a novel approach to elucidate the nature of illnesses, reveal insights into mechanisms as they play out in real life, and produce knowledge that is relevant to the individual patient. This view suggests that ESM may allow us to "open the black box of what we call a disorder [and discern] the network structure of interconnections between symptoms" [4]. Questionnaires and clinical interviews may not be able to reveal small but repetitive and relevant patterns of emotional expression to which momentary assessment may be more attuned [5]. Furthermore, concern has also been raised that traditional assessments of emotional recognition and social function may not actually capture real life measures of function in this patient population when compared to ESM [6]. Instead, data suggest that the earliest stages of expression of psychosis vulnerability may be noted in subtle momentary personal and environmental interactions that ESM captures [7]. The utility of ESM in mental health is broad and not limited to certain diseases or states. A recent review of ESM in mental health concluded that ESM provides more detailed understanding of psychiatric and mental health phenomenology, and better insight into the dynamics of affective, psychotic, anxiety, eating, attention-deficit hyperactivity, and borderline personality disorders, thereby elucidating the dynamic interplay between environment and pathophysiological experiences [8].

Despite these advantages, ESM is not yet used in daily clinical interactions and decision-making. This conundrum is not new to the mental health field. More than 20 years ago, researchers began to realize the need for assessment strategies that would better describe patients in context and capture their subjective experiences. Nascent computer technology was envisioned as a mechanism to realize "a more precise description of subjectively experienced symptomatology" [2]. An often-raised concern with ESM is that there may be a substantial lag between the timing of an event and the patient's reporting of it [9]. A significant advantage of using computer technology for ESM is that electronic self-reports can be "time stamped" and are not subject to "back filling" like paper-and-pencil ESM. A pager alarm or timer beep is not a guarantee that a patient will actually fill out a paper-and-pencil diary entry. However, electronic ESM methods can record with exact precision when entries are recorded. One pilot study comparing paper-and-pencil-collected ESM versus mobile phone-captured ESM noted mood ratings on the mobile phone were significantly associated with clinician ratings of depression whereas paper-and-pencil ratings were not— - suggesting that electronic ESM data may have greater clinical validity [10]. Computer technology has matured since the 1980s and may now offer the ability to fulfill the potential of ESM in the clinical care of patients with mental health disorders. Smartphones, cellular phones with often large touchscreens and the ability to perform many functions of a computer including hosting operating systems able to run applications, in particular have rapidly evolved and the diverse role of of smartphone applications in health care was noted in a recent review [11] and the evolving potential for such was noted in another review [12].

ESM may be conducted with paper-and-pencil diaries or electronic tools such as handheld computers or smartphones. The feasibility and validity of electronic ESM using tools such as Palm computers has been studied in mood disorders research [13] and schizophrenia research [14]. Early research into smartphones has suggested their potential value for collecting real-time data from patients. One group provided smartphones for 1 week to patients with a diagnosis of psychosis and demonstrated that patients were able to utilize these devices to successfully complete rating scales of symptoms [15]. Another group also noted the feasibility of using smartphone applications for recording symptoms in patients with a diagnosis of psychosis and concluded that the graphical interface of such may led to better compliance and shorter entry times when compared to data collected via text messaging [16] or collected by classical paper-and-pencil diaries [10]. A practical clinical benefit of collecting smartphone-based data was recently demonstrated in a paper noting that results garnered on variability of self-reported mood symptoms may help predict thoughts of self-injury [17]. However, little is known about these health patients' prevalence of smartphone ownership or interest in using their own smartphones to download and run applications to track and monitor their conditions.

The rapid rise of smartphone technologies offers a novel mechanism for ESM collection. A recent study indicated that approximately 61% of the US population now owns a smartphone with ownership rates among mobile subscribers highest among the age group of 25-34 years at 78% and closely followed by 75% of the population between the ages 18 and 24 years [18]. However, there is little data on the prevalence of smartphone ownership among patients with mental illness in the United States or their interest and willingness to use mobile applications to monitor their conditions. This lack of knowledge serves as barrier to further research and development in the field of mobile application development for the mental health field. This paper aims to provide early data on rates of smartphone ownership, patterns of use, and interest in using mobile applications to monitor their conditions. We predict that the rate of smartphone ownership among patients with mental illness will be similar to that of the general population and patients will express interest in downloading and utilizing mobile applications on their personal smartphones.

Methods

Paper-and-pencil surveys were completed by 100 patients at routine mental health clinic appointments at Beth Israel Deaconess Medical Center, a 500-bed tertiary care urban teaching hospital in Boston. The outpatient psychiatry clinic treats patients older than 19 years of age and sees approximately 1000 patients per month. The most frequent disorders seen at this clinic are first, anxiety disorders; and second, depressive disorders. Patients were told by front desk staff of the

opportunity to complete the voluntary uncompensated survey. We estimate that 10% (100/1000) of patients took the survey over 1 month. The study was approved and monitored by the Beth Israel Deaconess Medical Center Institutional Review Board.

The survey was 1 page long and the questions are listed in Textbox 1. No personal health information was recorded to protect patient privacy. The data were analyzed using IBM SPSS software. *P* values were calculated using chi-square analysis and run on IBM SPSS software. Results were stratified by age groupings that were selected to best mirror the currently most comprehensive reported statistics by the Pew Research Center and Nielsen on smartphone demographics among the general population.

Textbox 1. Survey questions.

1. Do you have daily access to the Internet?
2. Do you currently own a mobile phone?
3. Can your phone receive and send text messages?
4. Can your phone be used to browse the Internet?
5. Can your phone download applications or “apps”?
6. Does your phone have built-in GPS?
7. Do you own a smartphone?
8. What is the brand and type of your mobile phone?
9. How many applications or “apps” do you have on your phone?
10. How many applications or “apps” do you put on your phone each month?
11. How many health care–related applications or “apps” do you have on your phone?
12. In the past 6 months, have you used your smartphone to access general health care information?
13. In the past 6 months, have you used your phone to access your personal health care information such as, for example, test results or to schedule appointments?
14. Would you want to be able to access general information related to your health via your smartphone?
15. Would you want to receive text messages on your phone related to your health from your doctor’s office?
16. Would you want to use your phone to help track your medical condition via an application or “app” on your smartphone?
17. Would you download an application or “app” to your phone to help monitor your health condition?
18. Would you be willing to use an application or “app” on your phone on a daily basis to help monitor your health condition?

Results

One hundred patients completed the survey. Sixty-four percent of participants were female, 33% were male, and 3% did not specify gender. Eighteen participants were younger than 30 years of age, 31 between 30 and 45 years of age, 26 between 45 and 60 years of age, and 24 older than 60 years of age. One participant failed to include age.

Of the 100 patients who completed the survey, 90% reported they had daily access to the Internet in some form. The age of patients stratified according to Internet access is shown in Table 1.

Of the 100 patients who completed the survey, 97% (n=97) reported owning a mobile phone and 72% (n=72) reported owning a smartphone. We verified self-reporting of smartphone ownership by checking that those who reported smartphone ownership characterized their phones as having daily access to the Internet, a touch screen, and the ability to download mobile applications. Only 67% (n=67) of patients owned a smartphone according to these criteria. Sixty-four participants wrote in the name of their phone and of these 64 responses, 33 were listed as Apple iPhones. Results are displayed in Table 2 below.

Use of smartphones was also reported. Patients provided the following information on number of applications they currently have on their smartphone, the number of those related to health care, and the number of applications they add to their smartphone every month. Results are reported in Table 3.

Patients were also asked about using their mobile phones to access either general or personal health care information in the previous 6 months. Using an analysis of variance, it was found that gender was not a significant factor in accessing health care information via phones; however, age group was a significant variable. Results are displayed in Table 4.

Finally, data were collected regarding willingness of patients to use text messaging versus a mobile application to monitor their mental health condition. Results are shown in Table 5 and Figure 1.

Table 1. Percent access to the Internet stratified by age (N=99).[a]

Age (yr)	n (%) access to Internet
<30 (n=18)	18 (100)
30-45 (n=31)	31 (100)
45-60 (n=26)	22 (85)
>60 (n=24)	18 (75)
Total (N=99)	89 (90)

[a]χ^2_3=12.172, *P*<.007

Table 2. Mobile phone and smartphone ownership (N=99).

	Percent mobile phone ownership[a]	Self-reported percent smartphone ownership[b]	Percent smartphone ownership by criteria[c]
Age (yr)	n (%)	n (%)	n (%)
<30 (n=18)	18 (100)	15 (83)	15 (83)
30-45 (n=31)	31 (100)	28 (90)	26 (84)
45-60 (n=26)	26 (100)	19 (73)	16 (62)
>60 (n=24)	21 (87.5)	9 (35)	9 (38)
Total (N=99)	96 (97)	71 (72)	66 (67)

[a]χ^2_3=9.668, *P*<.02
[b]χ^2_3=21.842, *P*<.001
[c]χ^2_3=15.874, *P*<.001

Table 3. Smartphone applications (N=86).

	Number of total applications currently on smartphone	Number of healthcare applications currently on smartphone[a]	Number of applications downloaded each month to smartphone
Age (yr)	mean (median)	mean (median)	mean (median)
<30	30 (28)	1.6 (1)	3.4 (3)
30-45	20 (15)	0.8 (0)	2 (1)
45-60	8 (2.4)	0 (0)	0.6 (0)
>60	9.7 (6)	0.6 (0)	0.6 (0)
Overall	17 (12)	0.6 (0)	1.6 (1)

[a]χ^2_3=35.759, *P*<.02

Table 4. Use of smartphone to access health care information (N=96).

	Percent accessed general health care information from phone in previous 6 months[a]	Percent accessed personal health care information from phone in previous 6 months[b]
Age (yr)	n (%)	n (%)
<30 (n=18)	12 (67)	7 (39)
30-45 (n=31)	18 (58)	9 (29)
45-60 (n=23)	3 (13)	3 (13)
>60 (n=24)	3 (13)	7 (29)
Total (N=96)	36 (38)	26 (27)

[a]χ^2_3=24.396, *P*<.01
[b]χ^2_3=3.989, *P*<.26

Table 5. Interest in using text messages and smartphone applications for mental health (N=98).

Age (yr)	Percent wanting to receive text messages from MD[a] n (%)	Percent wanting to access general health care information on phone[b] n (%)	Percent wanting to use a mobile application to track mental health condition[c] n (%)	Percent wanting to download an application to track condition[d] n (%)	Percent wanting to use application to track condition on a daily basis[e] n (%)
<30 (n=18)	10 (56)	15 (83)	14 (78)	13 (72)	13 (72)
30-45 (n=31)	21 (68)	27 (87)	25 (81)	26 (84)	26 (84)
45-60 (n=25)	14 (54)	16 (63)	18 (71)	19 (75)	16 (63)
>60 (n=24)	15 (63)	14 (58)	11 (46)	11 (46)	14 (56)
Total (N=98)	60 (61)	72 (73)	68 (69)	69 (70)	69 (70)

[a]χ^2_3=1.307, *P*<.727

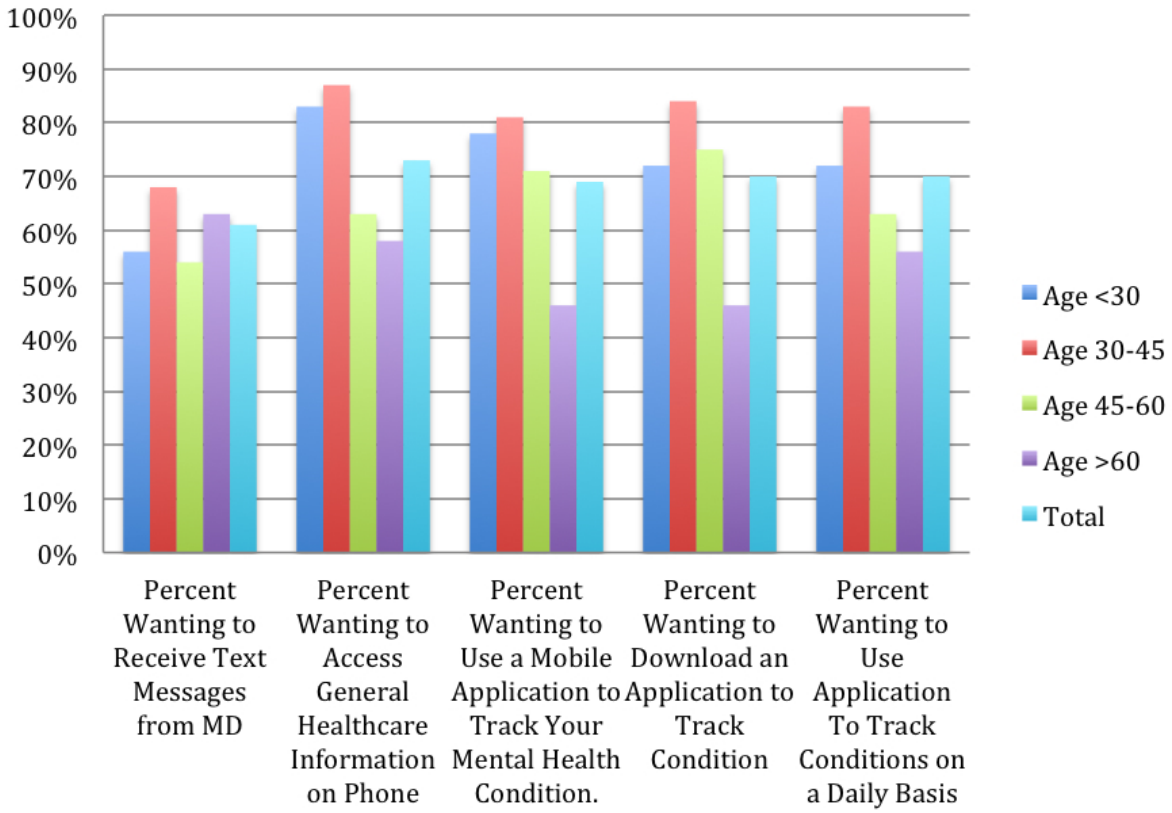
[b]χ^2_3=8.098, *P*<.04

[c]χ^2_3=8.684, *P*≤.034

[d]χ^2_3=9.862, *P*<.02

[e]χ^2_3=5.151, *P*=.16

Figure 1. Patients' willingness by age to monitor mental health conditions on smartphones.



Discussion

Principal Results

Our study provides early data regarding smartphone ownership among patients with mental health disorders as well as the first reported quantitative data regarding patient interest in smartphone applications to monitor mental health conditions. The overall rate of smartphone ownership among patients with mental health disorders was 67%, which is actually slightly higher than the national ownership of rate of 61% reported in March 2013 [18], indicating that mental health conditions may not be a barrier to smartphone ownership. Our results also indicate that patients report interest and willingness to try mobile applications designed to monitor their mental health condition with 67% indicating interest. Together, these results indicate that smartphones and mobile applications may represent a practical opportunity for the mental health field to explore new modalities of monitoring, treatment, and research. Whereas much previous work regarding mobile phones or smartphones

and mental health has used study devices, our data suggest that future studies may be conducted using patient-owned devices.

Our results indicate that patients in the age range of 30-45 years might be the most amenable and willing to download a smartphone mobile application to monitor their mental health condition. However, willingness to use such an application on a daily basis did not differ across age, suggesting that age itself is not a barrier to such. Interestingly, patients older than 60 years of age also reported a strong interest in using smartphones and mobile applications to track their mental health conditions. Their interest in using such an application was actually higher than those in the age group of 30-60 years of age. While those older than 60 years of age currently own fewer smartphones and use fewer mobile applications than other groups, their strong interest creates a unique opportunity to better understand and serve the growing geriatric psychiatry population.

Of note, there was a greater patient interest in using a smartphone application to track their mental health condition than in receiving text messages from mental health care providers. This may indicate that patients are more comfortable using mobile applications than the earlier technology of text messaging. Patients may prefer the anonymity of using a mobile application and feel more comfortable reporting symptoms in such a manner. Previous studies have indicated that a further benefit of mobile applications regarding mental health may be a reduction in stigma resulting in higher rates of compliance and treatment-seeking behavior [19].

It is also worth briefly mentioning that despite the numerous benefits, there are risks associated with smartphone use in mental health. The loss of patient and data confidentiality, and privacy remains a concern for smartphone applications [20] and the broader field of telepsychiatry itself [21]. Although some smartphones now include biometric security, despite advances in data encryption and network security technologies, privacy and security remain key issues.

Comparison With Prior Work

Our results are also in line with data collected in Australia regarding interest in utilizing mobile applications to help track and monitor mental health conditions with 67% in our study indicating interest versus 76% in the Australian study by Proudfoot and colleagues [22]. However, our results are distinct in that they were collected in a mental health clinic from patients and not the general population with and without mental health conditions as in the Australian study. Our results are also in line with recent work that has reported patient acceptance and ease of use of smartphones for self-reporting of symptoms. [15,16]. Another recent study looked at mobile phone ownership in patients with serious mental illness but did not address smartphone ownership or mobile applications [23].

Limitations

There are several limitations to this study. First, our results were obtained from a single general psychiatry clinic in an urban area of Boston. Rates of smartphone ownership and willingness to use mobile applications may be different at other clinics in other areas such as those that serve chronic and persistent mental illness. Second, we did not collect information regarding patient's diagnosis and thus may be overgeneralizing the results of this study. Third, our sample size of 100 patients is small and it would be important to examine these results in a larger scale survey. Fourth, our results are also limited by the fact that the questions in the survey were hypothetical and may not extrapolate into clinical practice. Fifth and finally, this study did not address what information patients would be willing to share and allow their mental health provider to access.

Conclusions

While the potential benefits of utilizing momentary assessment technology in mental health are well understood and include aiding diagnosis, personalizing patterns of emotions and behaviors, empowering patients to partake in care, and providing a low-cost adjuvant to treatment [16], less is known regarding the implementation and acceptability of such technology in mental health clinics. The high cost of supplying patients with smartphones as well as the technical difficulties encountered using new phones has been a limitation of several studies examining smartphone collection of ESM [24]. Allowing patients to use their own smartphones to run mobile applications may provide an effective and valid means of collecting real-time patient symptomology. This paper presented data indicating the feasibility of utilizing patient-owned smartphones to monitor mental health conditions via ESM. The ability of smartphones is not limited to data collection, but also creates the potential for mobile interventions as a future modality of treatment in mental health [25]. Future work is required to explore these concepts and realize the full potential of mobile technologies in the assessment and treatment of mental illness.

Conflicts of Interest

Conflicts of Interest: None declared.

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Abbreviations

ESM: experience sampling method

Edited by G Eysenbach; submitted 29.09.13; peer-reviewed by J Palmier-Claus, D Kimhy; comments to author 30.10.13; revised version received 11.11.13; accepted 23.12.13; published 21.01.14.

Please cite as:
Torous J, Friedman R, Keshavan M
Smartphone Ownership and Interest in Mobile Applications to Monitor Symptoms of Mental Health Conditions
JMIR mHealth uHealth 2014;2(1):e2
URL: http://mhealth.jmir.org/2014/1/e2/
doi:10.2196/mhealth.2994
PMID:25098314

Original Paper

Measuring the Lifespace of People With Parkinson's Disease Using Smartphones: Proof of Principle

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Abstract

Background: Lifespace is a multidimensional construct that describes the geographic area in which a person lives and conducts their activities, and reflects mobility, health, and well-being. Traditionally, it has been measured by asking older people to self-report the length and frequency of trips taken and assistance required. Global Positioning System (GPS) sensors on smartphones have been used to measure Lifespace of older people, but not with people with Parkinson's disease (PD).

Objective: The objective of this study was to investigate whether GPS data collected via smartphones could be used to indicate the Lifespace of people with PD.

Methods: The dataset was supplied via the Michael J Fox Foundation Data Challenge and included 9 people with PD and 7 approximately matched controls. Participants carried smartphones with GPS sensors over two months. Data analysis compared the PD group and the control group. The impact of symptom severity on Lifespace was also investigated.

Results: Visualization methods for comparing Lifespace were developed including scatterplots and heatmaps. Lifespace metrics for comparison included average daily distance, percentage of time spent at home, and number of trips into the community. There were no significant differences between the PD and the control groups on Lifespace metrics. Visual representations of Lifespace were organized based on the self-reported severity of symptoms, suggesting a trend of decreasing Lifespace with increasing PD symptoms.

Conclusions: Lifespace measured by GPS-enabled smartphones may be a useful concept to measure the progression of PD and the impact of various therapies and rehabilitation programs. Directions for future use of GPS-based Lifespace are provided.

(JMIR Mhealth Uhealth 2014;2(1):e13) doi:10.2196/mhealth.2799

KEYWORDS

Parkinson's disease; community; telemedicine; mHealth

Introduction

The Lifespace Construct

Lifespace is a measure of the geographic space in which a person lives and conducts their roles and activities [1,2], and captures the extent to which they travel and their patterns of movement within the community (Figure 1 illustrates the construct). As a construct, it arose from gerontological research, focusing attention on the relationship between the person and their environment [3,4]. It was originally conceptualized as concentric circles around the person representing expansion in the areas in which a person lived and interacted from their bedroom, to the house, and extending to the world outside the local neighborhood [1,4,5]. The research into Lifespace suggests that it is interconnected with a person's health and functional status [6-8], their environment, including available resources [9,10] and interventions focusing on the person, their health, and/or their environment [7,8,11]. Lifespace is an indication of the broader participation and quality of life outcomes [2,12]. It is thought to represent opportunity for community participation and social interaction [2,13] and also represents actual lived function and community access over a period of time [1,2,8].

Figure 1. Lifespace as it relates to a person, environment, intervention, and life outcomes.

Lifespace Individually Defined

There is no optimal amount of Lifespace. Like many aspects of quality of life and participation, it is individually defined. Individuals are likely to have different desired patterns and locations of community engagement [8,12]. The research into frail, community-dwelling older people in Japan has suggested that it is desirable that people leave their homes and engage in their neighborhood at least once a week to maintain function and health [14]. Xue et al [15] suggested that leaving the home less than four times a week was a risk factor or marker for future frailty, regardless of the way in which community mobility occurred or if assistance was required.

