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Merging Health Literacy with Computer Technology: Self-Managing Diet and Fluid Intake among Adult Hemodialysis Patients

Janet L. Welch *

School of Nursing, Indiana University, Indianapolis, IN, USA

Katie A. Siek,

Department of Computer Science, University of Colorado at Boulder, Boulder, CO, USA

Kay H. Connelly,

Computer Science Department, Indiana University, Bloomington, IN, USA

Kim S. Astroth,

Mennonite College of Nursing, Illinois State University, Normal, IL, USA

M. Sue McManus,

School of Nursing, Indiana University, Indianapolis, IN, USA

Linda Scott,

School of Nursing, Indiana University, Indianapolis, IN, USA

Seongkum Heo, and

School of Nursing, Indiana University, Indianapolis, IN, USA

Michael A Kraus

Medical School and Clarian Health Partners, Indiana University, Indianapolis, IN, USA

Abstract

Objective—The Dietary Intake Monitoring Application (DIMA) is an electronic dietary self-monitor developed for use on a personal digital assistant (PDA). This paper describes how computer, information, numerical, and visual literacy were considered in development of DIMA.

Methods—An iterative, participatory design approach was used. Forty individuals receiving hemodialysis at an urban inner-city facility, primarily middle-aged and African American, were recruited.

Results—Computer literacy was considered by assessing abilities to complete traditional/nontraditional PDA tasks. Information literacy was enhanced by including a Universal-Product-Code (UPC) scanner, picture icons for food with no UPC code, voice recorder, and culturally sensitive food icons. Numerical literacy was enhanced by designing DIMA to compute real-time totals that allowed individuals to see their consumption relative to their dietary prescription. Visual literacy was considered by designing the graphical interface to convey intake data over a

Corresponding author at: Indiana University School of Nursing, 1111 Middle Drive, NU 408, Indianapolis, IN 46202, USA, Phone: 317-274-8091, Fax: 317-278-1856.

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24-hour period that could be accurately interpreted by patients. Pictorial icons for feedback graphs used objects understood by patients.

Practice Implications—Preliminary data indicate the application is extremely helpful for individuals as they self-monitor their intake. If desired, DIMA could also be used for dietary counseling.

Keywords

informatics; self-management; hemodialysis; health literacy

1. Introduction

Health literacy, defined as “the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions” [1], is a growing concern for much of the United States population. Nearly half of U.S. adults, or about 90 million men and women, have trouble understanding and acting on health information [2–3].

Inadequate health literacy is a particular problem for chronically ill persons. Disease self-management, described as the daily decisions and activities individuals perform to live with and control illness [4], requires both knowledge of what to do and the ability to carry out the medical and lifestyle regimen [5]. To successfully self-manage chronic illness, individuals must know how to monitor disease, manage symptoms, carry out daily medical regimens, and interpret results of home-monitoring therapies. Poor health literacy hampers these important tasks. For example, inadequate health literacy has been associated with less asthma-related knowledge and improper use of metered-dose technique in asthma [6], poorer decisions by patients using home peritoneal dialysis [7], fewer diabetes self-management behaviors [8–9], and the inability of heart failure patients to read and understand standard medication labels [10].

Although poor health literacy is associated with problems in self-managing chronic illness [6], it is not associated with an individual’s ability to learn or retain information [11]. When written educational materials are developed for use by individuals with poor literacy skills, they should be readable and understandable by the intended audience; provide associations between new information and what is already known; involve participants in design; provide participants with active learning opportunities; and use visuals to emphasize the main message, reduce the amount of reading in text, provide visual cues, and be motivating [12].

Our research group works with patients who receive hemodialysis and are prescribed a complex dietary prescription. The purpose of this paper is to describe how we considered health literacy in the design of the Dietary Intake Monitoring Application (DIMA).

