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Development of a Smartphone Application to Monitor Pediatric Patient-Reported Outcomes

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Abstract

This paper is to document the development process of a smartphone app to track patient-reported outcomes (PROs) of children with chronic diseases, and to share the usability study results. A multidisciplinary research team including health services researchers, pediatric nurses, and software engineers worked synergistically in development. Group discussions and several rounds of feedback and modification were conducted. Ten pediatric patients, five parents, and two nurses participated in usability study. Qualitative content analyses were employed in development and usability evaluation. The app collects demographic information and PROs. The web-based administration portal helps to manage demographic information, questionnaires, administrators, and survey-conducting organizations. All participants felt this app was easy to use and the interfaces were friendly to children. Nurses thought administration portal interfaces were simple and data was convenient to download for further analysis. The app and administration portal have potential to promote PROs in assessing quality of life and symptoms in pediatric patients.

Keywords:

Patients, Mobile applications, Software design.

Introduction

The Patient-Reported Outcomes Measurement Information System (PROMIS) Pediatric Cooperative Group has developed pediatric self-report item banks for youth ages 8-17 years across five generic health domains (physical functioning, pain, fatigue, emotional health, and social health) [1, 2]. Our research team has been authorized to translate the PROMIS Pediatric and PROMIS parent proxy report short forms into Simplified Chinese. Pediatric PROMIS contains instruments for 8- to 17-year-olds [1, 2]. PROMIS Parent Proxy Report Scales for Children were developed for parents of children ages 5-17 years who were too young, too cognitively impaired, or too ill to complete a PRO instrument [3-5].Computer-assisted tools have been developed in recent years to collect PROs. However, computer-based tools are often only used in hospitals or clinics, which makes it hard to collect PROs when patients are at home in the break before the next treatment. Smartphone applications (apps) have the potential to collect PRO data with high efficiency and effectiveness. Our research team developed a smartphone app to track PROs of children with chronic diseases. This paper aims to document the app development process and share the usability study results.

Methods

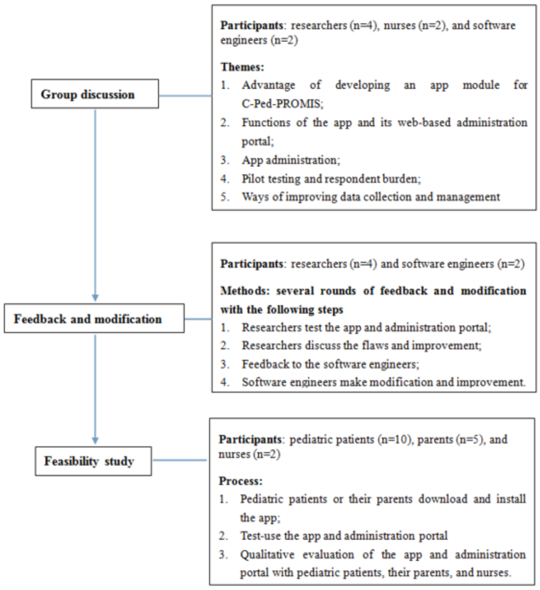
This study was conducted in Shanghai, China. This research received ethical review approval from the Second Military Medical University. The PROMIS central administration has authorized us to translate the PROMIS Pediatric and PROMIS parent proxy report short forms from English to Chinese, following the standard Functional Assessment of Chronic Illness Therapy Translation Methodology. All the translation steps and the final Chinese versions of the pediatric PROMIS short forms (C-Ped-PROMIS) have been approved by the PROMIS Statistical Center. The C-Ped-PROMIS items were semantically and conceptually equivalent to the original [6]. A total of 232 children and adolescents with cancer were interviewed with the C-Ped-PROMIS using traditional paper questionnaires. The strict and standard scale metrological test showed the C-Ped-PROMIS measures had good reliabilities and validities. Comparably, reliable and valid instrument systems can be applied in the measurement of symptoms and quality of life of children and adolescents with cancer in China, and then improve pediatric cancer care [7]. We use the validated C-Ped-PROMIS short form questionnaires in our app.

A multidisciplinary research team including health services researchers, pediatric nurses, and software engineers worked synergistically to design and develop the PROs module and administration portal. Figure 1 shows the workflow of the development process.