As Lifespace is a construct that fits within the person-environment and World Health Organization's International Classification of Functioning models, it is able to indicate the broad, enacted impact of health and environment on participation [16]. The research has shown that Lifespace can demonstrate the frequency and distance of independent community mobility or supported travel involving equipment or assistance from others, and therefore could be used to evaluate the impact of physical, cognitive, psychiatric, and sensory symptoms on life participation [1,5]. In addition, Lifespace is a construct that can capture how the design and resources available to an individual could enable high levels of participation and large geographic areas of engagement, even in the face of substantial symptomatology or disability. Indeed, optimal design of communities and resource allocation enable maintained Lifespace [16,17].

Reflecting its development in gerontology, Lifespace has been most widely applied in studies of the impact of ageing for people living in the community, for example, reference [15]. The longitudinal studies have indicated that even subtle restrictions in Lifespace can indicate prodromal changes in relation to illness and ageing, including future onset of functional deficits, for example, reference [14], cognitive impairment [18], and mortality [15]. Some studies on Lifespace have also described the differential adjustment to community life after hospitalization [7], the impact of falls [17], and the impact of roles including caregiving, for example, reference [19]. A number of the studies involving populations of older people have identified that illnesses or disorders affecting mobility

have a direct impact on Lifespace, and have specifically noted Parkinson's disease (PD) as affecting Lifespace, for example, references [9,14].

Lifespace and People With Parkinson's Disease

Lifespace has not been extensively studied for people with PD, although outdoor walking and community mobility have been researched, for example, reference [13]. It has clear relevance as the motor (difficulties with gait, tremor, and rigidity) and nonmotor symptoms (apathy, depression, sleep disturbance), as well as the most common reasons for hospitalization, (falls and psychiatric symptoms), could impact on a person with PD's desire and ability to regularly access the community [20]. Some studies into community walking for people with PD have highlighted the complex challenges associated with outdoor mobility. The impact of symptoms, confidence, and personal strategies, as well as environmental barriers, combine to impact on the community participation of people with PD [13,21]. The symptoms of PD have been shown to have variability over the short term within the overall trend of slow progression of the disease, rapid and unpredictable changes to symptoms may be seen. This has led to increased interest in monitoring the ongoing symptoms and outcomes for people with PD in their home environments [22].

Interventions for people with PD can target safe outdoor mobility, confidence with mobility, and ease with leaving the home [23,24]. Lifespace therefore gives an opportunity to monitor the implications of the combined impact of the symptoms of PD, the available supports, and the impact on daily life. Caregiving for someone with PD has been identified in a qualitative study as restricting Lifespace for the carer [19], indicating the broad impact of the illness and the potential utility of the approach for monitoring the quality of life and community participation for both people with PD, and their families.

As a global measure of community participation, Lifespace also has the potential to indicate the overall impact of treatments. As well as monitoring the impact of changes to symptoms on community participation, it can also capture the broader impact of the treatment itself. Qualitative investigation of the impact of PD and its treatments has indicated, for example, that medications requiring a strictly timed regime can result in surrendering of valued activities and roles because leaving the house needs to be arranged around medication requirements [25]. Also, intensive rehabilitation programs requiring frequent hospital-based attendance may affect patterns of Lifespace. Monitoring Lifespace may therefore serve to give an overall indication of the progression and nature of symptoms, complications, and impacts of treatment, and impact on the family and community as a whole.

Historically, Lifespace has been measured by self-report, or in an institutional setting, as reported by a staff member [1,4,5]. It has been operationalized using: (1) distances travelled, either as a direct measurement or as zones (eg, local neighborhood), (2) the frequency of travel to these destinations over the nominated period of time (eg, two weeks), and, if the focus is on independence in mobility, (3) the requirement of mobility devices or assistance from another person [1,4]. Accurately recalling and noting episodes of leaving the home over the period of a week or longer can be effortful and inaccurate, and, like all measures using self-report, can also potentially be affected by a social desirability bias [23,26]. In a study of community walking involving 50 people with PD, findings indicated that when asked to report their community mobility, 64% substantially overestimated and 10% substantially underestimated their community walking compared to accelerometer recorded walking [23]. An autonomous option for measuring community mobility is therefore warranted. The use of technology to measure Lifespace is an area of recent attention in the gerontology and health literature [2,26,27]. As global positioning system (GPS) sensors are available on most smartphones, and these are a relatively inexpensive and accepted form of technology, their potential use in monitoring Lifespace is being explored with different groups, for example, reference [2].

This study aims to examine whether GPS data collected passively on a smartphone can be used to give an indication of the Lifespace of people with PD. Using the available sample, the specific aims were: (1) to investigate whether Lifespace measured using GPS data could differentiate between people with PD and the control group, and (2) to explore whether symptom severity in PD relates to Lifespace measured by GPS.

Methods

Source of the Data

Data used in the preparation of this article were obtained from the Michael J Fox Foundation Data Challenge [28].

Information sheets were provided to and informed consent was obtained from all participants. Ethical approval was obtained from the Massachusetts Institute of Technology Committee on the Use of Humans as Experimental Subjects (Approval number 1105004497) and The University of Queensland Medical Research Ethics Committee (Approval number 2013001470). Participants were a convenience sample of people living in the community who had PD, or were a control participant approximately age and gender matched to the PD group. Participants were made aware of the study through Parkinson's disease support and research related networks and snowball sampling was used. Participants needed to be able to manage the smartphone and a custom built Android application (App) in terms of charging the device and turning the App on and off. Participants with PD needed to have been diagnosed for at least one year. Participants were provided with an Android smartphone and written instructions about how to use the device, and were requested to carry it on their person for at least 4-6 hours per day (a charge cycle) over a period of at least 8 weeks. Participants were also requested to charge the device overnight, then at the beginning of the day, turn on the device and the App, and conduct their normal regular activities. When the phone battery was low on power, the phone would vibrate and the participants were asked to recharge it. They were asked not to use the device when they were asleep, bathing, or swimming. The technology used to record from the sensors employed a custom built Android App that utilized the embedded sensors on the device. Data were streamed to a Web-based server via the Internet. Basic demographic information was collected from

all participants, and participants with PD also completed and returned a questionnaire containing two partial subscales of the self-report section of the Unified Parkinson's Disease Rating Scale (UPDRS) indicating the impact of motor and nonmotor symptoms on experiences of daily living at the beginning and end of the data collection period [29]. The data were collected between December 2011 and March 2012. Higher scores on the UPDRS indicate a greater impairment/disability for the participant. Included on the UPDRS were four nonmotor items (eg, cognition and apathy) and 13 motor items (eg, freezing of gait, difficulty with swallowing). Participants noted the presence and severity of these symptoms on a five point scale, with higher scores indicating more severe symptoms. The sensors on the phone collected a range of data including audio, accelerometry, and GPS. GPS data were collected while the phone was on and GPS signal was available. Only GPS data were used in the analyses reported in this study.

Global Positioning System Data

GPS sensor readings were available as part of the large dataset and were arranged by participant. The GPS dataset provided the longitude and latitude coordinates in one second intervals with corresponding time and date stamps. Initial analysis of this data involved plotting the individual points in the form of a two-dimensional scatter plot where the x- and y-axes were the respective latitude and longitude scales [30]. Further analysis involved creating visual representations of the Lifespace of participants over the data collection period and creating metrics of Lifespace. These metrics included the furthest distance travelled, mean daily distance, percentage of recorded time at home, and the frequency of trips to-and-from-home. The GPS data were treated as a time-series data. The distance from the home to a particular GPS (latitude, longitude) point was computed using the Haversine formula. This formula computes the distance between two points described by a latitude and longitude coordinate, time and date stamps were then used to calculate daily distances. The metrics either relied on the complete GPS dataset, or data that was segregated into days. "Home" was established mathematically as the statistical mode of recorded latitude and longitude points (ie, the longitude and latitude coordinates at which the most time was recorded). No information about the actual home address of participants was available to validate this approach. Due to limitations in the accuracy of GPS data, being at home was operationalized as being within 500 meters of the mathematically established home. To compute the frequency of trips to-and-from-home metric, a mathematical model referred to as finite-state machine (FSM) was implemented in the Python programming language. This model was defined as having two possible states: (1) subject is at home (SH), and (2) subject is not at home (SNH), transitioning between each state was determined by the corresponding GPS data. For each participant, the model stepped through each GPS coordinate, if the subject was seen to be more than 500 meters from their designated home and the current state of the FSM was set to SH, the FSM transitioned to a SNH state, and the date and time stamp of the current GPS recorded. Conversely, if the current state of the FSM is SNH, and the subject is observed to be less than 500 meters from home, the FSM transitions to a SH state, and the time and date stamp recorded. To minimize false trips that may be an artifact of the inaccurate GPS data, trips measuring less than 15 minutes were ignored.

The Lifespaces of participants with PD and control participants were compared visually and statistically. Participants with PD were then ordered according to reported symptom severity and Lifespace metrics, and visually examined. Due to the small sample size, nonparametric statistics were used. STATA software (version 12SE) was used for these statistical comparisons.

Results

Participant Data

Data were available from 9 participants with PD and 7 control participants. Participants lived within two states in the United States, Maine (14) and California (2). There were 12 that lived in metropolitan areas, and 4 lived in semirural regions. A summary of the basic demographic information and amount of data for each group is in Table 1. In the control group, 3 participants reported no health conditions, and 4 reported health conditions including endocrine and cardiac conditions. There were 5 of the participants with PD that reported no comorbidities, with the remaining 4 reporting between one and three comorbid conditions including cardiac, oncological, opthalmological, and renal conditions. The 9 participants with PD reported a median of 9 years since diagnosis, ranging from 2 years to 20 years. Initial scores on impact of motor symptoms ranged from 5 to 23 (median 9) out of a possible 39, and for nonmotor ranged from 0 to 6 (median 2) out of a possible 12. Scores at the end of the data collection period stayed reasonably stable, with 1 participant not completing this measure, and only 2 participants showing a change greater than one point (in both cases, a decrease in symptoms).

Table 1. Demographic characteristics of participants.

	n	Age years, median, (IQR[a])	Gender, n (%) male	Days recorded median, (IQR)
PD group	9	55 (55-65)	9 (78)	40 (20-64)
Control group	7	57 (53-77)	5 (71)	22 (13-47)

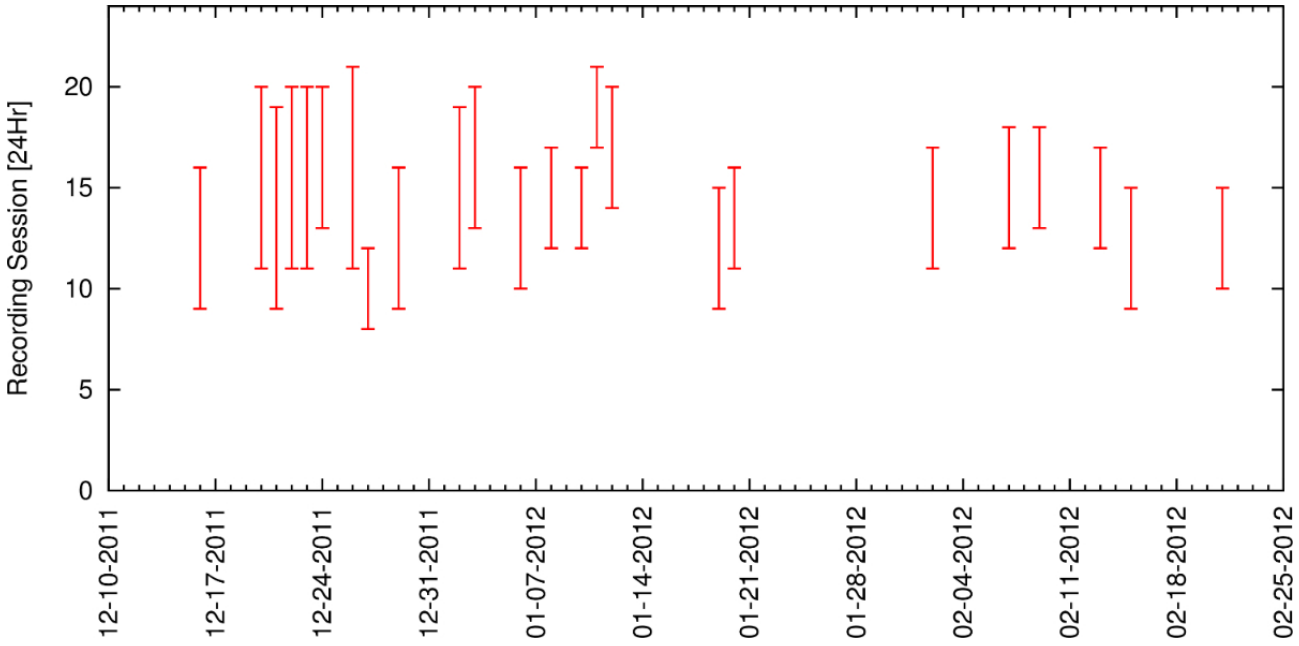
[a]IQR= interquartile range

Limitations of the Global Positioning System Data

Examination of the data revealed that the time periods represented in the dataset (days and times of day when the phone collected data) were not consistent, and also did not cover the full day (see Figure 2 shows the recording times). This should be taken into account when considering the data. Information about neighborhoods and zones, as they related to participants,

was not available, and neither was the amount and type of assistance required for community trips. Information about in-home mobility was also not available due to the insufficient accuracy of the GPS sensor to give reliable results. GPS accuracy is dependent on the receiver sensitivity, the size of the antenna, the number of scattering objects between the GPS transmitter and the smartphone, and the number of visible, operating GPS satellites. Although the Android operating system is capable of recording accuracy, this was not recorded in the provided dataset. Experiments performed by the authors showed GPS error is significant when used indoors, and thus, the inferred information about in-home mobility is likely very limited.

Figure 2. Recording periods of a participant. (Participant 3, Parkinson's disease, Aged 57).



Lifespace Comparisons of Participants With Parkinson's Disease and the Control Group

Figure 3 shows the visual representations of Lifespace that were created using scatterplots of the mean-subtracted latitude and longitude. To ensure the privacy of participants, scatterplots were produced using the mean-subtracted latitude and longitude coordinates rather than the raw values. The visual representations indicated that the control group was reasonably diverse in its Lifespace patterns. The Lifespace metrics were also compared between groups in Table 2. Daily Lifespace heatmaps were made for a member of each group, and the progression was visually compared (see Multimedia Appendix 1). An example heatmap, using local GPS based Lifespace data transposed into another location (in Shanghai), illustrates the nature of Lifespace heatmaps (Figure 4 shows this heatmap). Statistical testing using a Mann-Whitney *U* test indicated no significant difference between the Lifespace metrics for the control group and the PD group.

Table 2. Comparison of Lifespace of PD group and control group.

	Median maximum distance (km), (IQR[a])	Median daily average distance (km), (IQR)	% of time at home, (IQR)	Median of average number of trips each week, (IQR)
PD group	67 (27-664)	10 (8-17)	56 (27-66)	6.07 (5.25-8.96)
Control group	215 (23-1056)	12.5 (7-14)	42 (26-58)	3.97 (3.50-7.89)
Statistical comparison	z=0.05 *P*=.96	z=0.21 *P*=.83	z=0.85 *P*=.40	z=1.32 *P*=.19

[a]IQR= interquartile range

Figure 3. Scatterplots of Lifespace over recording period-Participants in Parkinson's disease and control groups in order of age.

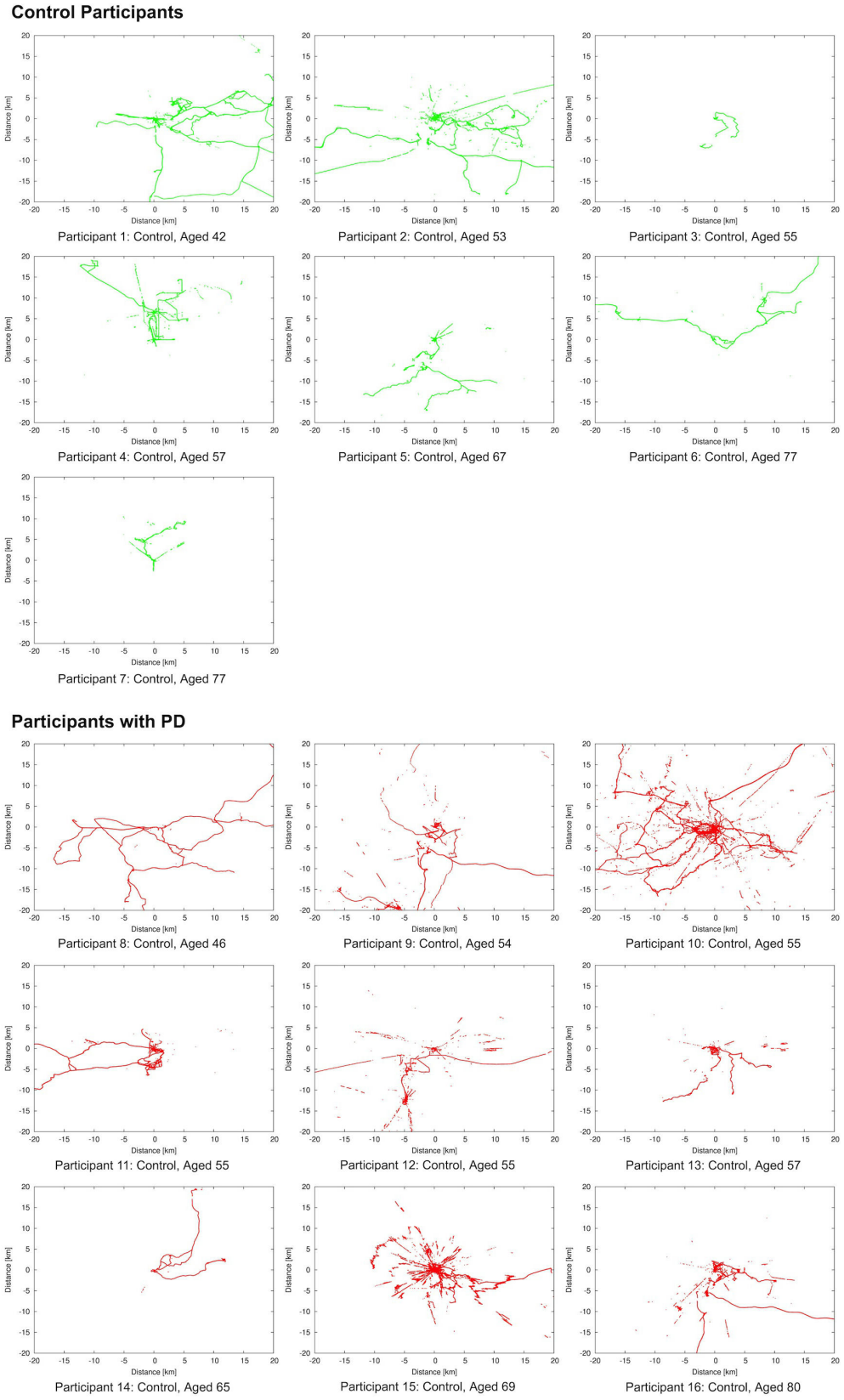
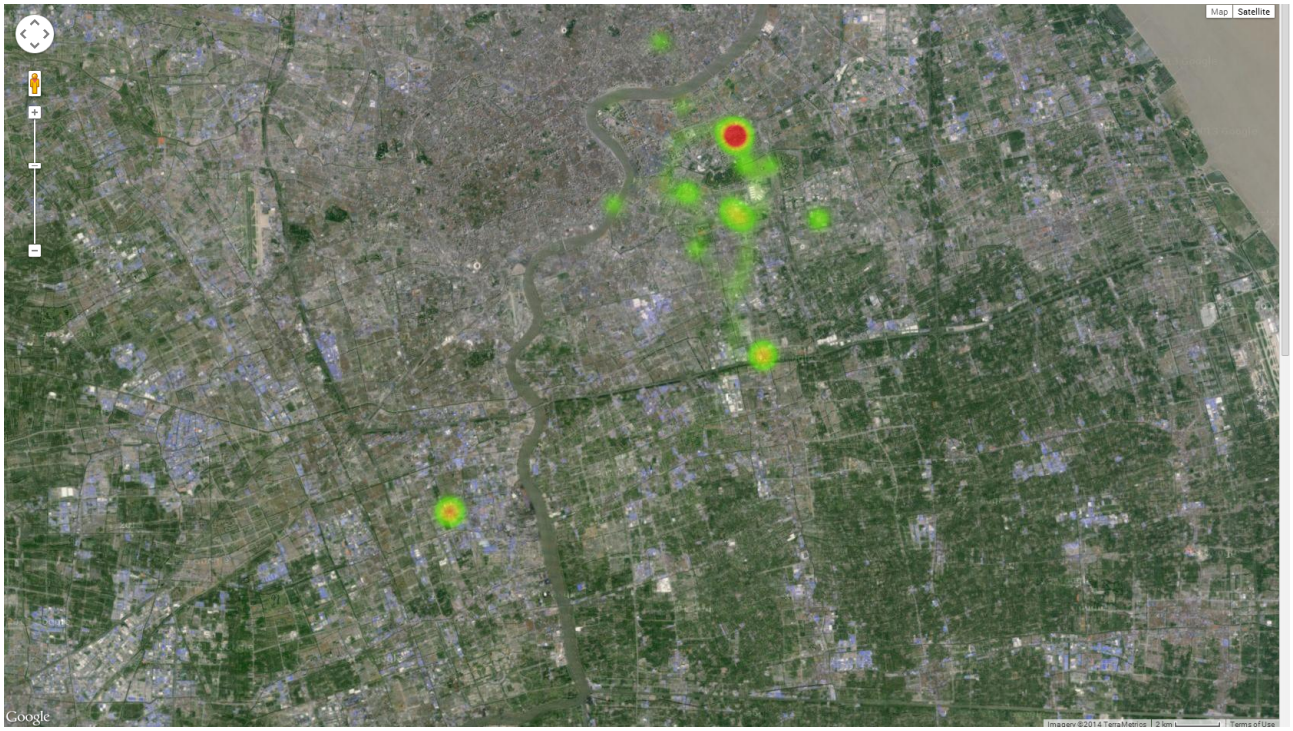


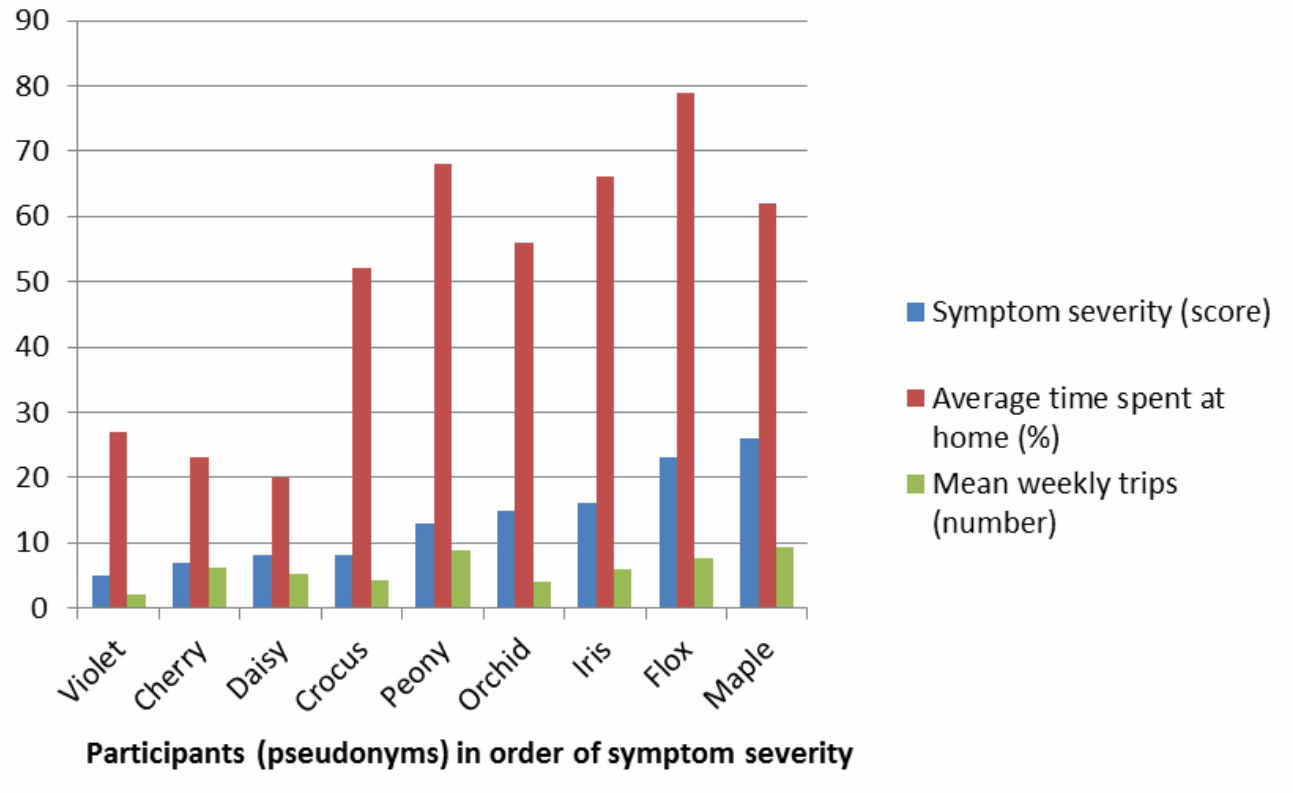
Figure 4. Illustrative heatmap of Global Positioning System (GPS) based Lifespace for the period of 1 week.



