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Development of a chronic kidney disease knowledge website with electronic personal health records for patients

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Objectives: To develop and evaluate a chronic kidney disease (CKD) knowledge website containing electronic personal health records (ePHR) for CKD patients.
Methods: A CKD knowledge website was developed based on the ADDIE model (Analysis, Design, Development, Implementation, and Evaluation) and usability guidelines. The user's needs were assessed by semi-structured interview with three pre-dialysis patients and the contents about CKD, nutrition, exercise, and medication were developed and validated by four experienced nephrologists. An F-shaped pattern and horizontal attention leans left with users' eye movements were applied. The ePHR was added to the website according to the literature review and was confirmed by using the CKD patient's needs analysis. The website was implemented on www.banraktai.com. To evaluate the website, 10 users were purposively selected. Data were gathered and analyzed using description statistics.
Results: Three main sections contained knowledge, ePHR, and community and communication. The CKD knowledge was categorized into four essential topics containing CKD, nutrition, exercise, and medication. An ePHR consisted of electronic forms for recording personal information, medication, laboratory test, dietary pattern, and exercise activity. The website usability evaluation was conducted by using the USE (Usefulness, Satisfaction, and Ease of use) questionnaire (7-point Likert scale ranged from 1= mostly disagree to 7=mostly agree). The average scores of usefulness, ease of use, ease of learning, and satisfaction were 5.03, 5.25, 5.63, and 5.24, respectively. Usability problems were identified by usability test. The average time used for all tasks was 32 minutes compared to 30 minutes by experience users, indicating the efficiency of this website. The effectiveness was determined by accuracy and completeness of the test. The results showed that 89% of all attempts were completed, 9% were partially completed and 2% failed. In addition, the results from direct observation and question were helpful for the improvement of the website.
Conclusion: This study was the preliminary development of a patient education website focusing on CKD knowledge, nutrition and ePHR. This website will be implemented for CKD patients to determine the effectiveness.

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Background and Rationale

Chronic kidney disease (CKD) is an important public health problem. The incidence and prevalence of this disease has increased in the past few years in Thailand. Most of CKD patients are unlikely to recover fully and need to receive ongoing treatment incurring significant cost, especially end stage kidney disease (ESKD) patients.[1] At the early stage of CKD, encouraging good health behaviors can help to prevent the progression of kidney disease due to eventual kidney failure. Promoting positive behaviors such as a proper nutrition, physical activities and lipid profile and sugar level management are important for patients to slow down the loss of kidney functions.[2] However, according to several studies, only a small group of people can appropriately answer questions about basic kidney etiology, cause and severity of CKD, treatment, and medication. Some patients and families were unable to remember medical information to prevent kidney failure. Most CKD patients neither know the stage of their kidney disease nor know how to slow the progression of the disease.[2-5] Consequently, bad nutrition and self-care can result in negative health effects. Therefore, CKD patients should also have essential knowledge of CKD including nutrition and self-care and be aware of their individual risks.

There are many ways to reach health care and medical information. The internet is convenient and widely available. Health information is one of the most important topics to be found online, especially specific health condition issues. Online searches of specific illnesses can provide knowledge and improve patients' understanding of their medical condition.[6] Moreover, a personal health record (PHR) can promote better health by helping patients have awareness and manage their health condition.[7] Previous studies found that a personal health record booklet (PHRB) has the potential to improve self-efficacy and self-regulation in patients with diseases.[8, 9] Generally hospital staff usually provide small booklets for recording information, but it is possible that there is not enough space for disease information or note-

taking. Online recording is a method for reducing the constraints of a paper based booklet. A recent study showed that CKD patients would use an electronic personal health record (ePHR) if available.[10] Another study regarding a design of personal health diary on mobile application for CKD patients also reported a positive attitude towards the system.[11]

The purpose of this research was to develop and evaluate a CKD knowledge website containing electronic personal health record (ePHR) for CKD patients.