Group discussion: researchers, nurses and software engineers

Based on the literature review and previous experience of developing an app with a "self-assessment questionnaires" module [8-9], we conducted the first round of focus group discussion with four researchers, two nurses, and two software engineers. The discussion was conducted in a conference room at a medical university in Shanghai and lasted between 120 and 150min. All of these researchers have been involved in translating and testing C-Ped-PROMIS short forms with an educational level of a master degree or above. The nurses had more than ten years of working experience with pediatric patients and have a good understanding of C-Ped-PROMIS. The software engineers were experienced in developing medical-related software or apps.

Discussions were recorded and continued until the same themes and issues emerged from the interviewees. Discussions were transcribed verbatim within two days. Based on the functions described by the researchers, software engineers developed the beta version of the app and web-based administration portal with basic structure, functions, and interface.



Participants: researchers (n=4), nurses (n=2), and software engineers (n=2)

Themes:
1. Advantage of developing an app module for C-Ped-PROMIS;
2. Functions of the app and its web-based administration portal;
3. App administration;
4. Pilot testing and respondent burden;
5. Ways of improving data collection and management

Participants: researchers (n=4) and software engineers (n=2)

Methods: several rounds of feedback and modification with the following steps
1. Researchers test the app and administration portal;
2. Researchers discuss the flaws and improvement;
3. Feedback to the software engineers;
4. Software engineers make modification and improvement.

Participants: pediatric patients (n=10), parents (n=5), and nurses (n=2)

Process:
1. Pediatric patients or their parents download and install the app;
2. Test-use the app and administration portal
3. Qualitative evaluation of the app and administration portal with pediatric patients, their parents, and nurses.

Figure 1 - The workflow of the development process

Feedback and modification: researchers and software engineers

Four researchers tested the beta version of the app individually, and then a group discussion was held to brainstorm about the disadvantages and improvement of the app. Software engineers modified the app according to the feedback. The second version of the app was developed and sent to the researchers. Another round of testing, feedback, and modification was conducted until there were no more items needed to be improved. After software engineers finished developing the web-based administration portal, researchers tested and provided feedback to the engineers for further improvement, following the same procedures as with the app's modification.

Usability study: pediatric patients, parents and nurses

Pediatric patients and parents were recruited in the Children's Hospital of Soochow University and Shanghai Children's Medical Center during August 2015. The research team introduced the app and the usability study project. No study procedures were performed until study participants signed the informed consent. The eligible pediatric patients were aged 8-17 years old with chronic diseases. The eligible parents had a child aged 5-7 years old with a chronic disease. The pediatric patients and parents were able to communicate fluently in Mandarin Chinese and had at least one Android smartphone in their family.

We first helped the pediatric patient or his/her parents and the eligible parents to install the most updated version of the app on their smartphones. The participants were asked to register and log in to fill in their basic demographic information in the app first. Then, they entered the questionnaire system to enter answers. The nurses and researchers tested the administration portal to see whether it received the accurate data users entered, and whether it was convenient to export the data for further analysis.

After the usability test, semi-structured interviews were conducted with all research participants. They expressed their positive and negative experiences related to both the app and administration portal.

Data Analyses

Descriptive statistics were used to characterize the study participants. Two researchers transcribed the recorded qualitative data and analyzed the transcripts independently. A qualitative content analysis aimed at finding manifest, and latent meaning of data was applied to analyze the information. A stepwise approach was adopted for the content analysis. Firstly, the transcribed data was read several times by the researcher to find the theme of the whole. Secondly, the segmentation of information was done to organize the segments and sub-segments of information. Thirdly, the significant information related to research questions was extracted. Finally, data was coded and grouped into categories and abstracted into subthemes and a main theme.

Results

Basic function of the app

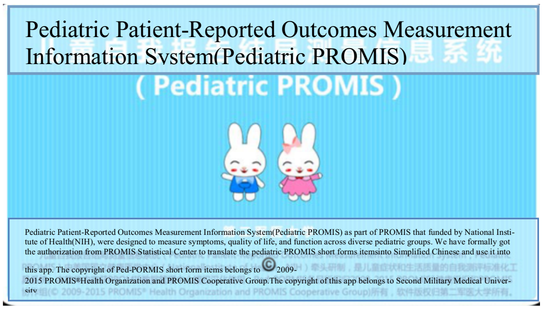
Six rounds of feedback and modification of the app were conducted before the final version of the app was developed. The app mainly has two modules: the demographic information module and the questionnaire module. Figure 2 (2a-2b) shows the welcome page of this app. Users need to register and log into the app. They need to fill in the demographic information and upload it as required, so they can enter the questionnaire module.