Lifespace and Severity of Parkinson's Disease Symptoms

To explore the relationship between the severity of PD symptoms at baseline and Lifespace, the metrics were visually compared based on symptom severity (Figure 5 shows this image), indicating a trend of decreasing Lifespace with increasing severity of reported symptoms as measured by the initial partial UPDRS score. Due to the participant numbers and distribution of scores, statistical testing was not conducted.

Figure 5. Symptom severity and Lifespace metrics for participants with PD.



Discussion

Global Positioning System Data From Smartphones Can Indicate Lifespace

This study indicated that Lifespace might provide an objective outcome measure embedded in the person's local context that is useful for monitoring the lived community access and participation of people with PD. This study used a released dataset to explore whether Lifespace could be meaningfully identified and analyzed from passively collected GPS data from smartphones. As a proof of principle, the findings of this study indicate that GPS data can be analyzed to give visual representations, metrics, and may relate to the self-reported severity of PD symptoms.

Lifespace Metrics

The Lifespace metrics showed expected trends for people with more symptoms spending additional time at home and travelling shorter distances, indicating a more constricted Lifespace. This finding is also supported by other studies that investigated the Lifespace of older people, and indicated the strong impact of movement disorders such as PD on Lifespace outcomes, for example, references [9,14].

The use of passively measured Lifespace data to monitor outcomes for PD may have a number of applications. As has been done in establishing early or prodromal periods in cognitive impairment, for example, reference [15], monitoring Lifespace may help to better understand and predict the onset and course of PD. Another application may be in investigating the impact and effectiveness of interventions for PD. Medical and surgical treatments for PD have often been monitored at the symptom or symptom-related quality of life level, for example, reference [28], but they can have broader impacts on participation. Some recent published trials and reviews of rehabilitation programs for PD have suggested the need for measurement of lived outcomes in a way that is not arduous for participants who may have cognitive and physical impairments [24,31].

No Statistical Differences in Lifespace Between Parkinson's Disease and Control

The current study indicated that people with PD could not be statistically differentiated from approximately age and gender matched controls on the basis of Lifespace alone. This is not a surprising finding as Lifespace is not an illness or symptom specific measure and can be affected by numerous characteristics of the person, their environment, and the supports that are available to them. The control group data indicated quite varied Lifespace metrics. Other Lifespace studies have indicated the impact of ageing, for example, reference [5], illnesses, for example, reference [32], different forms of treatment [7], and life roles including caregiving, for example, reference [19] in creating a restricted Lifespace. Based on this, it seems likely that a heterogeneous group like the control group would have diverse Lifespaces. It should also be noted that the control group appeared quite different from the PD group in how much data they recorded. The PD group chose to have their phones actively recording for more days and longer periods than the control group. This possibly reflects greater interest or higher motivation on the behalf of the participants with PD, due to the focus of the study. Due to the potential bias towards active parts of the day or week, the Lifespace findings from the recorded periods cannot be directly extrapolated into the nonrecorded time periods, and as such, cannot be easily compared across groups with different amounts of data collected (such as the control group).

Established and New Ways to Report Lifespace

This study combined established and new ways to report Lifespace. The most commonly used metric for reporting Lifespace requires calculating a score based on frequency and assistance required for movement within specified zones (eg, home, local neighborhood), for example, reference [1]. This information was not available from the shared dataset, so this score could not be approximated. Because of this, different metrics and visual methods of representing Lifespace were therefore developed. The approach for creating scatterplots of latitude and longitude coordinates used in the current study has been previously used in exploring GPS data to give insights into Lifespace, for example, reference [33]. The other metrics analyzing GPS data mathematically to determine the location of "home", relate time spent away from this location, and trips away from this location were new developments in Lifespace research. Future research should explore the validity of this metric, comparing it to established methods of measuring time use and Lifespace.

A Comparison of Study Findings

A comparison of the findings of the current study can be made with Lifespace and time use studies. Xue et al [15] used a categorization of Lifespace restriction over a week, severe (never leaving home), moderate (leaving home, but never leaving the neighborhood), slight (fewer than four trips away from the neighborhood), and no restriction (leaving the neighborhood more than four times). While neighborhood zones could not be established from the GPS data in the current study, it is possible that some participants were moderately restricted, some slightly restricted, and others would show no restriction. No participants recorded zero episodes of leaving home. Time use studies use self-reported time diaries to account for how time is spent over a week. A study of 195 older community-dwelling people in Australia, which was validated against the national time use statistics, found that, when measured over a week, older people spent about 85% of their time at home, and recorded eight episodes of leaving the home [32]. The findings from the current study show much higher proportions of time spent out of home and fewer trips, but this is likely to reflect the different participant groups and methodology. The current study did not record over a full day, instead, recording for a single charge cycle when participants turned on the phone. As participants chose when and how often to switch the smartphones on, this is likely to affect the comparative representativeness of the Lifespace data. It is possible that people were more likely to switch on the smartphone when they were going out, and therefore the percentage of recorded time spent at home reflects this more active portion of their life. Future studies, using a more set recording protocol, will enable this comparison to be explored more fully. Further investigation will also be needed

to compare the smartphone-based method of recording Lifespace with validated approaches for measuring Lifespace and time use.

Participants and Transferrability

The use of a shared database, which provided limited information about the process of recruitment or the demographic information about the small number of participants, means that it is difficult to establish whether the findings from this study would be transferrable to other contexts. As a proof of principle, it seemed reasonable that the participants represented the general age range and gender profile as larger studies of community-based people with PD, for example, reference [34]. They represented a range of severity of PD, and the length of disease varied between participants, indicating that this approach may be useful throughout the duration of the disease for community-dwelling people with PD.

Using Smartphones to Measure Lifespace via Global Positioning System Data

The use of a smartphone App to passively measure GPS is a promising approach for measurement of Lifespace. Although it could be argued that dedicated GPS loggers would provide for more accurate GPS recording due to their dedicated electronics and longer battery life, the ubiquitous nature of smartphones makes this an accessible and acceptable technology to consumers. Their inclusion of other sensors within the smartphone such as accelerometer, gyroscope, and compass, that can be used in future work, makes the choice of smartphones as the data logger of choice more appealing. Local testing using the GPS logger on a typical smartphone indicated that it has negligible effect on the battery status and the operation of the phone.

Limitations and Future Directions

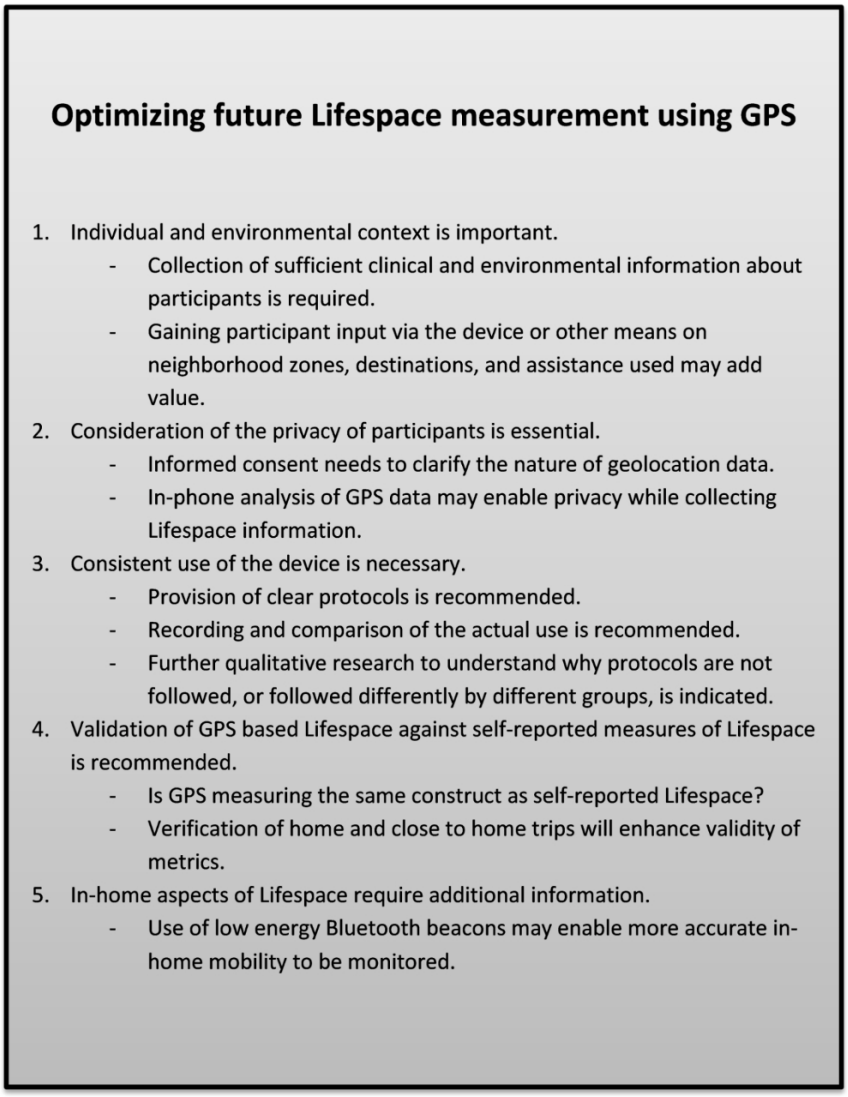
This study aimed to provide a proof of principle that GPS data collected passively via smartphones could be used to indicate the Lifespace of people with PD. It also enabled exploration of the limitations and issues encountered in measuring Lifespace via GPS in a clinical population. Some recommendations for future directions have been made (Figure 6 shows the recommendations). Despite the potential usefulness of Lifespace for monitoring the community engagement of this population, a number of limitations in the current study are discussed with particular reference as to how they might be overcome in future research. As well as using a small convenience sample that may not be representative, insufficient information was available about the objective health of or context (eg, local community resources, geography, climate) for participants, which may all be expected to influence Lifespace. The actual location of home could also not be verified. In addition, there was not a consistent protocol followed in terms of times when the smartphone collected data. This may affect the validity of the collected data in reflecting the lived experience and in enabling meaningful comparison between participants. The Lifespace metrics could not be validated against self-report measures of Lifespace due to limited information about in-home mobility, assistance required for community mobility, and reasons for and satisfaction with community travel. While the use of a partial section of the UPDRS which utilized self-report of symptoms rather than clinical evaluation reduced participant burden and study costs through not requiring clinical assessments, it is also likely to be less valid than a full clinical evaluation.

A further limitation of this approach was in the provision of GPS data in latitude and longitude coordinates. While this approach enabled accurate measuring of participants' movements, it also revealed their locations at home and in community destinations. Care needs to be taken in collecting and sharing data of this nature or in clarifying with participants the type and detail of data collected. In the current study, the anonymity of participants was preserved in presenting the results via the calculation and reporting of mean-subtracted latitude and longitude. In recording GPS positions, having information about position accuracy is important. The accuracy of the reported latitude and longitude values can vary depending on the number of GPS satellites visible by the sensor, whether the sensor is located indoors or outdoors, ambiguities due to atmospheric changes, and interfering signals. Although the Android operating system has the capability of determining the accuracy of the GPS reading, this was not recorded and this is a limitation of the current data. To account for this, a cautious threshold of 500 meters for determining whether the person was at *home* was set. However, assuming the GPS sensor was located outdoors, it was quite likely to obtain an average accuracy of approximately 10 meters based on testing completed by the authors. Future research should record GPS accuracy to enable more valid assumptions to be made. A consequence of GPS logging is the invasion of privacy. It is expected that not all consumers or research participants would be comfortable with this. As an alternative, it is possible to log the current cellular tower to which the participant's phone is connected. While this would give coarser information on subject location and travels, it would be less intrusive and not rely on the embedded GPS sensor. The measurement of Lifespace is also complicated when participants are indoors, as the accuracy of reported latitude and longitude values degrades in this setting, as described earlier. Future work could include the use of low energy (or low power) Bluetooth beacons for more accurate indoor monitoring. We believe this will be a low cost approach and allow the smartphone to become the primary Lifespace recording device.

Future research can expand on this work through the investigation of the Lifespace of a larger group of community-dwelling people with PD and the collection of more objective baseline data about their health and local context. In addition, subjective information about their trips (eg, purpose of trip, satisfaction) could also be collected. More consistent recording of Lifespace could be enabled through the use of specific recording protocols that detail the time and duration of smartphone use. The use of smartphones could be further developed to enable better monitoring of in-home mobility and protection of the privacy of participants by allowing them to opt in and out of data collection, and converting data to a different form for analysis and sharing. The validity of the Lifespace metrics could be compared to established measures of Lifespace, time use and participation. Future research could also investigate the relationship between Lifespace and other outcomes for people with PD including presence of particular

symptoms, mood, activity participation, and quality of life. The relevance of Lifespace as a measure of the effectiveness of therapeutic interventions should be further explored.

Figure 6. Future directions for use of GPS to measure Lifespace.



Conclusions

This study provides a proof of principle that Lifespace is a relevant concept for monitoring the community access of people with Parkinson's disease. Further, it can be collected passively through smartphones. While the Lifespace data collected over a period of two months did not statistically differentiate between people with PD and a control group, it did point to a relationship between the severity of reported PD symptoms and Lifespace. Measuring Lifespace using GPS-enabled smartphones may be an economical and user friendly option to measure the community access and participation of people with PD, but further research within a more robust experimental design is required.

Acknowledgments

We acknowledge the Michael J Fox Foundation in sharing its dataset as part of the Michael J Fox Foundation Data Challenge. The authors prepared a broader response to the challenge that is summarized in a video presentation (see Multimedia Appendix 2), which includes some of the findings reported in this manuscript.

Conflicts of Interest

Conflicts of Interest: None declared.

Multimedia Appendix 1

Video comparing daily Lifespace of a participant with PD and a control participant.

[MP4 File (MP4 Video), 401KB - mhealth_v2i1e13_app1.mp4]

Multimedia Appendix 2

Authors' broad video response to the Michael J Fox Foundation Data Challenge.

[M4V File, 66MB - mhealth_v2i1e13_app2.m4v]

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Abbreviations

App: application
FSM: finite-state machine
GPS: Global positioning system
PD: Parkinson’s disease
SH: subject is at home
SNH: subject is not at home
UPDRS: Unified Parkinson’s Disease Rating Scale

Edited by G Eysenbach; submitted 28.06.13; peer-reviewed by P Boissy, W Conte, X Zhang, S Lim Choi Keung; comments to author 17.09.13; revised version received 21.01.14; accepted 07.02.14; published 12.03.14.

Please cite as:
Liddle J, Ireland D, McBride SJ, Brauer SG, Hall LM, Ding H, Karunanithi M, Hodges PW, Theodoros D, Silburn PA, Chenery HJ
Measuring the Lifespace of People With Parkinson's Disease Using Smartphones: Proof of Principle
JMIR Mhealth Uhealth 2014;2(1):e13
URL: http://mhealth.jmir.org/2014/1/e13/
doi:10.2196/mhealth.2799
PMID:25100206

Original Paper

Who Uses Smoking Cessation Apps? A Feasibility Study Across Three Countries via Smartphones

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Abstract

Background: Smartphone use is growing worldwide. While hundreds of smoking cessation apps are currently available in the app stores, there is no information about who uses them. Smartphones also offer potential as a research tool, but this has not previously been explored.

Objective: This study aims to measure and compare the uptake of a smoking cessation app over one year in Australia, the United Kingdom, and the United States. It also assesses the feasibility of conducting research via an app, describing respondents' characteristics (demographics, smoking status, and other health related app use), and examining differences across countries.

Methods: This is a cross-sectional exploratory study of adults 18 years and older, passively recruited over one year in 2012, who downloaded this study app (Quit Advisor) via the two largest app stores (Apple and Android).

Results: The total number of app downloads after one year was 1751, 72.98% (1278/1751) of them were Apple operation system users. Of these 1751 participants, 47.68% (835/1751) were from the United States, 29.18% (511/1751) were from the United Kingdom, and 16.68% (292/1751) were from Australia. There were 602 participants, 36.75% (602/1638) that completed a questionnaire within the app. Of these 602 participants, 58.8% (354/602) were female and the mean age was 32 years. There were no significant differences between countries in terms of age, operation system used, number of quitting attempts, and language spoken at home. However, there were significant differences between countries in terms of gender and stage of change. There were 77.2% (465/602) of the respondents that were ready to quit in the next 30 days and the majority of these had never sought professional help (eg, "Quitline"). More than half had downloaded smoking cessation apps in the past and of these, three-quarters had made quitting attempts (lasted at least 24 hours) using an app before. Respondents who had attempted to quit three times or more in the previous year were more likely to have tried smoking cessation apps (OR 3.3, 95% CI 2.1-5.2). There were 50.2% (302/602) of the respondents that had used other health related apps before. Of these, 89.4% (270/302) were using health related apps at least once a week, but 77.5% (234/302) never checked the credibility of the health app publishers before downloading.

Conclusions: A smartphone app was able to reach smokers across three countries that were not seeking professional help, but were ready to quit within the next 30 days. Respondents were relatively young and almost demographically similar across all three countries. They also frequently used other health related apps, mostly without checking the credibility of their publishers.

(JMIR Mhealth Uhealth 2014;2(1):e4) doi:10.2196/mhealth.2841

KEYWORDS

smartphone; handheld computers; health promotion; tobacco and smoking; global health; prevention; apps; health Informatics; public health

Introduction

Smartphones and Apps

A smartphone is a mobile phone handset with advanced hardware and software capabilities that enable it to perform complex functions [1]. Consumers can utilize the advanced functionalities of smartphones and download applications (apps) from app stores. These apps are as capable as those that can be run on laptops, and can replace them in most functions, such as Web browsing, document processing, video and music playing, and task management. The smartphones' portability makes apps available to consumers anytime and anywhere, which saves time and offers more privacy and anonymity. Such proximity to the consumer gives the smartphone great potential as a health promotion tool.

By the end of 2012, smartphone ownership accounted for 76% of all mobile phone handsets in Australia [2], 39% in the United Kingdom [3], and 55.5% in the United States [4]. The Android operating system (OS) and Apple OS devices dominate these uptake rates [2,4,5]. However, Android smartphone ownership is almost double that of Apple OS devices in both the United Kingdom and the United States [4,5].

App stores are not ordinary Web-based stores. They attract millions of users who seek apps for their smartphones. The largest are the Google Play (previously known as the Android Market) and the Apple App Store. In 2009, after nine months in business, the Apple App Store had uploaded one billion apps to its users [6]. In 2012, Apple users had downloaded 40 billion apps, up from 15 billion in 2011 [7,8]. Android users downloaded 25 billion apps in 2012, up from 10 billion in 2011 [9,10]. The app stores also allow the app owner to select which countries they want their app released in, allowing only users in those countries to see the app and download it. This offers an opportunity for researchers to explore the efficiency or effectiveness of health apps in a selected country without contaminating the results from users from other areas of the world. However, the accuracy of such function has never been tested before.

Smartphones and Smoking Cessation Programs Delivery

The most widely used self-help smoking cessation program delivery method is printed documents [11,12]. However, printed self-help materials have disadvantages such as printing costs, limited distribution, lack of interactivity, and are limited in their ability to tailor for individual needs [11,12]. By contrast, computerized smoking cessation interventions eliminate printing costs, make updating easier, and can include interactivity and tailored intervention features [13,14]. Updating them, however, requires the user to download updates from the Internet, CD, or other computer media. The only advantage of computer-based interventions over Internet-based interventions is that computers do not require an Internet connection. Internet-based smoking cessation interventions have the advantages of anonymous online chat groups, bulletin discussion boards, and email, where health consumers can discuss sensitive personal health issues more comfortably than they can face-to-face in self-help groups [15].