1.1. Dietary prescription for adults receiving hemodialysis

Individuals receiving hemodialysis are asked to self-manage a complex and restrictive diet and fluid regimen to reduce the accumulation of electrolytes and waste products between treatments. Compared with average American intake of 3.8 grams sodium, 2.8 grams potassium, and 1.4 grams phosphorus [13], a typical prescription for individuals receiving hemodialysis is 2 grams sodium, 2 grams potassium, and 1 gram phosphorus [14], although this may vary depending on individual factors. Individuals are also asked to limit fluid intake to 1000 milliliters per day [14] to prevent an excessive accumulation of body fluid between treatments. In addition to these limitations, current guidelines recommend a protein intake of 1.2 grams per kilogram body weight per day and a dietary energy intake of 35 or 30 to 35 kilocalories per kilogram body weight per day for, respectively, individuals under

and over 60 years of age [15]. The difficulty individuals encounter when implementing this complex diet is reflected by estimates of dietary adherence ranging from 33% to 98% [16–20] and of fluid adherence from 7% to 59% [18,21–23]. Adherence varies because, for example, individuals have different dietary habits, knowledge, geographical climates, living conditions, and personal reactions to prescribed limitations.

1.2 Barriers to self-management

Hemodialysis patients must have certain skills to comply with the complex diet described here, such as the ability to read, interpret, and calculate daily intake on an ongoing basis. Although patients are taught about portion sizes, they must be able to adjust food intake behavior [24]. Even if patients can read labels, they must be able to convert between different units of measure (e.g., milliliters to ounces) or add amounts over the course of a given day, abilities not to be assumed in the target population [25]. Various strategies are suggested to assist patients in limiting fluid intake on a daily basis, such as measuring daily allotted fluids into a pitcher and only taking liquids from that pitcher, but this limits a patient's drink choice and social activities [26].

Another problem is that food labels do not typically provide all information needed for self-monitoring; for example, phosphorus and potassium are often omitted. Usually patients are simply instructed to limit or avoid foods with high amounts of potassium (e.g., bananas), phosphorus (e.g., milk products), and sodium (e.g., ham). Avoiding or even limiting certain food items is not realistic for patients because many foods are culturally integrated into diets or individuals simply have a strong preference for particular foods [27]. We lack tools, however, that would assist these individuals in making informed food choices.

1.3. Paper and electronic self monitoring

Self-monitoring, that is, recognizing the occurrence of a behavior and systematically recording the observation [28], has traditionally been done using paper diaries. The purpose of self-monitoring food and fluid intake is to increase awareness of consumption. Self-monitoring food intake is one of the most effective non-invasive techniques used in the treatment of obesity [29]. Estimates of actual compliance with completing paper diaries, however, range from 11% to 14% [30–31]. Self-monitoring can be individually accomplished using an electronic device such as a PDA. PDAs have been used to report symptoms in a variety of health contexts [32–34], including to track equipment-generated values such as blood glucose levels in diabetes [35] and to assess situational cues associated with smoking [36–37]. Furthermore, studies have found actual compliance rates with completing electronic diaries to range from 94 to 95%, much higher than for paper diaries [30–31], suggesting that electronic self-monitoring is easier, and patients often prefer this method [38].

When electronically self-monitoring diet, individuals are able to enter and track what they consume and how often they eat. Individuals receiving hemodialysis do not demonstrate impaired cognitive function [39–40] that would interfere with use of electronic devices, and such self-monitoring has shown initial promise for effectively self-managing their dietary and fluid prescription [41–43]. However, these previous studies used commercial products that had some limitations. For example, patients had difficulty using the standard interface widgets – the scrolling bar was too small for them to touch with the stylus and pushing the PDA down button was not intuitive for novice users. In addition, the applications required patients to traverse through many screens and asked for specific values that required memory and high numeracy skills. Finally, everything is in written form, including portion size. Patients often did not understand how to read these values and the concept of subtracting what they consumed from the dietary prescription was confusing to them [43].

The overall goal of our project was to create DIMA to provide dialysis patients with the ability to track their fluid and nutritional consumption by either scanning a UPC on a food item or by selecting an appropriate food icon on a graphical user interface. Developmental details are reported elsewhere [44–45]. The purpose of this paper is to describe how we used an iterative, participatory approach to design an appropriate interface for low literacy users.