儿童自我报告结局测量信息系统
（Pediatric PROMIS）

第二军医大学

儿童自我报告结局测量信息系统（Pediatric Patient-Reported Outcomes Measurement Information System，Pediatric PROMIS）由美国国立健康医学中心（NationalInstitute of Health，NIH）牵头研制，是儿童症状和生活质量的自我测评标准化工具系统。本软件内容获PROMIS数据管理中心授权汉化使用，Ped-PORMIS条目版权归2009-2015 PROMIS®健康组织和PROMIS协作组(© 2009-2015 PROMIS® Health Organization and PROMIS Cooperative Group)所有，软件版权归第二军医大学所有。

Figure 2a - Welcome page


Pediatric Patient-Reported Outcomes Measurement Information System(Pediatric PROMIS)

(Pediatric PROMIS)

Pediatric Patient-Reported Outcomes Measurement Information System(Pediatric PROMIS) as part of PROMIS that funded by National Institute of Health(NIH), were designed to measure symptoms, quality of life, and function across diverse pediatric groups. We have formally got the authorization from PROMIS Statistical Center to translate the pediatric PROMIS short forms itemsinto Simplified Chinese and use it into this app. The copyright of Ped-PORMIS short form items belongs to © 2009-2015 PROMIS®Health Organization and PROMIS Cooperative Group.The copyright of this app belongs to Second Military Medical University

Figure 2b - English translation of welcome page

There are two entrances in the questionnaire module as is showed in Figure 3 (3a-3b). One is for pediatric patients aged from 8 to 17 years old and who are able to report by themselves, while the other entrance is for parents of pediatric patients aged from 5 to 7 years old or pediatric patients who need help from parents to report.

Figure 3a - Two entrances of questionnaire module page

Figure 3b - English translation of two entrances of questionnaire module page

There is a voice guide, once users enter the questionnaire module, “Welcome to Pediatric PROMIS, please respond to each question or statement by choosing an item according to the feeling of the past 7 days”. The interface of the voice guide page is showed in Figure 4 (4a-4b). There are eight short questionnaire forms: Physical Functioning-Mobility, Physical Functioning-Upper Extremity, PainInterference, Fatigue,Depression symptoms, Anxiety, Peer Relationships, and Anger. If the title button of the short form is gray, the user does not need to answer that form. In other words, users can answer any of the short forms with a colored title.


语音提示：“欢迎进入本测量系统，请根据过去七天的情况回答下列问卷的每一个问题，点击选择合适的答案。”

Figure 4a - Voice guide page

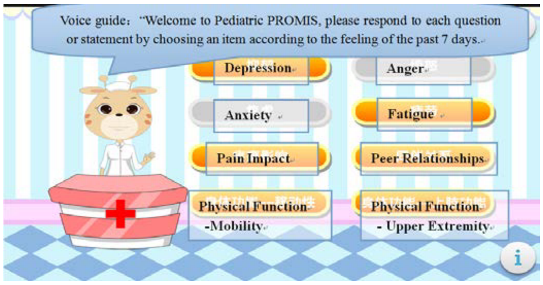

Voice guide: “Welcome to Pediatric PROMIS, please respond to each question or statement by choosing an item according to the feeling of the past 7 days.

Figure 4b - English translation of voice guide page

When all the items of one short form are answered, feedback will be provided to the user regarding the current status and care suggestions. We have added audio assistance in this app. If the pediatric patient cannot fully understand the words of any item, he/she can click the cartoon rabbit in the left corner as shown in Figure 5. The item will then be read out loud to him/her. We tried to make sure that the pronunciation and intonation of the voice have neutral emotion, so it does not affect the response of pediatric patients.


在过去七天内，
疼痛让我感到愤怒

Figure 5a - Questionnaire item page


In the past 7 days,
I felt angry when I had pain.

Figure 5b - English translation of questionnaire item page

Basic function of administration portal

Three rounds of feedback and modification of the administration portal were conducted before it was finalized. There are two types of administrators: the super administrator and the sub-administrator. The super administrators have access to all functions of the administration portal, while the sub-administrators do not have access to the management of administrators. Every administrator has a specific username and password. Sub-administrator’s username and password are assigned by the super administrator. The super administrator has access to all of the user data, while the sub-administrator has access just to data that he/she has collected.