The smartphone apps bring together the advantages of computer-based and Internet-based smoking cessation interventions. They also overcome their limitations. When there is no Internet connection, the user can still benefit from the computational interactive function and static information in the apps. The apps can host all kinds of multimedia, such as static and interactive rich-text, pictures, audio and video, and get more content when there is an Internet connection, without any user effort. Smartphone apps can also aid interactive self-monitoring by letting users add data about their health in various ways, including question and answer forms, text writing, and audio or video recordings. The apps can process, organize, and graph this self-monitoring data to help users understand their progress. Using this data can help the users in every step of their quitting journey, providing text information about quitting, letting them see how many days they are nicotine-free, providing diaries for their quitting attempts and craving triggers, and sending them reminders and motivational messages.

Dozens of smoking cessation apps are in smartphone stores, some with exaggerated claims of effectiveness [16]. No studies have yet assessed their uptake or their feasibility to be used as an intervention as well as a research tool. Protocols of randomized controlled trials to examine the effectiveness of smartphone apps to assist smokers in their quitting are emerging. A recent published protocol will examine a health care professional consultation plus smartphone app versus a standard counseling in participants recruited at primary care centers with 6 months follow up [17]. The study has not mentioned the OS that will be utilized [17]. Furthermore, another trial protocol by the authors will examine the effectiveness of an interactive smoking cessation self-help app versus standard smoking cessation information (including information about smoking consequences, quitting options, etc) that will be provided via a smartphone app [18]. The participants will be recruited directly from the Apple app store via one app that after identifying eligibility will randomize the participants to one of the subapps and follow their quitting attempt at 4 time points (10 days, 1 month, 3 months, and 6 months) [18]. Both studies are examining various ways to utilize smartphone apps in smoking cessation assistance and via different recruitment methods [17,18]. Pending the results of these two studies, more information is needed about the actual users of smoking cessation apps to help in customizing future interventions to target these users and to assess the feasibility of using smartphones to collect data. In addition, more information about smoking cessation apps' uptake and users' demographics in different OSs will help future research decide which systems to target.

In 2011, a study analyzed the content of 47 smoking cessation apps in the Apple App Store and found most of them were not evidence-based, particularly the most popular ones. Very few provided information about nicotine replacement or other effective quitting methods [16]. In addition, harmful prosmoking apps have found their way onto the market. In a recent paper, we identified 107 prosmoking apps; 42 were from the Android Market and downloaded by an average of 11 million users [1]. Some of those apps claim they can help people quit smoking

[1]. Therefore, efforts are needed to bring evidence-based smoking cessation materials into this new medium.

Very little is known about app users or the ability of app stores to reach smokers. Thus, before examining the effectiveness of smoking cessation apps, we must know as much as we can about their potential users.

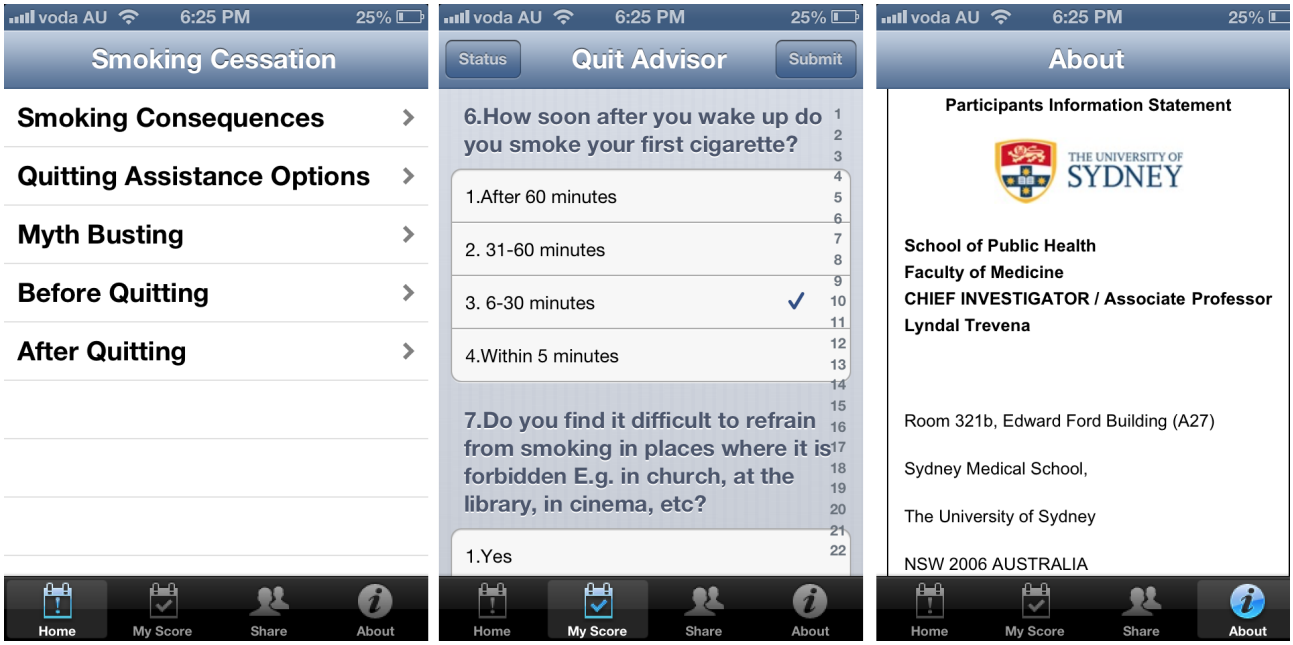
This exploratory study examined the feasibility of a free smoking cessation smartphone app developed for this study and published in the Apple App Store and Android Market to reach smokers. The study was designed to: (1) measure and compare the uptake of a smoking cessation app over one year in Australia, the United Kingdom, and the United States; (2) assess the feasibility of the smartphone as a research tool describing respondents' characteristics (demographics, smoking status, and other health related app use); (3) examine differences between respondents from each country; and (4) investigate the association between smoking status and smokers' use of smoking cessation apps.

Methods

Design and Recruitment

This is a descriptive, cross-sectional, exploratory study of a convenience sample of adults 18 years and older, passively recruited over one year, who downloaded Quit Advisor (QA) via the app stores. As part of this study, we developed a free smartphone smoking cessation app (QA) and released it in the Apple and Android stores in Australia, the United States, and the United Kingdom in April 2012. Consumers in those stores and countries downloaded the app after viewing the study information and consent. The app page summarized consent information before download and we also included it in the terms of use agreement. We also included the consent form and participant information sheet inside the app "About" section so users can get back to it easily (Figure 1 shows a screenshot of the study app).

Figure 1. Screenshots of the study app.



App Design and Data Collection

QA is a smartphone app developed specifically for this study. It contains two major parts: (1) evidence-based information about smoking cessation, and (2) a questionnaire. The questionnaire collected data about demographics, smoking behavior, and nicotine dependency using the Fagerström scale [19], stage of change [20,21], previous use of smoking cessation apps, and general use of health related apps. When the user opened the app for the first time, it extracted the unique device identifier, encrypted it, and registered the user in the study's database. This allowed anonymous data collection, eliminated the need for registration, and prevented duplication, as each device has only one chance of being in our records, even if the user reinstalls the app or the OS. The app's first section, "Home" (Figure 1), contained information such as health effects of smoking and quitting options collected from recent research and health reports. The average level of the information on the Flesch-Kincaid readability test was 8th grade (age 14). Any time the user opened a category, the app sent the time and date of each view to the Web-based database as soon as an Internet connection was available. At the end of each category there was: (1) a reference list, and (2) an optional Likert-scale question to rate the motivational effect of the provided information in each category. In the second section, "My Score" (Figure 1), users completed the questionnaire. After submitting it, they received feedback about their nicotine dependency. Answers automatically went to the study's database. Participants could only submit the questionnaire once, even if they deleted and reinstalled the app. Participants could not submit the questionnaire without completing all questions. The app was pretested by a group of users in various situations to assure the accuracy of the transferred data, and to test the other app functions such as country detection. In addition, to minimize the possibility of some users installing the app on more than one device, we have implemented a server-side Internet Protocol

(IP) monitoring that can identify the users that use different devices connected to the same Internet network at similar times. Although this function was pretested successfully, no cases were identified during the data collection. Finally, because the app stores accuracy of limiting the app to specific countries is unknown, we have implemented a location identification function to know the users country the first time they open the app.

Analysis

Descriptive analysis was used to assess the uptake of the app and the characteristics of the users' ratings of the information categories. Bivariate analysis (chi-square and one way analysis of variance) helped examine the differences between countries in terms of user characteristics. Logistic regression controlling for demographics (age, gender, country, and education level) was used to investigate variables related to prior use of smoking cessation apps and the effect of app type on quit attempts.

Results

Uptake

Figure 2 shows, in one year, 1751 users downloaded the app from both stores, 72.98% (1278/1751) from the Apple Store and 27.01% (473/1751) from the Android Market. Of those 1751, 47.68% (835/1751) were from the United States, 29.18% (511/1751) from the United Kingdom, 16.68% (292/1751) from Australia, and 6.45% (113/1751) from other countries. The lowest Android download rate was in Australia at 9.7% (46/473), compared with 19.25% (246/1278) for Apple OS. After excluding users who submitted the questionnaire from other countries, 602 had submitted it, with an overall response rate of 36.75% (602/1638). The highest response rate was 44.8% (131/292), from Australia.

Participants' Characteristics

Of those 602 who submitted the questionnaire, 50.0% (301/602) were from the United States, 28.2% (170/602) from the United Kingdom, and 21.8% (131/602) from Australia. The majority of participants 76.4% (460/602) were using Apple devices. The participants' mean age was 32 and the median 31 years (18-67). Female participants outnumbered males by 17.6% (106/602). The most common level of education reported was "High School." A chi-squared (χ^2) test showed a significant education-level difference between countries (Table 1). Countries differed significantly in gender distribution, with women only outnumbering men in the United States. After assuring the homogeneity of variance a one-way analysis of variance revealed no significant differences between countries in terms of age–$F_{2,601}$= 2.6, P=.07. Furthermore, there were no significant differences between countries in term of language spoken at home and OS used.

Smoking Status

The Fagerström scale puts 44.5% (268/602) of the participants at a low or very low nicotine dependency, and 55.5% (334/602) at a medium to very high nicotine dependency (Table 1). After assuring the homogeneity of variance, a one-way analysis of variance revealed significant national differences in nicotine dependency scores, $F_{2,601}$=4.4, P=.01. Post hoc comparisons using Tukey's HSD test indicated that the mean score for Australia (mean 5.4, SD=2.4) was significantly higher than that of the United States (mean 4.6, SD=2.4). UK participants (mean 4.7, SD=2.7) did not differ significantly from either Australian or US participants.

Most participants 77.2% (465/602) were willing to quit in the next 30 days (preparation stage of change), and most of them 67.6% (407/602) had attempted to quit at least once in the previous year. A quitting attempt was defined as one that had lasted at least 24 hours. There was a significant difference between countries in terms of willingness to quit, but none in terms of previous quitting attempts.

There were 88.7% (401/452) of participants that had not contacted the "Quitline" services in their countries in the last year, with no significant variation between countries χ^2=0.7, P=.71. Moreover, 71.7% (324/452) of participants had not contacted their health care professionals regarding quitting in the last year. However, here there was a significant variation χ^2=7.9, P=.019, with 38% (36/93) of Australian participants contacting health professionals compared to 30.0% (36/120) in the United Kingdom, and 23.4% (56/239) in the United States.

There were 54.5% (328/602) of the participants that had used smoking cessation apps in the past, and the majority 75.6% (248/328) had made a quitting attempt that lasted at least 24 hours using an app. There were no significant differences between countries in terms of using smoking cessation apps in the past and making quitting attempts using those apps. There were 33.0% (82/248) of those who made quitting attempts using an app that had lasted more than one week abstaining from smoking.

Three or more quit attempts in the past year were associated with previous smoking cessation app use (OR 3.3, 95% CI 2.1-5.2). There was a suggestion of a dose-response relationship between the number of quit attempts and smoking cessation app use with two or more attempts also being associated (OR 2.9, 95% CI 11.8-4.7). In addition, difficulty to refrain from smoking in banned areas was associated with the likelihood of the participants trying smoking cessation apps (OR 1.5, 95% CI 1.0-2.1).

"Smoking counter" apps were the most frequently used, followed by "motivation" apps (Table 2). We have investigated if the use of any of these app types was associated with quitting attempts, controlling for age, gender, country, and education level. To do this, we asked users if they have used smoking cessation apps previously, what type of apps they have used, and if they tried to quit using these apps. We found an association between "smoking counter" apps and participants quitting attempts in the past (OR 2.2, 95% CI 1.2-3.6).

Figure 2. Flowchart of the recruitment process. The percentages were rounded up to the nearest whole.

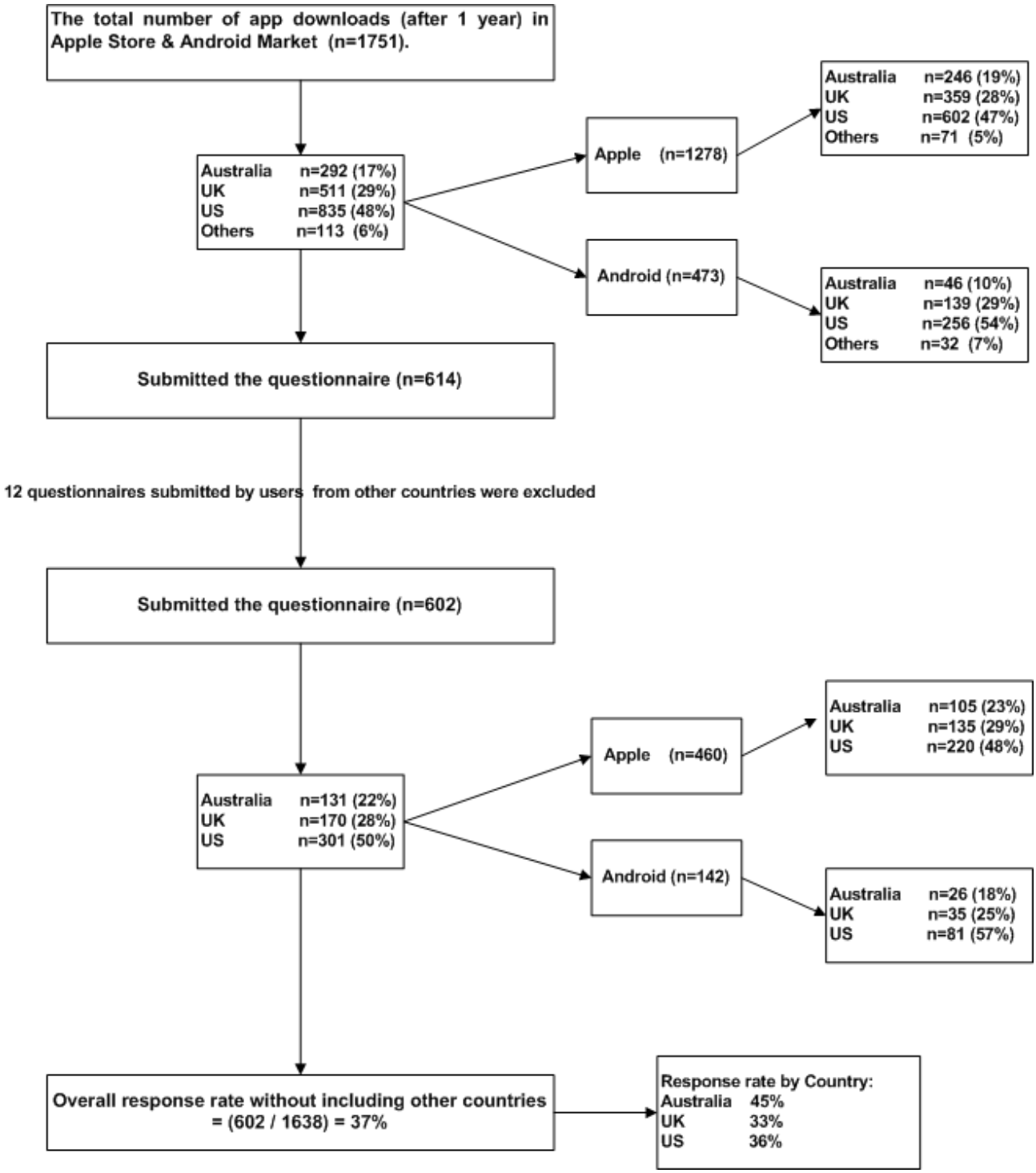


Table 1. Participants' characteristics by country (n=602).

Characteristics		Country			Total	χ^2 (*P*)
		AU n (%)	UK n (%)	US n (%)	n (%)	
Age, mean (SD) (years)		33.2 (9.4)	30.8 (9.9)	32.6 (10.2)	32.2 (9.9)	-
Sex						30.4 (.001)
	Female	65 (49.6)	79 (46.5)	210 (69.8)	354 (58.8)	
	Male	66 (50.4)	91 (53.5)	91 (30.2)	248 (41.2)	
Education						28.7 (.001)
	High school	73 (55.7)	67 (39.4)	161 (53.5)	301 (50.0)	
	Diploma/Associate	12 (9.2)	33 (19.4)	57 (18.9)	102 (16.9)	
	Graduate (Bachelor)	21 (16)	25 (14)	32 (10)	78 (13)	
	Master Degree or higher	5 (3)	5 (2)	19 (6)	29 (4)	
	Others	20 (15)	40 (23)	32 (10)	92 (15)	
Language spoken at home						5.5 (.64)
	English	117 (89.3)	157 (92.4)	287 (95.3)	561 (93.2)	
	Others (14 Languages)	14 (10)	13 (7)	14 (4)	41 (6)	
OS						3.7 (.15)
	Apple	105 (80.2)	135 (79.4)	220 (73.1)	460 (76.4)	
	Android	26 (19.8)	35 (20.6)	81 (26.9)	142 (23.6)	
Nicotine dependency (Fagerström)						20.9 (.009)
	Very low (0-2)	21 (16.0)	39 (22.9)	64 (21.3)	124 (20.6)	
	Low (3-4)	23 (17.6)	39 (22.9)	82 (27.2)	144 (23.9)	
	Medium (5)	17 (13)	28 (16)	39 (13)	84 (14)	
	High (6-7)	43 (32.8)	31 (18.2)	82 (27.2)	156 (25.9)	
	Very high (8-10)	27 (20)	33 (19)	34 (11)	94 (15)	
Stage of change						11.2 (.02)
	Next 30 days (preparation)	93 (71.0)	125 (73.5)	247 (82.1)	465 (77.2)	
	Next 6 months (contemplation)	28 (21.4)	31 (18.2)	45 (15.0)	104 (17.3)	
	Not thinking of quitting (precontemplation)	10 (7)	14 (8)	9 (3)	33 (5)	
Number of quitting attempts last year						4.9 (.55)
	1 time	35 (26.7)	33 (19.4)	56 (18.6)	124 (20.6)	
	2 times	21 (16.0)	36 (21.2)	66 (21.9)	123 (20.4)	
	3 or more	32 (24.4)	46 (27.1)	82 (27.2)	160 (26.6)	
	Never	43 (32.8)	55 (32.4)	97 (32.2)	195 (32.4)	
Used smoking cessation apps before?						1.4 (.48)
	Yes	77 (58.8)	93 (54.7)	158 (52.5)	328 (54.5)	
	No	54 (41.2)	77 (45.3)	143 (47.5)	274 (45.5)	
Made quitting attempt using an app? (n=328)						1.0 (.60)
	Yes	56 (46.2)	74 (79.5)	118 (74.6)	248 (75.6)	
	No	21 (53)	19 (20)	40 (25)	80 (24)	

Table 2. Number of participants who have used any type of smoking cessation apps in the past.

		Made quitting attempt		
Type of smoking cessation app	Used by number of participants[a]	Yes n (%)	No n (%)	χ^2 (*P*)
Smoking counters (eg, count smoke free days or number of smoked cigarattes)	174	143 (82.2)	31 (17.8)	7.9 (.005)
Motivation (provide motivational messages)	113	86 (76.1)	27 (23.9)	0.0 (.99)
Text information (provide text info about smoking cessation)	76	59 (77)	17 (22)	0.1 (.75)
Combination of different types	68	46 (67)	22 (32)	2.4 (.12)
Hypnosis	51	42 (82)	9 (17)	1.0 (.29)

[a]Some participants have used more than one app.

Participants' Use of Other Health Related Apps

Half of our respondents 50.2% (302/602) had used other health related apps in the past. Of these, 89.4% (270/302) were using health related apps at least weekly and 21.2% (64/302) daily. Participants were asked–"Have you ever checked the credibility of the developer or publisher of the health apps that you are currently using?", and we found that 77.5% (234/302) of them had never checked and there was no difference by country (χ^2=0.3, *P*=.86). Of those who had used health related apps in the past, 51.9% (157/302) used "Diet and Weight Management" apps, followed by 36.4% (110/302) "Training and Physical Activity," 31.7% (96/302) "Health and Medication Information," 23.2% (70/302) "Pregnancy and Ovulation Calculators and Calendars," and 19.5% (59/302) "Medication Intake Reminder." Very few participants had used "Diabetes Management" and "Asthma Control or Management" apps, 4.3% (13/302) and 3.3% (10/302) respectively.

Information Ratings

Few app users rated the information, with most rating only some sections. "Smoking Consequences" information received ratings from 105 participants; with 75.2% (79/105) agreeing it had motivated them to quit. "Quitting Assistance Options" received 93 ratings; with 54% (51/93) agreeing it motivated them to quit, and 8% (8/93) disagreeing. "Myth Busting" also received 93 ratings, 64% (60/93) agreeing and 10% (10/93) disagreeing. "Before Quitting" received 87 ratings, with 70% (61/87) agreeing, "After Quitting" received 85, with 89% (76/85) agreeing. "After Quitting" and "Smoking Consequences" received the most positive responses, while "Quitting Assistance Options" received the least. However, the average number of times participants looked at any information category was 5.4, with no significant differences by country (χ^2, *P*=.85). Chi-square analysis revealed a significant difference in stage of change between participants who looked at the five information categories, and those who did not (*P*=.03). Further logistic regression analysis controlling for age, gender, education, country, and time of recruitment showed that being in the "Preparation stage" or "Willing to quit in the next 30 days" were associated with looking at all the information (OR 1.7, 95% CI 1.1-2.7).