Methods

Website Development

A CKD knowledge and nutrition website was developed based on ADDIE model (Analysis, Design, Development, Implementation, and Evaluation).[12] Researchers conducted a needs analysis of the target users by semi-structured interview. Three pre-dialysis patients who had previously searched for CKD information on the internet were selected by purposive sampling. Contents were developed and validated with four experienced nephrologists. F-shaped pattern and horizontal attention leans left with users' eye movements were applied in the design phase.[13, 14] Storyboards were drawn in shot and sequence on paper before website production. The website comprised of three sections, section I: CKD knowledge and nutrition, providing details of CKD knowledge with a good looking graphic, section II: ePHR (by user input), based on a PHRB for CKD,[15] and section III: community and communication for user-to-user and user-to-webmaster. The graphic design was created by Adobe Photoshop CS6 and Adobe Illustrator CS5.1, and then the website was developed with Sublime Text 2 in HTML code and implemented on www.banraktai.com.

Evaluation: Usability testing

Usability testing is a method to evaluate website users using interface to seek for the best way to present information on the website and to determine how a website is easily usable. Usability testing was tested in two steps with ten users. First, a USE (Usefulness, Satisfaction, and Ease of use) questionnaire, developed by Lund,[16] was applied to measure usability. The seven-point Likert scale questionnaires with 30 items focused on four topics: usefulness, ease of use, ease of learning, and satisfaction. Second step was a one-on-one with think-aloud method, ten specific tasks. Efficiency was measured by task-time (task-time = end time – start time). Effectiveness was measured by three rates. A rate of "completed" or "correct" meant "good and adequate answer", "partially completed" meant "reasonable but incomplete answer", and "failure" meant "stopped or completely wrong answer". The researcher observed how users reacted to the website (performance data) as well as asking questions about what they liked and disliked, what was easy or difficult, and what could be improved (preference data).[17]

Results and discussion

Content titles and recording forms

CKD knowledge for CKD patients was categorized into four essential topics: basic kidney etiology and chronic kidney disease, nutrition, exercise, and medication. An ePHR form consisted of personal information, medicine information, laboratory test, dietary pattern, and exercise activity. The record forms are addable, recallable and editable and considered for individual and private use. The titles and subtitles were re-arranged by content network chart and the website was developed by HTML code (Figure 1-2).

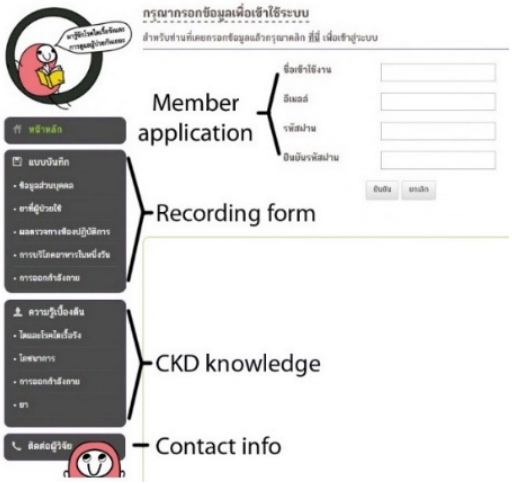


Figure 1. Website composition

Figure 2. Example of web page in the website

USE questionnaire

The demographic data showed that the female to male percentage was 70% and 30%, the percentages of age ranges were 20-29 (20%), 30-39 (70%), and 40-49 (10%) and the educational level of the sample group was mostly bachelor's graduates. CKD stages were distributed in stage 2 (10%), stage 3 (60%), and stage 4 (30%). All samples were computer and language literate. The measuring usability by the USE questionnaire (7-point Likert scale) showed the average scores of usefulness was 5.03 (somewhat agree), ease of use was 5.25 (somewhat agree), ease of learning was 5.63 (mostly agree), and satisfaction was 5.24 (somewhat agree) (Figure 3). The users rated "somewhat agree" in the usefulness of the website mainly due to the fact that the internet was not a primary source of information. Most of

these users generally obtain knowledge directly from physicians and may find additional information on the internet later. The users rated “somewhat agree” in ease of use and “mostly agree” in ease of learning, indicating that the website was not difficult to use and learn. It was probable that this website contained consistency of platform and layout. However, the users rated “somewhat agree” for satisfaction.