The administration portal lists all the demographic information that users entered. Administrators can download the information as a comma separated values file, which can be opened/imported by Microsoft Excel and almost all statistics packages. The frequency data of some demographic information can be view directly as a pie chart in the administration portal. The administrator can send specific questionnaire forms to specific participants. User ID, child’s name, survey time, short form name, total scores, and total standard scores of the short form are listed in the administration system. The total standard scores are calculated according to the PROMIS Scoring Manual [10]. The administrator can also see the score of a specific item of any short form. These data can be exported to most statistical software.

The results of the usability evaluation

A total of ten pediatric patients, five parents, and two nurses participated in this usability test. The pediatric patients were aged from eight to thirteen years old. Five of them were boys.

They were diagnosed with a kind of cancer and were currently under treatment. The parents were aged from twenty one to thirty-three years old. Their children were aged from five to seven, and were diagnosed with cancer. Three of the parents were female. Two nurses were aged from 32 to 43. Both of them were female and had a college degree. Their years of working experience with pediatric patients ranged from 10 to 22 years.

After testing the app, the pediatric patients and parents felt that there was no difficulty in completing this process. All participants felt that this app was easy to use and the interfaces were friendly to children. No pediatric patients felt that the audio of the eight short forms' items affected their response to questions. The administration portal recorded all the data accurately. Nurses who tested the administration portal thought that the interfaces were simple, and it was convenient to download the data for further analysis. They spoke highly about the different ways of downloading survey results because they satisfy different aims of studies. Overall, the app and administration portal met the demand of researchers and clinical nurses. Moreover, the app was easy to use and did not add burden for pediatric patients or their parents.

Discussion

Researchers began to collect survey data through the internet years ago [11-12]. Substantial data collection efficiency, low cost, and widespread availability of internet access among diverse groups are stimulating an increased usage of web-based surveys [13]. However, while a mobile phone is now essential to people's daily lives, the research literature on using mobile apps for survey research is sparse. Although both the cost and time to program apps are high, the cost and time to collect data of a large number of participants are low [8-9]. Therefore, the app is a promising tool to collect longitudinal data because users have their own ID number and username.

The target users of this app are pediatric patients aged from 8 to 17 years old, and parents of pediatric patients aged from 5 to 7 years old. Our research team has been authorized to translate the PROMIS Pediatric and PROMIS parent proxy report short forms into Simplified Chinese. By including these two scales, this app enables researchers and practitioners to measure the quality of life and symptoms of children in different age groups.

Based on the preference and interest of children, all the interfaces of the app were designed in cartoon styles. Cartoon images of a rabbit, bear, and giraffe were designed to be appealing to children. The lovely cartoon images may reduce their response burden and sense of boredom in answering the questionnaires. Some children even thought it was interesting to answer the questions because they loved the carton interfaces.

Due to chronic disease and treatment, some children cannot attend school like other same-age children. Some of them are undereducated to read all questions in the survey. Therefore, we added audio assistance for all items in the PRO survey. Pediatric patients usually use this app in the wards. Due to the noisy environment of wards, children tend to focus on the content of the items more than the pronunciation or intonation of the audio assistance. To some degree, the audio feature also adds interest to the survey.

The web-based administration portal collects and stores all the data users uploaded. The data can be easily downloaded in different forms for further analysis with statistical packages. The super administrators are researchers in our research team and have access to all the data. According to the authorization we received from PROMIS Health Organization, other Chinese researchers who want to use this app need to be approved by both PROMIS Health Organization and our research team. Approved researchers will receive sub-administrator status to collect and access their own data. With our super administration role, we will be able to perform multi-site PRO research in the future.

Conclusion

This study described the process of developing a smartphone app to monitor pediatric patients' reported outcomes. The multidisciplinary research group held group discussions to clarify the app functions of the app and administration portal. Several rounds of feedback and modification were conducted to finalize the app and its administration portal. The results of the usability study showed that the app was well accepted by target users. We conclude that the App and its web-based administration portal are with good usability, and can be applied for clinical research in regards of pediatric patients' self-reported symptoms. Smartphone apps have the potential to collect survey data with high efficiency. This app is promising to promote the use of C-Ped-PROMIS in assessing the quality of life and symptoms in pediatric patients.

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