Discussion

Results Summary

In this study, 1638 participants from Australia, the United Kingdom, and the United States downloaded a free smoking cessation app over a 1-year period, and 36.75% (602/1638) of them completed an in-app questionnaire. The majority of respondents 77.2% (465/602) were willing to quit within the next 30 days, and 67.6% (407/602) have tried to quit at least once in the past year. Almost half had used smoking cessation apps in the past, and most had never checked the credibility of their health apps' publisher. Most respondents never sought "Quitline" help 88.7% (401/452), or health care professional help 71.7% (324/452) in the last 12 months. Those who tried to quit twice or more in the last year, and those who find it difficult to refrain from smoking in banned areas, were more likely users of smoking cessation apps in the past.

Number of App Downloads

In this study, we have examined the app uptake naturally without external promotion, and this may explain the small number of downloads over one year. In addition, the fact that smoking prevalence in the included countries varies from 15% to 20% with the lowest in Australia 15% [22] and highest in the United Kingdom 20% [23]. Therefore, the app downloads might be affected by the country population, prevalence of the condition, and the smartphone uptake in each country. Moreover, apps can also be affected by the app store rankings (where the apps are ranked higher), resulting in more exposure, and consequently more downloads [24].

Although the ownership of Android OS devices is twice that of Apple devices, the uptake of this study app was more than 2 times less in the Android Market over the 12-month period. Another study reported a low uptake of Android apps in the United States, where only 45 participants downloaded the study app during 2 months [25]. Interestingly, the study reported that more than 100 email messages and phone calls were received from Apple users showing interest in downloading the app whenever it was available in the Apple App Store [25]. Thus, even though Android OS users are double the Apple OS users, due to the fact that some Android devices are very inexpensive

compared to Apple devices, we assume that some Android users are not recognizing it as a smartphone and are therefore not interested in apps, or maybe they do recognize it, but just do not have a need for the apps.

A number of users from other countries have been able to download the app at 6.8% (32/473) in the Android Market and 5.56% (71/1278) in the Apple store. Future studies should not take the app store function of limiting the app to a specific country for granted, and they may have to implement extra functions in the app to validate if the users are actually from the countries of interest, for example, a location identification service to know the users' country the first time they open the app (as was used in this study). The ability of users from countries outside of this study to download this study app might be due to their using app store accounts registered for one of the countries of interest, or some other users might be using a proxy Internet connection that uses an IP of one of the countries of interest in this study.

This study app was able to reach smokers in the countries included in this study. Participants were similar in age and number of previous quitting attempts, and most sought smoking cessation help only in this new medium and not from professionals. This might be due to the app's easier accessibility, privacy, anonymity, and portability. However, the documented low quality of smoking cessation apps, exaggerated claims of effectiveness, and the large number of prosmoking apps that claim smoking cessation, all help decrease these apps' usefulness and lead to failed quitting attempts. Although there were almost 75.6% (248/328) of participants who had tried smoking cessation apps in the past to quit for good, only 33.0% (82/248) abstained for more than one week, which might reflect the available apps' low quality.

Number of Smoking Cessation Attempts

Previous quit attempts were associated with a two-fold increase in the use of smoking tracking cessation apps. Investigators have not yet explored the reasons for this. However, it might be due to design, popularity, or smartphones' constant proximity, letting users monitor their progress anywhere and anytime [26], reinforcing tracking's already documented effectiveness [27-29].

A three-fold increase in smoking cessation app use was associated with three or more quit attempts in the previous year. This might be due to the documented positive relationship between motivation to quit and number of quitting attempts [30,31], and the number of previous quitting attempts as an independent predictor of making a new quitting attempt [32]. In addition, respondents who found difficulty in refraining from smoking in banned areas were approximately twice as likely to try smoking cessation apps. This finding is consistent with other studies that found that smokers who lived or worked under a smoking ban were more likely to report quitting attempts [33,34].

Previous Health Apps Use

There were 50.2% (302/602) of participants that used health related apps in the past, and of those, about 89.4% (270/302) used them at least weekly, but 77.5% (234/302) never checked the credibility of the health app publisher. Although we have not provided a specific definition of app "credibility" and relied on the users' self-definition, this still poses a problem since many studies indicate low reliability and quality in all health related apps covering such topics as smoking [1,16], asthma [35], cancer [36], and pain management [37]. Thus, there is a need for better, evidence-based health apps, and more information about the quality of the current ones. App stores might also cooperate with public health institutions and researchers to improve the quality of health related apps and their reach.

Response Rate

The feasibility of using smartphones as a research tool shows some promise with an unprompted response rate of 36.75% (602/1638) to our in-app questionnaire, and response rates as high as 44.9% (131/292) in Australia, and as low as 33.3% (170/511) in the United Kingdom. However, the response rate for rating the page content was very low and may be due to the fact that the page rating did not provide the users with feedback as was done in the questionnaire. A recent study explored using personalized feedback as incentive to increase compliance in Web-based questionnaires [38]. In addition, the variation in the rating responses may be due to the design of the rating process, as we have included the rating of each information page at the end of it. Asking the participants to rate all the pages at once after reading them all at once may eliminate the response variation problem.

Study Limitations

This study also examined the feasibility of a new research recruitment methodology. There are no data available to adjust the nonrespondents or self-selection bias for such a study. Moreover, one of the limitations of this study cross-sectional methodology is the inability to identify the nonrespondents characteristics. Although the sampling method of this exploratory feasibility study was limited by selection bias, it provides for the first time to our knowledge, some useful data to suggest that smoking cessation apps are being used by people who want to quit and may also be a feasible tool for smoking cessation support and evaluation. Future studies could increase the response rate by implementing a reminder function in the app or use the push-notification services.

Conclusions

This exploratory feasibility study shows that smartphone apps are a promising medium to reach smokers in Australia, the United Kingdom, and the United States. The countries differed little in some demographics and smoking status. Current smokers from the three countries, mostly ready to quit in the near future, but eschewing professional help, have downloaded smoking cessation apps in the past and tried using them to quit; however, the low quality of apps in the field undermines these efforts. Thus, this study has shown that smartphone smoking cessation apps can reach smokers across multiple nations. This paper has also shed some light on participants' use of other health related apps and identified an alarming trend of consumers using health apps without knowing the credibility of its publishers.

Acknowledgments

The University of Sydney's Human Research Ethics Committee approved this project.

Authors' Contributions

Authors' Contributions: NB was responsible for conceptual development, data collection, and drafting of the manuscript. LT and NB were responsible for the study design. NB and KM were responsible for the data analysis. All authors participated in editing and revising the manuscript. All authors read and approved the final manuscript.

Conflicts of Interest

Conflicts of Interest: None declared.

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Abbreviations

apps: applications
IP: Internet Protocol
OS: operating system
QA: Quit Advisor

Edited by F Pinciroli, C Pagliari; submitted 23.07.13; peer-reviewed by R Brady, M Orton; comments to author 19.09.13; revised version received 24.10.13; accepted 05.12.13; published 06.02.14.

Please cite as:
BinDhim NF, McGeechan K, Trevena L
Who Uses Smoking Cessation Apps? A Feasibility Study Across Three Countries via Smartphones
JMIR Mhealth Uhealth 2014;2(1):e4
URL: http://mhealth.jmir.org/2014/1/e4/
doi:10.2196/mhealth.2841
PMID:25098439

Review

Comparison of Mobile Apps for the Leading Causes of Death Among Different Income Zones: A Review of the Literature and App Stores

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Abstract

Background: The advances achieved in technology, medicine, and communications in the past decades have created an excellent scenario for the improvement and expansion of eHeath and mHealth in particular. Mobile phones, smartphones, and tablets are exceptional means for the application of mobile health, especially for those diseases and health conditions that are the deadliest worldwide.

Objective: The main aim of this paper was to compare the amount of research and the number of mobile apps dedicated to the diseases and conditions that are the leading causes of death according to the World Health Organization grouped by different income regions. These diseases and conditions were ischemic heart disease; stroke and other cerebrovascular diseases; lower respiratory infections; chronic obstructive pulmonary disease; diarrheal diseases; HIV/AIDS; trachea, bronchus, and lung cancers; malaria; and Alzheimer disease and other dementias.

Methods: Two reviews were conducted. In the first, the systems IEEE Xplore, Scopus, Web of Knowledge, and PubMed were used to perform a literature review of applications related to the mentioned diseases. The second was developed in the currently most important mobile phone apps stores: Google play, iTunes, BlackBerry World, and Windows Phone Apps+Games.

Results: Search queries up to June 2013 located 371 papers and 557 apps related to the leading causes of death, and the following findings were obtained. Alzheimer disease and other dementias are included in the diseases with more apps, although it is not among the top 10 causes of death worldwide, whereas lower respiratory infections, the third leading cause of death, is one of the less researched and with fewer apps. Two diseases that are the first and second of low-income countries (lower respiratory infections and diarrheal diseases) have very little research and few commercial applications. HIV/AIDS, in the top 6 of low-income and middle-income zones, is one of the diseases with more research and applications, although it is not in the top 10 in high-income countries. Trachea, bronchus, and lung cancers are the third cause of death in high-income countries but are one of the least researched diseases with regard to apps.

Conclusions: Concerning mobile apps, there is more work done in the commercial field than in the research field, although the distribution among the diseases is similar in both fields. In general, apps for common diseases of low- and middle-income countries are not as abundant as those for typical diseases of developed countries. Nevertheless, there are some exceptions such as HIV/AIDS, due to its important social conscience; and trachea, bronchus and lung cancers, which was totally unexpected.

(JMIR Mhealth Uhealth 2014;2(1):e1) doi:10.2196/mhealth.2779

KEYWORDS

apps; different income zones; leading causes of death; mobile apps; World Health Organization (WHO)

Introduction

The advances in science and medicine in developed countries have caused an elderly population and long-term survival of individuals who suffer chronic diseases due to modern treatments and cures. This has increased the quality of life expectation of health care consumers [1]. For satisfying this expectation, there have been important improvements in health care delivery supported by the use of the Internet, also known as eHealth, defined by the International Telecommunication Union as the paradigm that encompasses all of the information and communication technologies necessary to make the health system work [2,3]. This paradigm has evolved significantly to the point of creating mobile health (mHealth) as a branch of eHealth.

There are many definitions of mHealth. For some authors it is an area of eHealth that provides health services and information via mobile technologies such as mobile phones and PDAs [4,5]; for others, the term is defined as "emerging mobile communications and network technologies for healthcare systems" [6]. What is clear is that mobile devices are used for providing health care. More important than the definitions are the impressive development and dissemination this field has been achieving, to the point that Atienza et al (2011) have suggested that mobile health may be the "killer app" for cyberinfraestructure for health in the current century [7]. The reality is that important advances in technology and communications have been achieved in the past few years and mHealth has taken advantage of them [8-12]. mHealth is supported by many mobile telecommunications technologies, such as 3G (third generation) or 4G (fourth generation) technologies, for example [13-18].

The potential for mHealth applications is rather well-documented [19-21]; for example, move away from face-to-face visits at the doctor's office, access to a wide array of educational resources including information on disease-specific topics and general self-management tools, view your own electronic medical record, access information relative to medications, and continuous surveillance of vital or physiological signs.

In addition to this, advances in technology for smartphones and tablets have caused their incredible growth, especially in high-income countries. There were 6 billion mobile subscriptions in 2011 and more than 1.7 billion mobile phones sold in 2012, 712.6 million of which were smartphones. With these numbers, it is obvious that these devices must be used in the field of mHealth to assist every person with one of these gadgets. Indeed, mHealth is already using them as shown by the great number of health applications currently available [22-25].

These devices can be especially useful for the prevention and management of those diseases that cause high rates of mortality. The World Health Organization (WHO) estimated a total of 56.8 million deaths in 2008 and, excluding 5.1 million that were caused by injuries, the remainder were produced by diseases and health conditions [26]. Some of the leading causes of death are presented in Figure 1, which shows the percentage of deaths caused by these diseases and distributed according to different income zones [27].

The 6 leading causes of death for each zone and worldwide in 2008 are shown. When these diseases have 0% deaths represented in determined zones of Figure 1, it means that the diseases are not among the top 10 in this zone, but not that there are not deaths caused by those illnesses. Some data are presented below.

Considering randomly 1000 individuals dead in 2008, statistically 159 would have come from high-income countries, 677 from middle-income countries, and 163 from low-income countries [28]. Cardiovascular diseases (CVDs) are the deadliest diseases—17.3 million people died from CVDs in 2008, representing 30% of all global deaths [29]. Among these diseases, ischemic heart disease (IHD) is the leading cause of death globally with an estimated 7.3 million deaths [30-34]. Stroke produces not only death, but also disabilities and high probabilities of death in the future. Its burden is projected to rise from approximately 38 million DALYs (disability-adjusted life years) worldwide in 1990 to 61 million DALYs in 2020 [35-38].

Lower respiratory infections (LRI) are the leading causes of child mortality in the world, producing 1/5 of mortality in children under 5 years. The respiratory syncytial virus (RSV) is the single most important cause of severe respiratory illnesses in children and can provoke pneumonia, which causes 90% of these deaths due to the virus [39-43]. Sixty-five million people had chronic obstructive pulmonary disease (COPD) and more than 3 million died in 2005 [44-48]. Diarrheal disease is a major problem in developing countries and the second leading cause of mortality in children under 5 years of age, killing 1.5 million children every year [49-52].

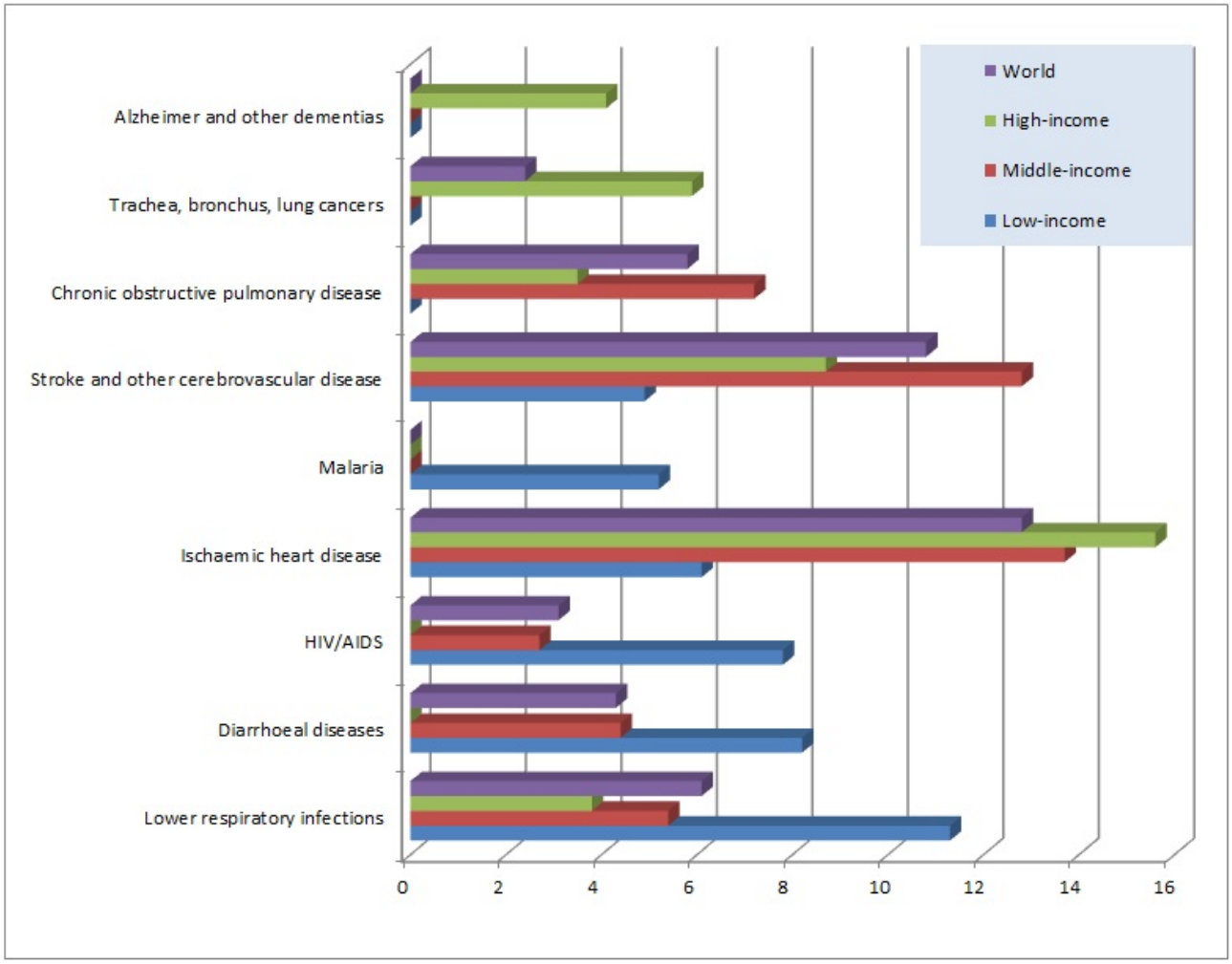
Human immunodeficiency virus/acquired immunodeficiency syndrome (HIV/AIDS) is a major global public health issue. In 2011, there were 34 million people living with HIV and 1.7 million of whom died because of it. The political commitment, social mobilization, and HIV/AIDS funding done by almost every country in the past years have contributed to the total of 95 million people tested in 2010 and more than 8 million receiving antiretroviral therapy [53-57]. According to the WHO, there were 219 million cases of malaria and 660,000 deaths in 2010 [58-60]. However, other studies have worse numbers: Murray et al (2012) estimated 1.24 million deaths globally in 2010 [61].

Cancer caused 7.6 million deaths worldwide in 2008, with the majority caused by lung cancer (1.37 million deaths). Tobacco is the most important risk factor for developing cancer (not only lung cancer), causing 22% of cancer deaths and 71% of lung cancer deaths [62-65]. There are 35.6 million individuals suffering from dementia and 477,000 annual deaths worldwide.

Among the different dementias, Alzheimer disease is the most common with a contribution of 60%-70% of the cases and a median life expectancy of 7.1 years [66-70].

The main aim of this paper is to continue the research begun by the authors about mobile apps for the most prevalent health conditions [71], focusing on the diseases and conditions that are leading causes of death by the WHO grouped according to different income regions [27]. For this purpose, two reviews have been done. The first was a literature review carried out by searching published articles in several systems, and the second was a review of commercial apps done in the most important mobile phone apps stores considering the market share of the operative systems used for smartphones. The main objective is to find out which diseases are more researched and which have more apps, comparing these findings with their weight in mortality, not only globally but also distributed according to different income regions. This study is only limited to a general search of applications, without studying or analyzing them due to the significant extension of that work, which is enough for additional research.

Figure 1. Percentage of deaths caused by the leading causes of death grouped by zones.



Methods

Overview

In April 2013, two reviews were developed: a literature review and research in commercial applications stores. The procedures used for each review are explained below.

Literature Review

For the literature review, a search of published papers was developed in the following databases and systems: IEEE Xplore, Scopus, Web of Knowledge, and PubMed. When searching for a specific disease, a combination of search words was used. If the number of results obtained was too low, another combination of words was used until a more significant number of results was obtained. These terms were used on all the systems mentioned. The process was repeated with each disease studied. The search strings were used only for metadata and the article search was limited to the past 10 years, from 2003.

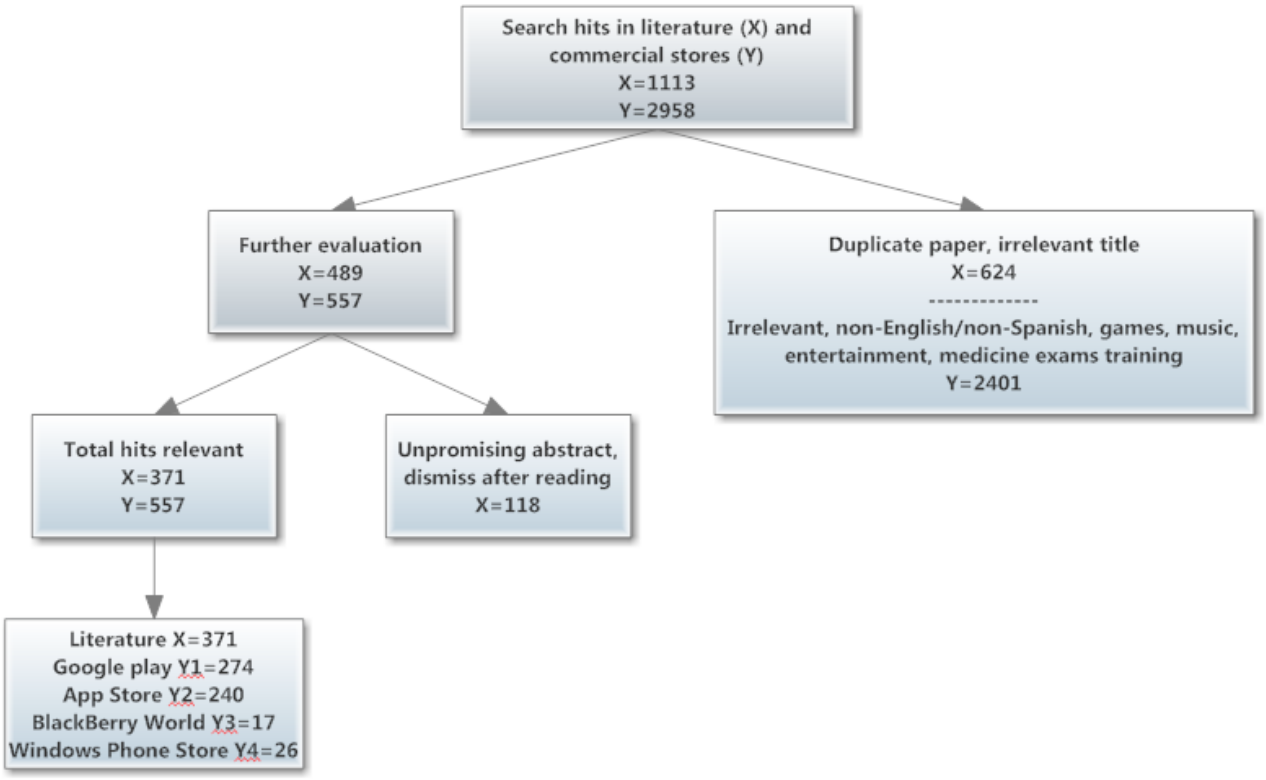
Table 1. Terms used in the literature search strings of each disease.