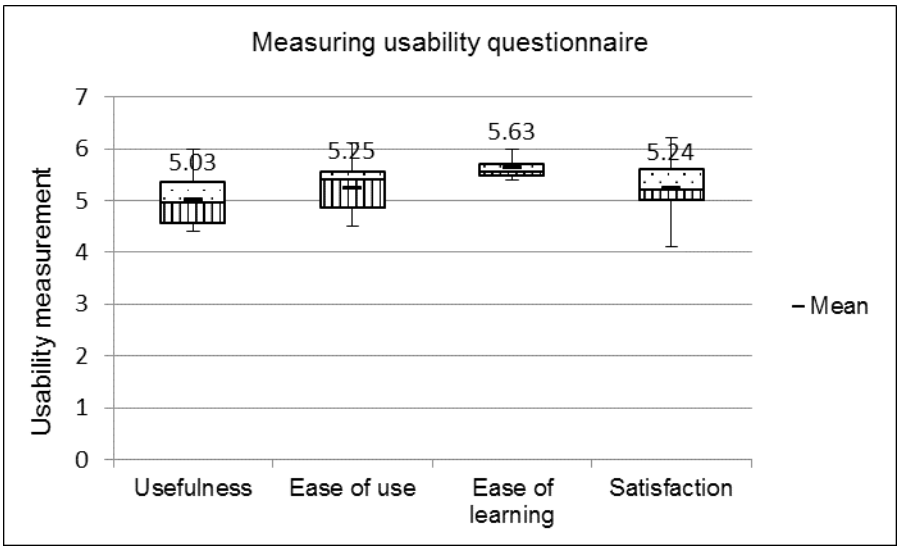


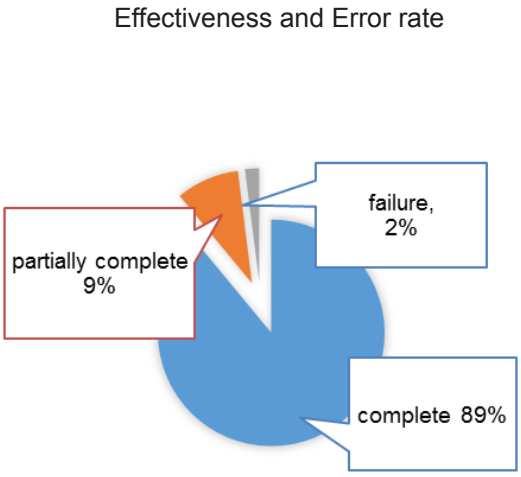
Figure 3. Average scores from USE questionnaire. (7-point Likert scale)

Usability Testing

This test was employed to identify usability problems from the result of the USE questionnaire. In this part, the average task-time with all tasks was averaged to 32 minutes compared to 30 minutes by experience users. The result also showed that there was one user who took nearly 51 minutes to complete. However, most of the users completed the tasks within 30 to 40 minutes, indicating the efficiency of this website. Effectiveness was determined by accuracy and completeness of the test. The results showed that 89% of all attempts were completed, 9% were partially completed and 2% failed (Figure 4). Partial completion arose on ePHR part mainly from incomplete input of the ingredients in the dietary record session. The failed attempts were caused by a lack of input of laboratory results.

The results from direct observation of a specific task in the think-aloud sessions explained the users recognized the unattractive button. In some sessions participants were required to spend a significant time clicking until the task was complete. Several technical terms and words in the laboratory testing record appearing in the test also made users feel annoyed and some parts in the website also had poor navigation. Therefore, proper explanation should be performed in the layout, which can make users easily understand the guidelines.

This study found 42 usability problems. The results showed that a single test user could generate the problems of approximately one-third of the total (35.7%), while three users triggered the problems of approximately 73.8%. It was noted that adding more users meant researchers learnt less and less problems because we were seeking the same thing again and again.[18] Therefore, 10 users in this usability test are enough to find all usability problems.



Figu rrect, partially complete and failure with all specific tasks.

This part of the study is helpful for researchers to improve the website and reduce or prevent errors which may occur during the completion of details or searching for on the website. There were suggestions to improve the website from direct observation, questions and follow-up interviews. These suggestions included designing more attractive buttons, site autofill forms on the web for reducing the number of clicks, a process to finish the session, create clear forms and samples, design a consistent approach to platforms and navigation to adapt quickly to use the website, automatically hide words or technical terms, reappear when moving a cursor to the button area and using less colors in the website layout.

Conclusion

This study was the preliminary development of a patient education website focusing on CKD knowledge, nutrition and ePHR. This educational website will be implemented for CKD patients to determine the effectiveness. In future a mobile application may be developed in order to increase access to the website.

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