2. Methods

2.1 Design

Iterative design is a well recognized, cyclic process in which designers create a prototype of a system, test the prototype with users, analyze the user study findings, modify the prototype based on results, and retest the prototype until all stakeholders are satisfied with it.

Stakeholders included not only the dialysis patients, but also our multidisciplinary team.

Participatory design is also a well recognized process that attempts to get the target population involved as much as possible in the iterative-design process [46].

All of the developmental studies were *in situ* – conducted in the dialysis unit or in patients' everyday lives. Some of our studies were designed based on tasks because we wanted to evaluate how target users would fare trying to complete a specific task using the prototype interface. All of the studies employed a think-aloud protocol and participants were asked to verbalize what they were thinking while completing tasks. For example, when a participant was asked to input what they ate for breakfast and looked at Figure 1, they may say, "I'm not sure where to begin. Well, I had some coffee and that image [pointing to nutritional supplements] is just Boost. I guess I would push this image here [pointing to fluids]. Yep – there it is!"

Dialysis patients were actively involved in this project during user study sessions when we would confirm our analysis of previous findings with the target population. For example, after one prototyping study [27], we showed participants in our next study the top two preferred and readable interfaces. We asked which interfaces they preferred and asked them to complete tasks with each interface to identify which ones were understandable. We also encouraged participants to modify or create their own paper-based interfaces to express their preferences. We verified our findings with unit renal dietitians and nurses by showing them the interfaces and identifying which were preferred by the target population. We recorded the dietitians' and nurses' comments and discussed them at our research team meetings to determine how the interfaces should be modified.

2.2 Procedures

The user studies followed a typical, higher-level design approach in which user needs were identified. Based on user needs, the research team brainstormed appropriate technology and input devices and evaluated them through a task-based, think-aloud protocol with dialysis patients [47]. Once an appropriate device was identified, paper pictures, or low fidelity prototypes, of what the interface could look like [48] were generated. Such prototypes provide a quick, inexpensive way to evaluate interface designs before investing the time and effort in implementing a computer version of the interface. Subjects evaluated the low fidelity prototypes and based on their feedback, a high fidelity prototype was created and evaluated in two user studies: (1) a study to verify that they could utilize the system to track intake and (2) a study in which subjects used the application during two week-long periods; a research assistant met with participants every 2–4 days to discuss their remote usage log files, usability issues, and opinions of self management with an electronic device [49–50]. Changes to the prototype were made based on feedback from participants.

3. Results

Sensitivity to health literacy is likely to improve clinical outcomes [51] and we developed DIMA for adults receiving hemodialysis to successfully self-manage dietary intake regardless of health literacy levels. We considered the following literacy skills as outlined by the National Network of Libraries of Medicine [52] when designing the application: (a) computer literacy or the ability to operate a computer, (b) information literacy or the ability to obtain and apply relevant written information, (c) numerical or computational literacy or the ability to calculate or reason numerically, and (d) visual literacy or the ability to understand graphs or other visual information. These four health literacy components and how they were considered as design decisions were made about DIMA are summarized in Table 1.

3.1. Sample

Following approval by the university Institutional Review Board, we iteratively designed DIMA over the course of user studies. We recruited participants who attended an inner-city urban dialysis center and were (a) over 21 years of age, (b) able to make their own food or go out and purchase food, (c) willing to meet with researchers during dialysis sessions for the study, (d) willing to carry the PDA and scanner with them and input food items they consumed. We conducted user studies during dialysis sessions because participants were only available during that time. More information about development is reported elsewhere [53].

Mean age of participants was 52 years (SD 17.5), 85% were African American, and 55% were female. Though literacy levels were not formally measured during development, qualitative data provided some information about the literacy levels of the participants. For example, one participant described how he drew pictures of what he ate for the dietitian.