Disease	Term1	Term2
LRI	lower respiratory infections	application
	respiratory infections	application
	respiratory diseases	application/app
Diarrheal diseases	diarrhoeal diseases	application
	diarrheal diseases	application
	diarrhea	application/app
	diarrhoea	application/app
HIV/AIDS	HIV/AIDS	application/app
	HIV	
IHD	ischaemic heart disease	application/app
	ischemic heart disease	application
	heart disease	application/app
Malaria	malaria	application/app
Stroke and other cerebrovascular diseases	stroke	application/app
	cerebrovascular disease	
COPD	chronic obstructive pulmonary disease	application/app
	copd	
Trachea, bronchus, lung cancers	trachea cancer	application/app
	bronchus cancer	
	lung cancer	
	respiratory system cancer	
Alzheimer and other dementias	Alzheimer	application/app
	dementia	

Figure 2 shows a flowchart with the steps followed in both literature and commercial reviews. All the systems returned 1113 results, with 624 repeated or with an irrelevant title for this study. Of the remaining 489 papers, 118 were dismissed after reading their abstract or the whole paper when necessary. Finally, a total of 371 papers (33.3%) were selected as relevant. For considering a paper relevant, it had to fulfil some criteria: it must be focused on applications using mobile phones or devices, it must be written in English, and it has to be about a mobile app or apps designed for the sought condition. This means that papers centered on applications for several and different diseases were dismissed even if one of the illnesses treated was the one sought.

For the search strings, in some cases Britain and US terms for the same word were used to ensure that every relevant document was revealed. The combinations of words used were the following: Term1 AND mobile AND Term2, Term1 AND m-health; Term1 AND “mobile phone”; Term1 AND smartphone; where Term2 was app or/and application and for Term1 it was used the terms used for each disease that is shown in Table 1.

Figure 2. Flow chart of the steps followed in the reviews.



Commercial Apps Review

The second review was carried out in the most important applications stores of the smartphones industry considering the market share of the operative systems for smartphones [23-25,72]. In descending order of this market share, the stores are Google play of Google Android [73], iTunes of Apple [74], BlackBerry World of BlackBerry [75], and Windows Phone Apps+Games Store of Microsoft [76].

The process is similar to the one followed in the literature review. Table 2 shows the different terms used in the search of the applications related to each disease and the flowchart of Figure 2 shows the steps followed in the commercial review. A total of 2958 apps were initially found although, after checking whether the apps were relevant to the study and whether some conditions were fulfilled, only 557 (18.8%) met these requirements. The requisites to include an app in the study were applications not in English or with the description in a different language from English or the one of the country where the search was done (Spanish) were dismissed, the same as those included in the categories of games, music, or entertainment. Applications that use flashcards for helping medical students in their exams and applications for conferences were also dismissed.

Table 2. Strings used in the search of commercial apps for each disease.

Disease	Search String
LRI	respiratory infections
Diarrheal diseases	diarrheal disease
HIV/AIDS	HIV
IHD	“heart disease”
Malaria	malaria
Stroke and other cerebrovascular diseases	stroke; “cerebrovascular disease”
COPD	”chronic obstructive pulmonary disease”; copd
Trachea, bronchus, lung cancer	“trachea cancer”; “bronchus cancer”; “lung cancer”
Alzheimer and other dementias	alzheimer; dementia

Results

Mobile Apps in Literature

The results of relevant papers for each condition and each system are presented in Table 3. The last column shows the total number of different papers found on all the systems. The results of the search of the respiratory system cancers can be broken down into nine results for lung cancer and no results for the rest of the search strings (trachea cancer, bronchus cancer, and respiratory system cancer).

In light of the results, heart diseases are the most researched ones. It is followed by HIV/AIDS, Alzheimer and other dementias, and stroke and other cerebrovascular diseases. LRI and COPD hold the fifth and sixth places, respectively, in descending order of research done and the last places are for malaria, trachea, bronchus, lung cancers, and diarrheal diseases with very little investigation; only 28 articles among them.

The majority of papers found were relative to the design, development, or implementation of mobile systems, whole systems [77], complement systems to a mobile phone [78], or part of the system [79]. There are also evaluations and validations of these mobile systems [80]. Other types with a great number of papers found are interventions using mobile systems [81], apps [82], or mobile phones [83] and the studies and evaluations of these interventions [84]. Another type of paper found, but less frequent, are those dedicated to applications for smartphones, with add-on complements [85] or without them [86] and reviews of the existing apps for a specific objective [87].

Table 3. Results of the literature review.

Disease	IEEE	Scopus	Wok	PubMed	Total
LRI	9	21	9	3	24
Diarrhoeal diseases	0	3	1	0	3
HIV/AIDS	4	77	38	42	86
Heart diseases (IHD)	41	81	47	32	121
Malaria	1	15	9	8	16
Stroke and other cerebrovascular diseases	7	30	13	9	36
COPD	5	20	10	7	23
Trachea, bronchus, lung cancers	2	7	4	3	9
Alzheimer and other dementias	16	49	20	7	53

Mobile Apps in Stores

The findings of the commercial apps review are revealed in Table 4. Each cell shows the number of relevant apps out of the total number of results found in each commercial store. The last row contains the addition of the applications found for all the diseases at each store and the last column presents the addition of the applications found at all the stores for each sought disease. Nevertheless, this number does not represent the total number of different apps in all the stores, because there are apps developed by the same creator for different operative systems, being the same (or similar) app for different smartphones software. For example, the application AIDSinfo HIV/AIDS Glossary, created by the National Library of Medicine at National Institutes of Health (NIH) [88], is available on iTunes [89] and on Google play [90].

There are some diseases issued by the WHO that are actually a group, so in Table 4 these groups are divided into its illnesses. This way, the groups stroke and other cerebrovascular diseases and Alzheimer and other dementias are divided each one into two rows, one for stroke and cerebrovascular diseases and another for Alzheimer and dementia, respectively. The same occurs with the group trachea, bronchus, and lung cancers, split into three rows corresponding to the three types of cancer.

Focusing on the number of applications for each disease, the ones with more apps are Alzheimer and other dementias with 128, followed closely by HIV/AIDS. The third position is for heart diseases with 111 applications and the fourth is for stroke and other cerebrovascular diseases despite the fact that there are no results for cerebrovascular diseases. After a gap of more than 40 apps, COPD holds the fifth position and trachea, bronchus, and lung cancers the sixth, although there are no apps for the two first mentioned cancers, only for lung cancer. The seventh and eighth positions are malaria and diarrheal diseases, and the last is LRI with only 6 apps.

Table 4. Results of the commercial apps review.

Disease	Google play	iTunes	BlackBerry World	Windows Phone Store	Total
LRI	5/57	1/17	0/0	0/0	6
Diarrheal diseases	12/88	8/12	0/0	0/5	20
HIV/AIDS	54/238	56/121	7/8	7/19	124
Heart diseases (IHD)	60/249	44/79	3/4	4/21	111
Malaria	12/51	7/25	1/2	2/8	22
Stroke	27/480	45/530	4/46	3/105	79
Cerebrovascular diseases	0/0	0/2	0/0	0/0	0
COPD	20/50	17/37	0/0	1/3	38
Trachea cancer	0/0	0/1	0/0	0/0	0
Bronchus cancer	0/1	0/0	0/0	0/0	0
Lung cancer	14/88	14/54	1/3	0/2	29
Alzheimer	38/175	25/96	1/2	6/14	70
Dementia	32/185	23/70	0/0	3/10	58
Total apps per store	274	240	17	26	

The main types of apps for LRI are guides and calculators for health care professionals, although there are also some informative apps for patients. In the case of diarrheal diseases, the most common apps are natural and personal remedies as well as some guides. Referring to HIV/AIDS, there are many guides for health care professionals, patients and public in general, centering, in this case, on educational aspects. There are also a significant number of apps with news regarding HIV/AIDS. The great majority of apps for heart disease are heart rate monitors for patients and algorithms and calculators for specialists [91]. The principal focus of malaria apps is to use the smartphone as a mosquito repellant, followed by informative apps about it. The most usual apps for stroke and other cerebrovascular diseases are stroke detectors and stroke scale calculators. There are also some informative apps.

Referring to COPD, the majority of apps are informative and guides for health care professionals, followed by some COPD trackers and apps for learning to use inhalers, both destined for patients. Focusing on lung cancer (there are no specific apps for the rest of cancers studied), most apps are destined for cancer stage determination and help in its diagnosis for professionals. For patients, informative apps are common. Finally, typical apps for Alzheimer and other dementias are games useful for their prevention, supportive apps for patients and relatives, as well as trackers and apps for auto-checking the status of a dementia.

Figure 3-5 show three graphs, which present the percentage of the number of apps found in the applications stores for each of the top 6 causes of death for each region, excluding the rest of the total (100%).

The diseases with a higher percentage of apps in low-income and middle-income countries are heart diseases (IHD) and HIV/AIDS, whereas in high-income countries these diseases are Alzheimer and other dementias, and heart diseases (IHD). LRI is the disease with the least percentage of apps in all the zones, followed by diarrheal diseases in low- and middle-income countries and trachea, bronchus, and lung cancers in high-income countries.

Figure 3. Percentage of apps (%) related to the top 6 causes of death of the low-income zone.

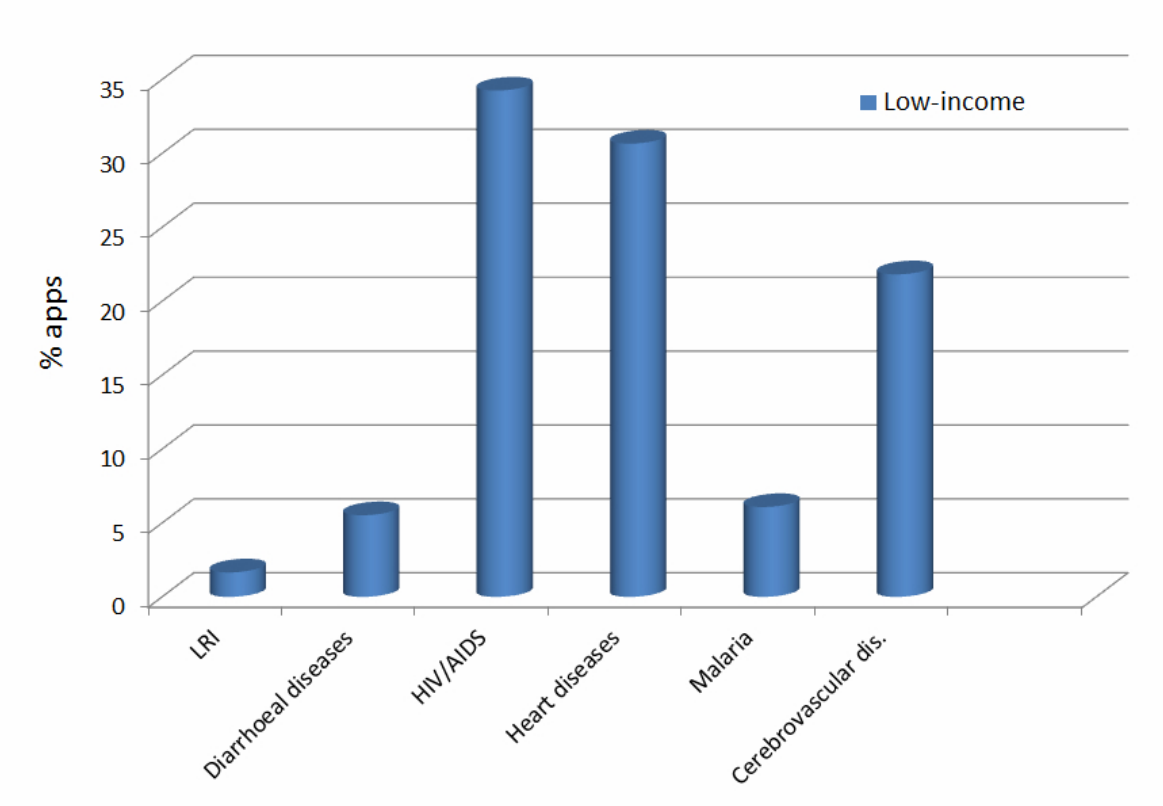


Figure 4. Percentage of apps (%) related to the top 6 causes of death of the middle-income zone.

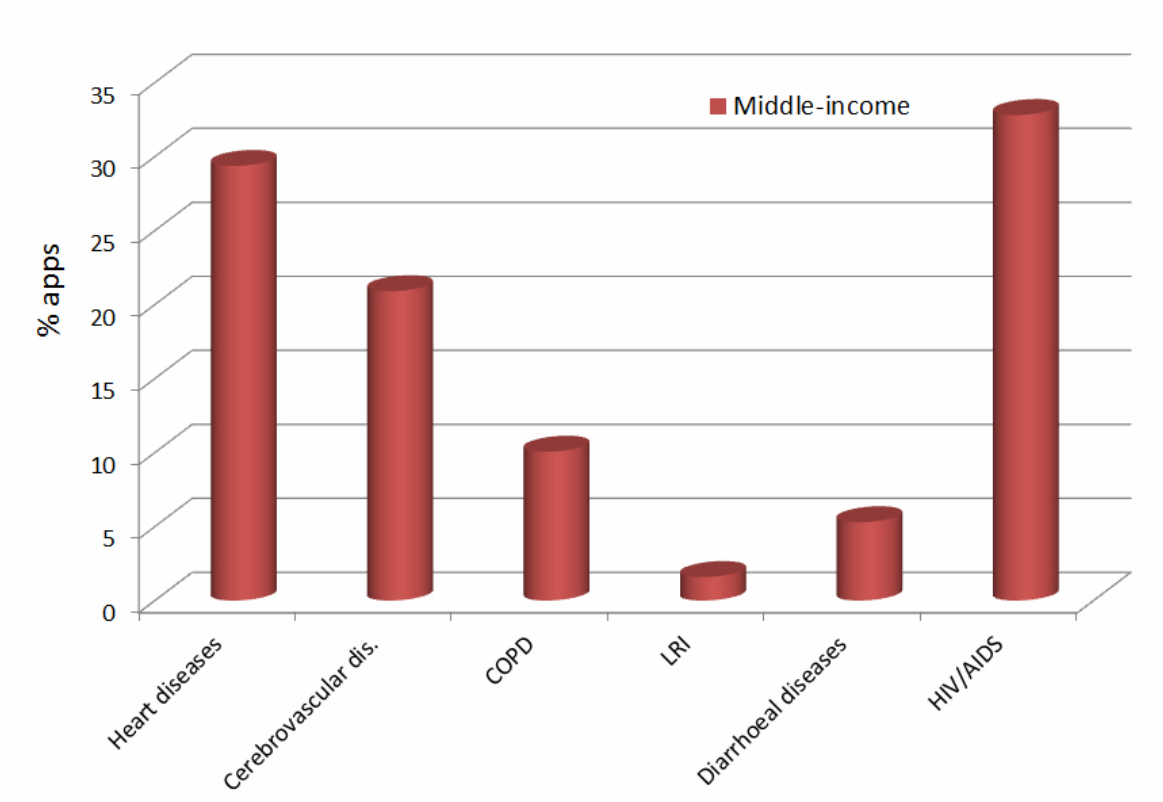
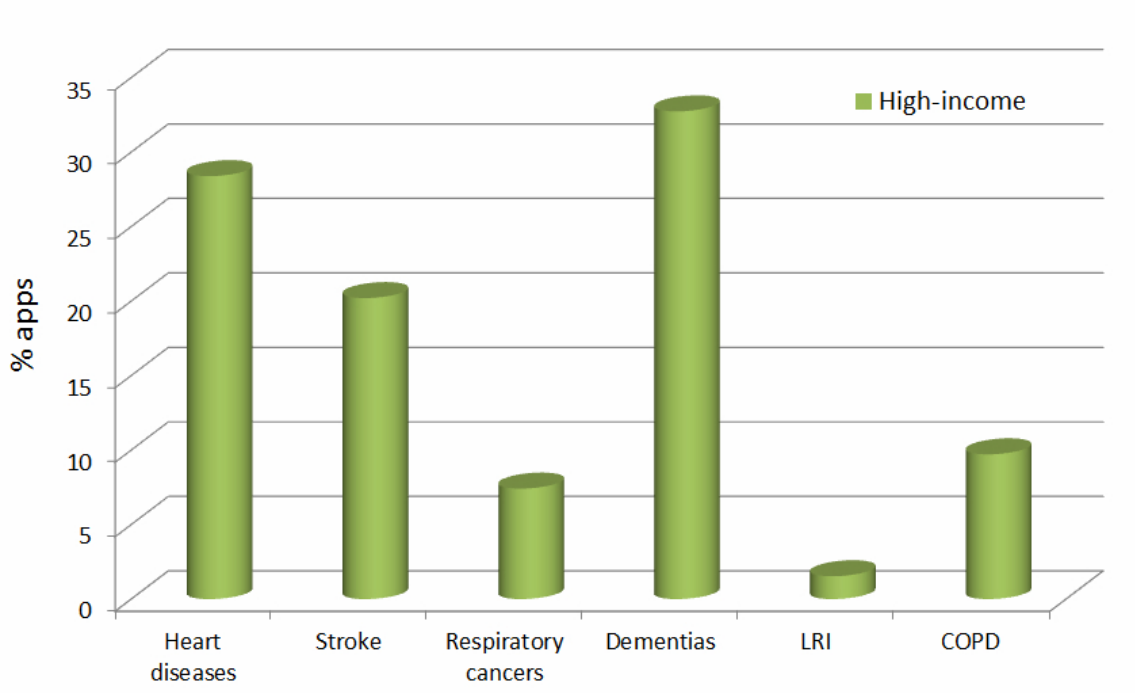


Figure 5. Percentage of apps (%) related to the top 6 causes of death of the high-income zone.



Discussion

Principal Findings

Some important conclusions can be obtained from the analysis of the results. Comparing the numbers of the literature review with the numbers of the commercial apps review, it is clear that there is more work done in the commercial field than in the research field. This is quite logical because the main objective of developers is earning money with their apps and, therefore, they focus on commerce. However, to create a good application, it is necessary to do some research [92], and this research can be a market study and/or an investigation about the application itself, including aspects such as the type of application, the necessity to cover, or the target public, among others. Unfortunately, what can be extracted from the results of this study is that most developers only do the market investigation or they do not publish the results of their studies while developing their apps. Contrasting the literature review with the commercial review, there are two differentiated groups. On one hand, there are four diseases with the highest percentage of work done in developing research and applications. These diseases are Alzheimer and other dementias, heart diseases, HIV/AIDS, and stroke and other cerebrovascular diseases. The numbers of the commercial apps review for the first three diseases mentioned before are similar and over 100 apps while for stroke and other cerebrovascular diseases the number of apps is much higher than the rest, which enforces the idea of two groups. On the other hand, the second group is formed by the rest of diseases, having much less work done in both research and commercial fields.

Another piece of information extracted from this comparison is that the position held by a disease in number of apps or papers found is similar in both reviews, with a maximum difference of two positions except for LRI with the fifth and ninth positions in the literature and commercial reviews, respectively. Hence, for the majority of the studied diseases, there is a concordance in the proportion of work done for each disease in both fields, which means that both researchers and developers generally agree on the importance given to each disease.

Contrasting the order of diseases according to the number of apps and papers and by mortality worldwide, there are some interesting issues. The most striking is that the diseases with more commercial apps, Alzheimer and other dementias, are not included in the top 10 causes of death worldwide. Therefore, why is there so much effort and work done in these illnesses? As exposed below, the answer is easy: Alzheimer and dementias are typical of high-income countries [27] where there is a social conscience of these illnesses and the population is very much aware of the consequences and dysfunctions that they cause, as shown by the great number of associations worldwide [93,94]. This reason, added to the facts that the majority of developers and developers groups are located in these countries [95-97] and designing apps for richer zones is more profitable, explains this issue.

The contrary occurs with LRI. Worldwide, this disease is the third leading cause of death, but the reviews carried out in this study show that its numbers do not correspond with this position (it is the fifth disease more researched and the last in commercial stores). This can be explained by several reasons: the first is that it is the first cause of death in low-income countries but it is not among the top 3 in middle- and high-income countries and, because developers are generally aware of these countries [95-97], this disease is not a priority for them. However, the previous reason alone is not enough to explain this case because LRI is the fourth and the fifth cause of death in middle- and high-income countries, respectively, above others such as HIV/AIDS, which has more apps and research.

Another important reason is that this disease is typical of children younger than 5 years old [40] and, as a result, developers have no reasons to create apps for LRI patients. One option could be the design of apps for parents, although people in developed zones are not very aware of this disease as they are with other illnesses such as HIV/AIDS [54,98] or diabetes [99], not giving it the importance it really deserves so it is underinvestigated. In addition, in developed zones, children are vaccinated against RSV [42], the most important cause of LRI. Thus, the combination of the previous reasons explains this situation.

There are other similar cases to the previous two, but not so extreme. Hence, as happens with Alzheimer, HIV/AIDS holds the second position in both reviews but it is only the sixth cause of death [54,98]. On the other hand, diarrheal diseases hold the fifth position in mortality but only the eighth and the last position in the commercial and literature review, respectively, quite similar to the case of LRI but more obvious, due to the fact that it is the second leading cause of death in children younger than 5 years old [49] and, in this case, it is not among the deadliest diseases in high-income countries [26,27].

Limitations

This study presents some limitations in the methodology followed for each review, typical for this type of revision [100]. The process of extracting the data presented a significant risk of uncertainty. Occasionally, the inclusion of a paper or an app in the study is not easy because the text is not clear and it can be misunderstood. To avoid this possible error, we enhanced the assessment process with independent verification. Thus, one author developed the search of literature papers, a second author developed the commercial review, and a third author inspected the results to check for possible errors.

The search results of the literature review were restricted to the past 10 years, from 2003 to the present day. This restriction did not affect the study because before 2003 there was a rather low number of smartphones and mobile devices, only dedicated to business, without commercial stores and health care applications as we know them today [101,102]. In addition, only papers dedicated exclusively to the disease searched were included in the study. Hence, there are papers dedicated to several diseases that can contain interesting information regarding the diseases studied dismissed.

Some limitations were found and addressed (if possible) in the commercial review. The results of the search of respiratory infections included some infections not specific to the lower respiratory system; hence, a discrimination of these results was necessary to select apps specific for lower respiratory infections.

Searching on iTunes, diarrheal disease provides no results, so in this case diarrhoea and diarrhea were used as search strings. The same was tried in the search of this disease on BlackBerry World but it returned no results. Because the disease name is so specific, no other terms could be used to obtain more results relative to it.

In the search of IHD, “ischemic heart disease” returned only 48 apps, very few for the most important cause of mortality. Hence, it was resolute to search only “heart disease” even though IHD is a specific type of heart disease. With this combination of words we found 353 apps, a much more significant number of apps. In addition to this, apps of diets or recipes were not included in the study, but those dedicated exclusively for cholesterol management were included because high cholesterol is a cause of heart malfunctions.

When inspecting the stores about trachea, bronchus, and lung cancers, apps for treatment or assistance in general cancer management that includes the searched cancer were taken into account. However, apps for quitting smoking were not studied despite the fact that smoking is the most important cause of lung cancer. We made this decision because there are other motivations to quit smoking, not only lung cancer, and those apps are not centered on the cancer itself.

In the case of Alzheimer and other dementias, there were a number of games designed for their prevention, although, as mentioned before, only those not included in the category of games were valid for the study (medical, health category). We did this because the majority of the found games included in the category games were not specifically designed for Alzheimer prevention and only took the commercial advantage of saying that they were useful for this purpose.

There were two issues with Google play. The first was that, in some searches, the store indicated that a certain number of results have been found but, while exploring the results pages, the last were blank. Because the number returned by the store and the real number of apps were different, we decided to use the last one, the number of applications shown. The other issue was that, when searching for stroke, the store returned more than 1000 results but only 480 apps were shown. In this case, the number used was the second one, 480. This last issue could affect our study because there are probably more apps apart from the 480 shown by Google. The current version of the store does not present these problems.

Another important limitation in the commercial review was the language used for the search strings. One of the objectives of this paper is to find and compare the existing apps for expressly mortal diseases in different income regions. Ideally, at least the most important low- and middle-income countries languages should have been used to obtain apps only developed in these languages. However, we only focused on the use of English, obtaining all the apps developed for this particular language, because it is the most extended and used worldwide. This barely affected the study of diseases typical of high-income countries because English is commonly used and extended there. Nevertheless, many results were shown in Spanish, because the stores detect the place where the search has been done, showing the apps and their summaries in the language of that place, if possible. In these cases, the apps were also included in the study, if relevant.

It is important to indicate that the search of IHD has actually become a search of “heart disease” in general, due to the lack of results with IHD alone in both reviews. Hence, we will talk about heart diseases instead of IHD. Nevertheless, it does not affect the study, because the applications found are for general heart diseases, including the one searched.

Conclusions

Comparing the number of apps and research done for disease with the position in cause of death for the three different zones, some interesting conclusions can be extracted. The leading cause worldwide and in middle- and high-income countries, heart diseases (IHD), is one of the most researched and with more apps, a logical fact because developers focus on typical diseases in high-income countries [98-100]. However, there are two diseases, the first and second of low-income countries, which have very little research and fewer commercial applications. These diseases are LRI and diarrheal diseases. The reason is the one mentioned previously: these illnesses are not common (diarrheal diseases) or there is no use of an app for the diseases (LRI), so that their research is not worthwhile, not to mention the fact that they are common in low-income zones where the technology for smartphones and tablets is not widespread [103,104] and, therefore, there are no market opportunities.

Another interesting case is what happens with HIV/AIDS, which is in the top 6 of low- and middle-income zones but even not being among the first 10 causes of death in high-income countries, it is the second disease with more research and applications. In this case, the illness is very popular not only in poor and developing zones but also in richer countries [101] in a way that, despite the fact that it is not one of the worst diseases in mortality in these rich countries, it has the attention of developers (as the numbers of this study show) and the population as a whole. At least, in this case all the countries can feature these apps for HIV/AIDS if they have the means needed.

The most curious case is the one with trachea, bronchus, and lung cancers. They are the third cause of death in high-income countries, but are included in the least researched diseases with regard to apps. The reason is not clear, because cancer in general is a common matter and there is a huge amount of information and applications about it. In fact, the search for “cancer” on the App Store returns 896 apps and 500 on Google play. Moreover, specifically these types have also an important social conscience principally for being consequences of smoking [63,64]. Therefore, it can be considered a good opportunity for developers to fill this empty space in mobile apps for health care.

Focusing on the types of the predominant apps for each disease, there is a common one for all of them: the informative apps, which can be for patients as well as for health care professionals. Excluding these apps, the rest have different purposes depending on the disease. Hence, developers have tried to take advantage of the characteristics of each illness. They centered on prevention in diseases with no cure or with a cure based on medications where no mobile phone aid is needed such as Alzheimer and dementias, with games useful for their prevention; and malaria, with mosquito-repellant apps. There are also several apps for HIV/AIDS focused on the prevention with educational apps for the public (and others for patients). Health care professionals are the objective of the apps designed for LRI, stroke, and lung cancer, which offer aid in the diagnosis or the assessment of the stage/status of the diseases. Finally, in the cases of diarrhea and COPD the majority of apps (excluding the informative ones) are designed for treatment: personal remedies for diarrhea (mild diarrheas), and COPD trackers as well as educational apps for the use of inhalers.

Finally, the enormous difference in the number of applications found in the distinct stores is surprising. Google play and iTunes are clearly the ones with more apps followed by far by Windows Phone Apps+Games and BlackBerry World, as previously observed [71]. The case of BlackBerry is unusual: in November 2012, it had a market share of 7.3% [72], but it barely has applications for the diseases searched. On the other hand, Microsoft Phone had less market share (3% in November 2012 [72]) but more apps, yet much less than the number of apps of Google play and iTunes. As a result, a great number of users of BlackBerry and Windows Phone would abandon their phones, changing them for others that have the maximum number of apps available. Indeed, this is already happening [72] and can be a reason for the lack of apps for Windows Phone and BlackBerry, because developers are discouraged from creating apps for these stores.

For future work, several things can be done. It is possible to develop a mobile app for LRI because of the absence of apps related to it and its importance in mortality (third cause of death worldwide). It can include the most common infections such as bronchitis or pneumonia. Another possibility is to fill the empty space in mobile apps related to the trachea, bronchus, and lung cancers, for example developing an assistive and informative application for aiding patients who are being treated for these cancers.

Acknowledgments

This research has been partially supported by Ministerio de Economía y Competitividad, Spain.

Conflicts of Interest

Conflicts of Interest: None declared.

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Abbreviations

COPD: chronic obstructive pulmonary disease
CVD: cardiovascular disease
DALY: disability-adjusted life year
HIV/AIDS: human immunodeficiency virus /acquired immunodeficiency syndrome
IHD: ischemic heart disease
LRI: lower respiratory infections
NIH: National Institutes of Health
PDA: personal digital assistant
RSV: respiratory syncytial virus
WHO: World Health Organization

Edited by G Eysenbach; submitted 04.07.13; peer-reviewed by P Gondim, M Fiordelli; comments to author 24.07.13; revised version received 07.08.13; accepted 03.12.13; published 09.01.14.

Please cite as:
Martínez-Pérez B, de la Torre-Díez I, López-Coronado M, Sainz-De-Abajo B
Comparison of Mobile Apps for the Leading Causes of Death Among Different Income Zones: A Review of the Literature and App Stores
JMIR Mhealth Uhealth 2014;2(1):e1
URL: http://www.mhealth.jmir.org/2014/1/e1/
doi:10.2196/mhealth.2779
PMID:25099695

Original Paper

A Classification Scheme for Analyzing Mobile Apps Used to Prevent and Manage Disease in Late Life

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Abstract

Background: There are several mobile apps that offer tools for disease prevention and management among older adults, and promote health behaviors that could potentially reduce or delay the onset of disease. A classification scheme that categorizes apps could be useful to both older adult app users and app developers.

Objective: The objective of our study was to build and evaluate the effectiveness of a classification scheme that classifies mobile apps available for older adults in the “Health & Fitness” category of the iTunes App Store.

Methods: We constructed a classification scheme for mobile apps according to three dimensions: (1) the Precede-Proceed Model (PPM), which classifies mobile apps in terms of predisposing, enabling, and reinforcing factors for behavior change; (2) health care process, specifically prevention versus management of disease; and (3) health conditions, including physical health and mental health. Content analysis was conducted by the research team on health and fitness apps designed specifically for older adults, as well as those applicable to older adults, released during the months of June and August 2011 and August 2012. Face validity was assessed by a different group of individuals, who were not related to the study. A reliability analysis was conducted to confirm the accuracy of the coding scheme of the sample apps in this study.

Results: After applying sample inclusion and exclusion criteria, a total of 119 apps were included in the study sample, of which 26/119 (21.8%) were released in June 2011, 45/119 (37.8%) in August 2011, and 48/119 (40.3%) in August 2012. Face validity was determined by interviewing 11 people, who agreed that this scheme accurately reflected the nature of this application. The entire study sample was successfully coded, demonstrating satisfactory inter-rater reliability by two independent coders (95.8% initial concordance and 100% concordance after consensus was reached). The apps included in the study sample were more likely to be used for the management of disease than prevention of disease (109/119, 91.6% vs 15/119, 12.6%). More apps contributed to physical health rather than mental health (81/119, 68.1% vs 47/119, 39.5%). Enabling apps (114/119, 95.8%) were more common than reinforcing (20/119, 16.8%) or predisposing apps (10/119, 8.4%).

Conclusions: The findings, including face validity and inter-rater reliability, support the integrity of the proposed classification scheme for categorizing mobile apps for older adults in the “Health and Fitness” category available in the iTunes App Store. Using the proposed classification system, older adult app users would be better positioned to identify apps appropriate for their needs, and app developers would be able to obtain the distributions of available mobile apps for health-related concerns of older adults more easily.

(JMIR Mhealth Uhealth 2014;2(1):e6) doi:10.2196/mhealth.2877

KEYWORDS

mHealth; app; Precede-Proceed Model (PPM); health care process; prevention; management; physical health; mental health

Introduction

Background

According to the United Nations [1], globally increasing life expectancy and decreasing birth rates have created a pervasive phenomenon of population aging, affecting both developing and developed countries. Countries are already experiencing public health challenges due to increased prevalence of chronic diseases, many of which are the result of poor health behaviors, and concomitant economic challenges, associated with increased medical expenditures for disease management and treatment. Projections indicate that by 2050, older adults (ie, individuals aged 65 years and older) will account for 21% of the global population [1]. Given data that suggest older adults consume over two thirds of medical resources [2], further aging of the population is likely to strain governments' ability to provide care [3,4]. In addition to increasing costs of care, chronic disease also directly affects the quality of life of both elders and their family members [5].

Concurrent with global population aging is the rapid development of mobile technologies that have the potential to improve the quality of life and enhance the independence of older adults. Mobile technologies are promising, as they offer continuous availability from anywhere at any time; offer interactive user interfaces with multimedia capabilities to engage users; require low levels of infrastructure provision, enabling their use in remote areas and providing significant economic benefits to these areas [6]; and offer the possibility of uninterrupted collection of personal health data for positive behavior change. Some examples of mobile technologies include remote monitoring of falls and physiological data collection through smart homes deployed with sensor networks, which enables the collection of data on a variety of health outcomes and has the ability to send the data to appropriate formal health care providers or informal caregivers [7-9]. Apps such as these, which are equipped with location-based services and covered by wire/wireless network signals, offer the potential to conduct pervasive and ubiquitous health interventions, and to reduce the high rates of attrition, which is often found in interventions that rely on participants' uploading of data [10]. The momentum, at which the volume and range of mobile apps have been steadily expanding, provides a foundation on which to promote the adoption of smartphones among older adults, as well as younger aged individuals, and further to promote the use of mobile technologies to improve the quality of life and enhance the independence of older adults [11,12].

The adoption of mobile technology is beginning to far outpace personal computer (PC)-based ones. Chen pointed out that in 2011, the annual global smartphone shipments reached 488 million, 62.7% growth, more than PC shipments [11]. Allied Business Intelligence (ABI) Research recently released a report predicting that the sport and health mobile app market would hit US$400 million in revenues by 2016, quadrupling the revenues of 2010 [12]. In 2010, there were only 5805 health, fitness, and medical apps available within the Apple App Store [13]. That number reached more than 13,600 by 2012, more than doubling in 2 years. Kahn pointed out that at the end of 2009, 80% of Americans owned a cell phone, a personal digital assistant (PDA) phone, or a smartphone, and that there were a rapidly growing number of people over the age of 65 using smartphones [13]. These trends demonstrate that it is feasible and likely that older adults will use smartphones to increase their knowledge of prevention and self-management of disease, both physical and mental health conditions, as well as to apply the appropriate tools that help with behavior change for healthy lifestyles. To respond to this increasingly large potential market, smartphones are being tailored for older adults with larger displays, easy-operating keyboards, and simple but powerful functions. Mobile apps also present the possibility for family caregivers to take care of their loved ones more efficiently and effectively, for example, by being notified through remote monitoring of a potentially dangerous fall, as well as for professional caregivers, who receive monitoring data in a more timely fashion, which allows for more prompt treatment.

Researchers have conducted a number of studies on how to design and develop useful mobile apps and how to improve user experiences, such as developing apps with low cognitive complexity, motivating the elderly in using apps, and taking vision and hearing impairment into account [14,15]. Moreover, mobile apps specifically for improving quality of life of older adults have been identified and developed [10,15]. For example, Boulos et al described the development of a smartphone app within Enhanced Complete Ambient Assisted Living Experiment (eCAALYX), which is targeted at improving the quality of life and health conditions for older adults. This smartphone app receives inputs from wireless health sensors and location sensors and sends these data to a remote server through the Internet, where they are accessible to professional caregivers, who can respond quickly, thus facilitating the fast response to at risk situations of older adults and improving quality of life [10].

Despite the surging trends in the development of mobile apps to improve health and health care conditions, a gap exists between available apps and the actual demands from users [15]. Because of the lack of comparable market information, this could lead to mobile application developers designing and developing a number of apps with similar functions and characteristics to those already in use, resulting in an imbalance in the availability and distribution of mobile apps. Few studies, however, provide insights regarding current trends and gaps of this increasingly crowded mobile health application market. Developers are not able to quickly make informed decisions on which areas to devote their development efforts, given the lack of state-of-the-art and dynamically varying mobile apps market information. This could potentially lead to wasted time and resources on the part of app developers.

There also exists a gap in the ability of older adults to choose mobile apps that are appropriate to their specific health concerns. For example, some older adults might want an app that provides information on how to manage anxiety or prevent diabetes, as well as an app that identifies reinforcing factors to help them in their health goals.

Our proposed research expands on the work by West et al [8], which categorized mobile apps by the Precede-Proceed Model (PPM) model (predisposing, enabling, and reinforcing factors) [16,17], by providing two additional dimensions: (1) whether the apps are for management of disease and/or prevention and (2) whether they are related to physical and/or mental health. These information have important implications for both older adults seeking apps for specific purposes, as well as for mobile app developers, to help them better understand the distributions of different kinds of mobile apps on the market.

Precede-Proceed Model

West and colleagues [8] took the important first step in mobile app classification by using both the Health Education Curriculum Analysis Tool (HECAT) and the Precede-Proceed Model (PPM) to analyze the existing health and fitness apps in the iTunes App Store. HECAT's classification criteria include specific health-related behaviors, such as alcohol consumption, healthy eating, tobacco consumption, and other drugs [18]. Using the HECAT system, West and colleagues concluded that apps related to physical activity and personal wellness were the most common. As to the PPM, they also found that most of apps were classified as predisposing (1776/3336, 53.24%) or enabling (2181/3336, 65.38%), with reinforcing apps being the least common (222/3336, 6.65%) and with very few apps possessing all three factors (62/3336, 1.86%). Conceptually, PPM is a stronger model than HECAT because PPM provides a framework for creating health promotion interventions that are not targeted to any specific health behavior. Nevertheless, PPM lacks the capability to incorporate specific health conditions, to which HECAT pays particular attention, and health care processes, which include prevention and management.

In this paper, we propose a new classification scheme to analyze mobile apps on the market, extending the PPM model to include two important additional dimensions: physical versus mental health and prevention versus management. We believe that this more comprehensive analysis of mobile apps offers several advantages when compared to the PPM model alone. First, since our scheme is built on the PPM model, it still retains the capacity of PPM to classify or analyze mobile applications into predisposing, enabling, and reinforcing categories. Second, our scheme incorporates prevention and management of disease. Since prevention and management of disease have different emphases and are both of great importance in health care processes, it is a natural addition to West's original classification scheme. Third, while not as detailed as the HECAT system, the proposed scheme does allow classification by physical/mental health. Finally, the proposed scheme allows us to analyze existing mobile apps according to either PPM, health/mental health, or management/prevention separately, as well as to examine the overlap of mobile apps in various categories (eg, mental health-related apps for prevention that provide information on enabling skills).

For testing and comparative purposes, we collected information on mobile apps for older adult health that were released in June and August, 2011 and August 2012 from the "Health & Fitness" category in the Apple iTunes App Store and applied the proposed classification scheme to categorize these apps. Our purpose was to develop a classification scheme to facilitate the selection of mobile apps by older adults so that they can choose most appropriate apps for them (eg, depending on whether they want an app that is predisposing, enabling, or reinforcing, whether they want an app for health or mental health conditions, and whether they are interested in prevention and/or management of disease), as well as to provide mobile app developers a way of obtaining more specific and valued insights into the field of existing mobile apps.

Methods

Design

After a qualitative content analysis of manufacturers' description of health and fitness apps was conducted by the research team, we constructed a classification scheme for the classification of mobile apps according to three dimensions: (1) the PPM [16,17], (2) prevention versus management of disease, and (3) physical versus mental health. Figure 1 shows the constructed classification scheme.

The x-axis of the classification scheme represents health conditions, including physical health conditions such as hypertension, diabetes, heart diseases, bronchitis, and stomach flu, as well as mental health conditions such as depression, social phobia, acute stress disorder, anxiety, and schizophrenia. We categorize health conditions into physical health conditions and mental health conditions because this categorization is reflective of the development structure of most health-related apps. Although mental health and physical health commonly impact each other [19], most current apps have their main objective to benefit either mental or physical health exclusively. However, if an app is clearly associated with both physical health and mental health conditions, it is coded in both categories.

The second dimension, the y-axis, represents health care processes. As mobile apps are increasingly playing a major role in facilitating the diffusion of health information, enabling positive behavior change, longitudinal and continuous collection of personal health-related data, remote monitoring and warning, and other health care activities, apps could be regularly and commonly used for the prevention and/or management of disease [20,21]. Prevention tools help individuals manage risks for certain diseases, by, for example, promoting healthy lifestyle behaviors, such as healthy diet and physical activity, which are risk factors for many of the major chronic diseases in late life. Apps for the management of chronic disease place an emphasis on providing individuals with the information, skills, and associated tools to monitor their conditions, to react promptly when a certain type of clinical intervention might be needed to avoid a worsening of symptoms and/or costly hospitalization,

as well as to aid older adults in the recovery process [22,23]. Therefore, we choose prevention and management of diseases to be the two components of the y-axis of the scheme. Similar to the physical/mental health dimensions, if an app is clearly associated with both prevention and management (eg, self-monitoring of blood pressure can serve both purposes), it is coded in both categories.

The third dimension, the z-axis, is adapted from the PPM model, which identifies the functions or goals of health-related mobile apps into three categories: predisposing, enabling, and reinforcing. According to the health promotion framework, predisposing factors include knowledge, attitudes, beliefs, values, perceptions, and motivations that predispose individuals to engage in specific behaviors. Enabling factors are those that facilitate a person's ability to obtain health-related services or engage in healthy behavior, and focus largely on the skills needed to engage in the behavior and the availability of resources (eg, cost factors and resource factors). Reinforcing factors aim to provide supports, which are necessary for individuals to maintain healthy behaviors, and can include social networks and positive reinforcement based on self-monitoring data and feedback information [17]. These three factors direct us to group mobile apps into three categories based on whether they focus on predisposing, enabling, or reinforcing factors that aim to affect behavior change [8]. A summary of mobile apps in relation to PPM model is provided in Table 1.

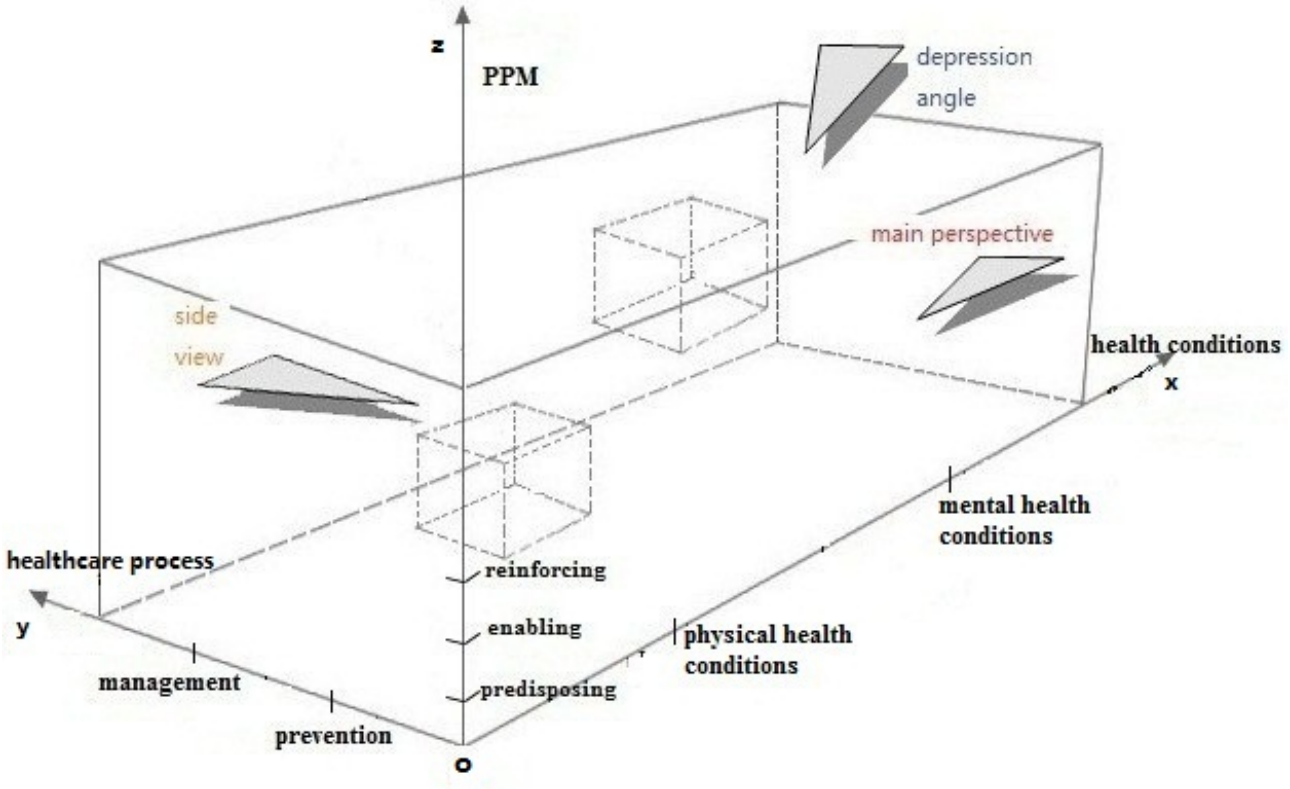
After we designed and constructed the classification scheme, we determined the face validity of this scheme by interviewing 11 people who had not been involved in the development of the study in any way; that is, they had participated in neither the construction of the classification scheme nor the content analysis [24]. They all agreed that this scheme accurately reflected the nature of this application.