3.2. Computer literacy

Although prior empirical studies have suggested that the health of an individual is not a barrier to technology use [54–56], an initial concern of our team was the acceptability of a computer-based program to a chronically ill population. We were also concerned about the patients' physical ability to use a computer because adults receiving hemodialysis often have bone disease [57] that may limit manual dexterity, and half of the national patient population has a diagnosis of diabetes mellitus [58], which may affect visual acuity. These concerns were addressed by conducting a series of user studies prior to developing DIMA. We began by determining whether, relative to younger persons, older healthy adults could use a PDA because we hypothesized that dialysis patients might have acuity and dexterity problems similar to those of many older adults. We found that, although older participants took relatively longer to physically manipulate the PDA, they were able to complete tasks [59].

Our assessment then turned to the target population to determine if they could complete traditional and nontraditional PDA tasks. We compared the dialysis participants' success rates with our results from younger and older adults. We found dialysis patients were able to press buttons, record messages, and scan bar codes just as well as our healthy adults. Similar to the older adults, however, the dialysis patients preferred 19 millimeter icons. Overall, the dialysis participants found all of the PDA tasks easy to complete [60].

Participants were asked if they used a computer and, if so, how often. In addition, they were asked what type of applications they used on the computer and what, if anything, they accessed on the Internet. Overall, those who used computers typically only used them for playing games and surfing the Internet. Participants were also asked about mobile phone

usage and the types of mobile phones they used. The few participants who owned a mobile phone typically had pay-as-you-go plans.

3.3. Information literacy

An individual must be able to read to be information-literate and to self-manage a diet and fluid prescription. Current clinical practices require hemodialysis patients to be able to read lists of foods to avoid and/or to be able to read and interpret food labels. No empirical data about reading levels for this patient population were found; however, the National Assessment of Adult Literacy [61] indicates that 40 to 44 million adults across the United States have low literacy skills. Poor reading skills are particularly prevalent in minority populations and those who are socio-economically disadvantaged [62]. Currently available dietary software programs using the USDA food database require the ability to read and spell when searching the database - skills some of our patients would not have.

The Nutrition Data System for Research [63] was used to specify serving size and nutritional information for DIMA. Dietitians with experience working with dialysis patients reviewed past food diaries from all patients in their caseload. These dietitians also drew from extensive experience to ensure that the DIMA database contained food icons that were culturally relevant to our population, suggesting additions such as chitterlings, ham hocks, pig's feet, tofu, jicama, couscous, Ramen noodles, and hot sauce. The PDA selected for DIMA included a voice recorder. If individuals could not find a food item in the database, they were asked to voice-record the item so we could add it to our database.

Technology can provide a bridge for individuals with low health literacy skills to overcome the barrier of poor reading skills and successfully self-manage their diets. We did this in two major ways. First, we incorporated a UPC scanner to provide patients with the ability to scan any food item containing a UPC code directly into the PDA. Second, we included picture icons for foods with no UPC code (Figure 1) [64]. To make the application user-friendly, we determined how patients cognitively organized food. We decided that the navigation should be circular, bringing the user back to the same page every time a food is entered. For example, when using this feature patients will see a series of screens displaying picture icons. The first screen shows six pictures that refer to groceries, fluids, prepared foods, snacks, nutritional supplements, and favorites. If, for example, they want to enter cherries, they would select the grocery icon and be taken to the next screen, which would display an additional six categories – fruits, vegetables, meats, breads, dairy, and oils. To reach the cherries, they would select the fruit icon. The next screen depicts red, blue, yellow, and green fruits, and an individual would select red for cherries. The next screen displays a picture of all red fruits and an individual would select cherries to add to his or her intake. This cherry example is shown in Figure 2 - an excerpt from the user manual we developed. Although participants had to traverse many screens, they reported that the number of steps wasn't a problem if the choice of next step was obvious.

3.4. Numerical literacy

Self-managing diet and fluid also depends upon health numeracy skills, defined as the “ability to read and understand numbers and perform basic mathematical computations” [65]. These skills are beyond those of some patients; our past research found that approximately one third of hemodialysis patients had difficulty performing simple calculations [25]. A major feature of DIMA is that it can compute real-time totals, allowing patients to see their intake relative to their dietary prescription for the day for six main categories – sodium, potassium, phosphorus, fluid, protein, and calories – without having to perform any calculations themselves. For example, when a patient selects a food item such as cherries, the program looks up the nutrients associated with a single serving of cherries

and updates the daily consumption of each nutrient appropriately. The total amount consumed is then displayed in both graphical and textual form, in comparison to their total daily limits (see Figure 3).