Prior to conducting the reliability analysis, two researchers and a research assistant (none of whom had been involved in the development of the study's classification scheme, content analysis, or determination of face validity) all received systematic training in the coding of the apps. Training sessions were held three times a week for 2 weeks, with each session lasting 50 minutes. The core elements of that training were to review the distinctions for coding apps into appropriate categories (eg, predisposing, enabling, and reinforcing factors of the PPM model; prevention and management for health care process; and physical versus health conditions for health conditions) and related procedures regarding study sample entry and app coding. The two researchers independently coded the study apps based on manufacturers' written descriptions of each app, to test the scheme for its ability to categorize all the potential apps in the health and fitness categories. In accordance with our classification scheme, each mobile app was coded based on the three dimensions discussed above.

Table 1. Mobile app functions in relation to PPM.

Mobile apps	Features	Core values
Predisposing apps	Provide health information to impact health perceptions, health beliefs, values, or attitudes toward behavior change (eg, providing information on risks of diabetes, including obesity).	Promoting correct perceptions about the relation between lifestyle behaviors and the development of chronic disease, as well as about the value of self-management in delaying onset of disease progression and functional loss.
Enabling apps	Teach a skill (eg, how to monitor blood pressure), provide a service; record/track behaviors (eg, an app that records blood pressure values).	Providing useful and direct help to enable people to do something.
Reinforcing apps	Interface with online community using a social network site; provide encouragement from trainers/coaches; evaluate users' self-monitoring (eg, give an evaluation based on blood pressure values).	Strengthening behaviors through interactions, typically positive feedback; emphasis on support through interaction with users.

Figure 1. Proposed scheme for apps classification.



Sample

A sample of existing mobile apps, currently available online from the "Health & Fitness" category in the Apple iTunes App Store (ordered by released time or by alphabet), was selected to test our classification scheme. There were more than 23,000 mobile apps in the "Health & Fitness" category available to download, so we decided to randomly choose apps released during certain time periods. Because the US Food and Drug Administration (FDA) released draft guidance for the development of mobile health apps in July 2011 [25], we included time periods before and after their release date to investigate its potential influence on mobile application development. Further, to analyze the change of year-on-year growth in the number of apps, we included apps released in August 2012 as well. As a result, the final study sample consisted of apps released in June 2011, August 2011, and August 2012, and the written description of each app was accessed and viewed.

Sample selection was based on the following inclusion and exclusion criteria. Inclusion criteria included: (1) apps that one had to pay for, as free apps often became upgraded apps into paid ones, leading to the possible double coding of the same app (eg, Vital mHealth released two versions of the mobile app "PainMonitoring", a free version with limited functionality and a paid version that recorded and monitored a user's pain level); and (2) apps whose written descriptions were in English for the purpose of global access and use. Exclusion criteria included: (1) apps misclassified and misplaced under the "Fitness and Health" category, as determined by the manufacturers' descriptions of function not being associated with health or health care, such as bread maker timer assistant and journey scene records; and (2) apps that did not specifically relate to health or health care of older adults (eg, apps for baby health-nursing, apps for disseminating pregnancy prevention, and birth control techniques). Apps with explicit age information and/or illustrations of older adults as their target population directly helped us to identify apps for older adults. For those apps without this information, there is typically a description of the targeted health condition and functional status for the app. Knowing the health condition being targeted, as well as the functional status, enabled us to identify health-related apps for elders with specific health conditions and levels of functional status. In sum, we relied on the three types of data (ie, age information/target population, type of health condition, and functional status) to identify health and fitness apps that were not relevant for older adults. Taking August 2012 as an example, on the basis of these inclusion/exclusion criteria, there were 657 apps in the health and fitness category, with 445/657 (67.7%) free apps, 61/657 (9.3%) non-English apps, 4/657 (0.6%) misclassified apps, and 99/657 (15.1%) apps not applicable to older adults. Thus, the final study sample for August 2012 consisted of 48/657 (7.3%) apps that could be employed for older adults' health and health care (Figure 2). App samples selected from August 2011 and June 2011 are represented in Figures 3 and 4, respectively.

Figure 2. Selection of apps sample in August 2012.

Figure 3. Selection of apps sample in August 2011.

Figure 4. Selection of apps sample in June 2011.

Measurement

Each app was coded according to the three dimensions in the classification scheme (see Multimedia Appendix 1). First, apps were coded in terms of health conditions, and could be coded for physical health, mental health, or both. Second, apps were coded in terms of health processes, and could be coded for management of disease, prevention of disease, or both. Third, apps were coded into the three categories of the PPM model [16,17].

Analysis

To check the reliability of the coding scheme and justify the validity of our scheme, inter-rater reliability was conducted by two researchers (not involved in any aspect of the study), who independently coded the app data [26]. There was also a third evaluator (a research assistant who had not been involved in any aspect of the study), who was called in when there was disagreement as to the coding of the apps. We chose the entire 119 sample of apps for the purpose of validation. There was agreement (an initial level of concordance) for 114/119 (95.8%) apps, and disagreement for 5/119 (4.2%) apps. The five apps on which there was initial disagreement between coders were discussed, and when they could not arrive at consensus, the third research assistant was asked to join them until they reached consensus. Consensus was reached on these five apps as well, resulting in agreement on the coding for all 119 apps.

We were also able to develop specific combinations from the three axes of the classification scheme to provide a more refined description of the apps (eg, identifying the ratio of physical and mental apps for prevention), focusing on enabling factors.

Results

Study Sample

We proposed a classification scheme for the classification of existing mobile apps on the market. By using our scheme, we coded all the study sample mobile apps (Tables 2 and 3).

In the process of study sample selection, there were 379 health-related apps, and about 31.4% (119/379) of them, relevant to older adults, were chosen in the study sample, which consisted of 48/119 (40.3%) from August 2012, and 45/119 (37.8%) and 26/119 (21.8%) from August 2011 and June 2011, respectively.

Coding Results

In August 2012, most apps were associated with physical health conditions (31/48, 64.6%), approximately two times that of mental health-related apps (17/48, 35.4%). In terms of prevention and management, apps targeted at management of disease were substantially more common than those for prevention (44/48, 91.7% vs. 6/48, 12.5%). Enabling apps took the dominant position in the PPM model (45/48, 93.8% vs. 4/48, 8.33% vs. 4/48, 8.33% for enabling, predisposing, and reinforcing, respectively), and there were few apps combining features of predisposing, enabling, and reinforcing factors. In fact, there were no such mobile apps in August 2011 or August 2012. As for physical health, apps for prevention were 16.1% (5/31), with 3.2% (1/31) apps for predisposing, 16.1% (5/31) apps for enabling, and 6.5% (2/31) apps for reinforcing. There were 64.6% (31/48) apps for management, with 3.2% (1/31), 100% (31/31), and 12.9% (4/31) apps associated with predisposing, enabling, and reinforcing factors, respectively. With respect to mental health, apps for prevention were 5.9% (1/17) and 94.1% (16/17) for management. Physical-related apps for both prevention and management were 16.1% (5/31), while mental-related apps for both prevention and management were just 5.9% (1/17).

Considering the study sample from August 2011, 64.4% (29/45) of apps were for physical health; the majority of apps (41/45, 91.1%) were used for management of disease rather than prevention of disease; enabling apps accounted for 95.6% (43/45), while predisposing and reinforcing apps were 8.9% (4/45) and 17.8% (8/45), respectively. As for physical health, 27.6% (8/29) of apps were for prevention and 93.1% (27/29) were for management, while in terms of mental health, 23.8% (5/21) of apps were for prevention and 90.5% (19/21) were for management.

Coding results of apps from June 2011 showed that 80.8% (21/26) of apps were related to physical health conditions, more than two times than that of mental health-related conditions (9/26, 34.6%). Apps for management were 92.3% (24/26) compared with 7.7% (2/26) for prevention; enabling apps were far more common than predisposing apps or reinforcing apps. In terms of physical health, 4.8% (1/21) of apps were for prevention and 95.2% (20/21) of apps were for management; and in terms of mental health, 11.1% (1/9) of apps were for prevention and 88.9% (8/9) apps were for management.

Table 2. Study sample (1) coding results.

Coding scheme	June 2011	August 2011	August 2012
Study sample	26	45	48
Physical-related apps, n (%)	21/26 (80.8)	29/45 (64.4)	31/48 (64.6)
Mental-related apps, n (%)	9/26 (34.6)	21/45 (46.7)	17/48 (35.4)
Prevention-related apps, n (%)	2/26 (7.7)	7/45 (15.6)	6/48 (12.5)
Management-related apps, n (%)	24/26 (92.3)	41/45 (91.1)	44/48 (91.7)
Predisposing-related apps, n (%)	2/26 (7.7)	4/45 (8.9)	4/48 (8.3)
Enabling-related apps, n (%)	26/26 (100)	43/45 (95.6)	45/48 (93.8)
Reinforcing-related apps, n (%)	8/26 (30.7)	8/45 (17.8)	4/48 (8.3)
Predisposing-enabling-reinforcing apps, n (%)	2/26 (7.7)	0/45 (0.0)	0/48 (0.0)

Table 3. Study sample (2) coding results.

Coding scheme	June 2011	August 2011	August 2012
Physical-prevention-predisposing, n (%)	0/21 (0.0)	1/29 (3.4)	1/31 (3.2)
Physical-prevention-enabling, n (%)	1/21 (4.8)	5/29 (17.2)	5/31 (16.1)
Physical-prevention-reinforcing, n (%)	0/21 (0.0)	2/29 (6.9)	2/31 (6.5)
Physical-management-predisposing, n (%)	2/21 (9.5)	1/29 (3.4)	1/31 (3.2)
Physical-management-enabling, n (%)	20/21 (95.2)	25/29 (86.2)	31/31 (100)
Physical-management-reinforcing, n (%)	8/21 (38.1)	6/29 (20.7)	4/31 (12.9)
Mental-prevention-predisposing, n (%)	0/9 (0.0)	0/21 (0.0)	0/17 (0.0)
Mental-prevention-enabling, n (%)	1/9 (11.1)	4/21 (19.0)	2/17 (11.8)
Mental-prevention-reinforcing, n (%)	0/9 (0.0)	1/21 (4.8)	1/17 (5.9)
Mental-management-predisposing, n (%)	0/9 (0.0)	1/21 (4.8)	3/17 (17.6)
Mental-management-enabling, n (%)	8/9 (88.9)	19/21 (90.5)	16/17 (94.1)
Mental-management-reinforcing, n (%)	0/9 (0.0)	3/21 (14.3)	2/17 (11.8)

Discussion

Principal Findings

In essence, our proposed scheme was a ternary relation group, represented by "HHP=<Health conditions, Health care process, PPM model>" with the capacity to identify mobile apps for disease prevention/management of physical and/or mental health conditions according to the three factors, and to classify apps with these three dimensions (Figure 1). The scheme provides a comprehensive way to classify existing mobile apps by taking into consideration of three factors, all of which are both relevant to older adults to enable them to choose the most appropriate apps to meet their needs, health care needs, and relevant to developers interested in the development of mobile apps for health care.

The main effects of the scheme (the domain between the y-axis and z-axis, projected on the yoz plane) reflected a binary relation, that is "HP1=<Health care process, PPM model>". This scheme did not include physical/mental health conditions, and was limited to an examination of health care processes (disease prevention/management) and PPM. Every element in this binary relation indicated what kind of apps could be used for prevention and/or management of disease. This enabled us to understand the general relationship between health care

processes and the PPM model, for example, what is the proportion of prevention apps targeted at predisposing, enabling, and reinforcing factors, respectively, and what is the ratio of prevention apps and management apps that are associated with enabling factors.

Likewise, from the depression view of our scheme (Figure 1), it was mapped to the xoy plane (between the x-axis and y-axis) and we denoted it by "HH=<Health conditions, Health care process>", expressing the relationship between health conditions and health care process, which allowed an examination of which prevention and/or management apps were appropriate to physical and/or mental health conditions. This ability offers the potential to facilitate user access to the most appropriate apps to satisfy their needs in taking prevention and/or management measurements for health conditions.

If examined from the side view, the scheme was mapped to the xoz plane (between the x-axis and z-axis), denoting a binary relation between health conditions and PPM model, and we expressed it by "HP2=<Health conditions, PPM model>", which allowed us to identify apps that deal with a certain health/mental health condition, by whether they provide predisposing, enabling, or reinforcing benefits. This is important, as behavior change theory posits that individuals benefit from specific factors in the PPM model in terms of preventing or managing their physical health and/or mental health conditions.

With the coding results of our study sample from June 2011, August 2011, and August 2012, we have the following observations and conclusions. First, compared with apps released in June 2011 (260), the number of apps in August 2011 (364) increased by 40.0%; and compared with August 2011 (364), the number of apps released in August 2012 (657) increased by 80.0% and increased 2.5 times compared with June 2011 (260). In addition, excluding free, misclassified, and non-English apps, apps applicable for older adults accounted for about one third of the entire study sample: 25.2% (26/103) for June 2011, 34.9% (45/129) for August 2011, and 32.6% (48/147) for August 2012. These data demonstrate that apps for older adults had an increase after the FDA released draft guidance to regulate their manufacture and use. It might be that app developers believed that more consumers would accept and use apps after the promulgation of FDA draft guidance related to app performance and safety, and that, as a result, they thought the timing was right for the development of new mobile apps for older adults.

Second, in terms of the PPM model, the most commonly coded apps in our study were enabling apps. Apps including all three factors of the PPM model (ie, predisposing, enabling, and reinforcing factors) were very few, supporting the findings of West et al [8]. This enhances the validity of our findings, as even though they are only related to apps targeting older adults, they arrive at a similar conclusion as West et al who included a larger range of apps appropriate for all age groups [8].

Third, mobile apps users and developers were able to obtain deeper and more comprehensive information about existing mobile applications in choosing and developing apps by using our classification scheme. Specially, the main motivation for the development of this scheme and its potential uses can be summarized as follows: (1) if combining the y-axis and z-axis, we obtained the relationship between health care processes and PPM, providing information on the relative distribution of predisposing, enabling, and reinforcing apps for prevention and/or management apps; (2) if considering the x-axis and z-axis together, we obtained relevant information about health conditions and PPM, providing information about the relative distribution of predisposing, enabling, and reinforcing apps for physical and/or mental health conditions; and (3) if examining both the x-axis and y-axis, we obtain the binary relation between health conditions and health care processes and further identify the relative distribution of prevention and/or management apps for a specific physical/mental health condition. In summary, the proposed classification scheme provides a more comprehensive way to analyze a mobile application from the view of health conditions (ie, physical and/or mental health conditions), health care processes (choosing which kind of health process, prevention or management of disease), and PPM (which factors influence behavior change).

Both older adult app users and mobile app developers could benefit from such a classification scheme. For older adult app users, our classification scheme can facilitate the choice of appropriate mobile apps according to their actual needs for prevention and/or management, physical and/or mental health conditions, and which kind of factor they are in need of for behavior change. For example, an older person, hoping to improve his/her physical health conditions with the second phase of behavior change, would receive a list of mobile apps related to physical health improvement, which provide enabling factors, such as tools to track physical activity level and diet.

For mobile app developers, our classification scheme has the capacity to reveal the relative distributions of each type of mobile apps. Our classification scheme does not just present developers simple statistical information about the ratio between prevention apps and management apps, or the relative number of physical health-related apps and mental health-related apps and the distributions of apps in predisposing, enabling, and reinforcing categories. Our scheme also provides valuable and concrete information when we combine different components of our scheme to classify existing mobile apps. For example, app developers would be able to identify the current availability of apps with predisposing factors for the prevention of mental conditions as well as the availability of apps with reinforcing factors for the prevention of mental conditions. Thus, our classification scheme has great potential in providing insightful and dynamic information to mobile app developers and in helping developers make informed decisions about the development of future mobile apps for the prevention and management of disease by using the proposed classification scheme to categorize all existing mobile apps on the market.

Limitations

This study presented one of the first of its kind to construct a classification scheme for the categorization of paid mobile apps publicly available in the Apple iTunes App Store in a comprehensive way by considering the following three dimensions: the PPM model, health care process (prevention and management), and health care conditions (physical health and mental health). However, there are several limitations to

the study. First, in constructing our classification scheme, we adopted a generalized, rather than a finer-grained one. For example, health conditions were grouped simply into physical health conditions and mental health conditions, but not classified more specifically as those listed in the HECAT, such as alcohol misuse, tobacco and other drug use, healthy eating, mental and emotional health, personal health and wellness, physical activity, safety, sexual health, and violence prevention [18]. This limited us from providing older adults with specific information regarding specific health conditions in which they might be interested. It also precluded us from providing mobile app developers with more specific information regarding the number of apps in each domain listed in HECAT and correspondingly, which kind of more specific apps were less available in the market. Instead, we provided a more general impression on app distribution in terms of physical health conditions and mental health conditions. Second, as indicated above, we chose to consider those apps that would have potential relevance for older adults, and not people of all ages. Our scheme has the capacity to categorize mobile apps for other age groups, such as babies, teenagers, and young adults, by providing target group relevant mobile apps as study samples. However, this was not the purpose of our study. Future research could use the age group of user as a covariate to our classification scheme, utilizing all existing mobile apps, which would assist other age group users in the choice of mobile apps that are appropriate to their specific health concerns. Third, while the goals of the mobile apps we included were to support older adults to prevent disease, maintain or improve their health and fitness, and manage their physical and mental health conditions, the classification scheme is unable to incorporate users' appraisals of the mobile apps included in the analysis. As a result, we have no idea about how end users (eg, older adults and their family caregivers) evaluated their effectiveness, usability, and/or acceptability, which could provide valuable information to app designers and developers, as well as to other older consumers looking for specific apps.

Conclusions

A number of mobile apps are available on the market, and these apps offer the promise of not only enhancing the self-management of disease among older adults, but also promoting health behaviors that could potentially prevent or delay the onset of disease. There are mobile apps for enhanced disease management for a number of chronic diseases, including diabetes, hypertension, and stroke; health care information education dissemination; and for collecting individual information and storing data in a center server accessible to professional physicians and/or family caregivers and transmitting the data to professional physicians and/or family caregivers.

For the purpose of acquiring a comprehensive view of available apps on the market, we put forward and constructed a classification scheme for the categorization of mobile apps by considering the following three dimensions: (1) the PPM (ie, predisposing, enabling, and reinforcing factors), (2) health care process (ie, prevention vs. management of disease); and (3) health conditions (ie, physical vs. mental health). Using our classification scheme, a content analysis of mobile apps was conducted to classify the study sample apps in the "Health and Fitness" category publicly available in the iTunes App Store. Face validity and test-retest reliability were demonstrated. We believe that the proposed classification scheme can potentially help older adult app users more easily locate appropriate apps for their specific needs. We also believe that the proposed classification system can potentially help app developers understand the existing distribution of mobile apps and provide important information to identify current gaps in available mobile applications, so that they can make better-informed decisions about the development of future mobile applications for the prevention and management of disease in late life. Future work could expand the classification scheme to all mobile apps, and include age as a covariate. In addition, future work would benefit by taking user appraisal into account when classifying mobile apps, enabling the quantification of users' subjective evaluation of apps.

Acknowledgments

This work was supported in part by the "111 Project" of Ministry of Education and State Administration of Foreign Experts Affairs under Grant No. B14025, by the "University Featured Project" of Ministry of Education under Grant No. TS2013HFGY031, the Chinese National Key Technology R&D Program under Grant No. 2013BAH19F01, by the International S&T Cooperation Program of Gansu Province under Grant No. 2013GS09921, and by National Institute on Aging, National Institutes of Health, through Grant Number R43AG041571 (its contents are solely the responsibility of the authors and do not necessarily represent the official views of the NIH). Dr Levkoff was supported by the South Carolina SmartSTATE Endowed Chair in Community and SocialSupport: SmartHOME.

Conflicts of Interest

Conflicts of Interest: None declared.

Multimedia Appendix 1

App coding form.

[PDF File (Adobe PDF File), 32KB - mhealth_v2i1e6_app1.pdf]

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Abbreviations

eCAALYX: Enhanced Complete Ambient Assisted Living Experiment
FDA: US Food and Drug Administration
HECAT: Health Education Curriculum Analysis Tool
PC: personal computer
PDA: personal digital assistant
PPM: Precede-Proceed Model

Edited by G Eysenbach; submitted 05.09.13; peer-reviewed by J Fozard, P Weitzman, O Blanson Henkemans, M Murfin, A Holzinger; comments to author 27.09.13; revised version received 29.10.13; accepted 12.11.13; published 17.02.14.

Please cite as:
Wang A, An N, Lu X, Chen H, Li C, Levkoff S
A Classification Scheme for Analyzing Mobile Apps Used to Prevent and Manage Disease in Late Life
JMIR Mhealth Uhealth 2014;2(1):e6
URL: http://mhealth.jmir.org/2014/1/e6/
doi:10.2196/mhealth.2877
PMID:25098687

Publisher:
JMIR Publications
130 Queens Quay East.
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