3.5. Visual literacy

We assessed patients' abilities to interpret graphic information about intake to help us select a graphical interface to convey intake data that would be interpreted accurately by patients. The renal diet includes four elements to be restricted and two elements to be consumed in adequate quantity, so we wanted the application to display these two types of information differently. Although many different types of graphical visualizations were tested, the patients could most accurately interpret the display that closely represented what they had used in the past. For example, participants preferred a water consumption icon that looked like a large glass of water. The participants all had received a large, liter-size container when beginning dialysis treatment to help them visualize how much they were allowed to consume. Thus, the digital fluid indicator was informed by the physical artifact participants were already using. As shown in Figure 3, the graphical information for sodium, potassium, phosphorus, and fluid is presented visually using bars in 25% increments. These four graphs were created such that, when individuals have consumed almost the prescribed limit, the background changes to red.

For nutrients that have a minimum to be consumed each day (i.e., calories and protein), a pie graph is used such that a smiling face will be completed when individuals consume 100% of each of these nutrients. The graph will fill in incrementally throughout a 24-hour period to indicate consumption. For example, as shown in Figure 3, this individual has consumed 100% of the minimal requirements for calories and 50% of the protein needed. The intake data for all six components are reset every 24 hours.

Much discussion occurred within the research team and with renal dietitians about how to label the feedback graphs to be understandable to patients and yet avoid the use of words. We selected a salt shaker for sodium, a heart for potassium, a bone for phosphorus, a water spigot for fluid, a steak for protein, and an individual running for calories (Figure 3) to be consistent with educational materials presented in the clinical setting. All participants were able to correctly label the images during later user studies.

4. Discussion and conclusion

4.1. Discussion

Individuals receiving hemodialysis are prescribed a complex and restrictive diet that requires many cognitive and behavioral skills for successful self-management. We designed DIMA using an iterative participatory design approach that considered computer literacy, information literacy, numerical literacy, and visual literacy skills. The DIMA is an electronic dietary self monitor designed to facilitate self-management and improve clinical outcomes.

We chose to use few words in the application. However, we have learned that some participants would like words associated with food icons to confirm their selection; we will add words in the future. We expected that the UPC scanner would decrease input time and would assist individuals with low literacy skills. However, the scanner frequently fell out of the PDA, frustrating patients. In addition, patients have difficulty using the scanner easily.

When developing written patient educational materials for low literacy individuals, people with adequate literacy skills are satisfied and don't mind using them [12]. We do not know, however, whether patients with adequate literacy will be satisfied with a technological application developed for individuals with low literacy skills. Will patients with adequate

literacy become too frustrated if they have to traverse too many screens? Future research will seek answers to this question.

4.2. Future Research

A pilot study is currently underway to obtain preliminary data about feasibility, usability, and efficacy of DIMA. Anecdotal data collected during this study indicate that the application is helpful and usable. In addition, participants are choosing to use icons more often than the UPC scanner. Several participants have asked to keep the PDA after completing the self-monitoring portion of our pilot study so they could continue self-monitoring after study participation.

A large randomized controlled trial is being planned. Important components that will need to be considered include analysis of cost and patient clinical outcomes. In addition, technological advances progress very quickly over time. Therefore, if DIMA is found to be feasible, usable, and efficacious, in the future we may need to consider the use of other devices that are now available to make integration into daily living more practical for those with chronic illness.

4.3. Limitations

There were several limitations of our developmental work. First, we did not formally measure literacy levels and collected limited demographic data during development. We are measuring literacy levels during the current pilot study to determine whether it is an important moderating variable. Second, the sample size was small during development of DIMA. The sample size, however, was typical for development of software applications. Third, feasibility and usability testing for DIMA has not been completed.

4.4 Practice Implications

If usable and efficacious, the application will provide a powerful tool for patients to use when making daily decisions about diet and fluid intake despite varying health literacy skills. It also has the potential to be a useful tool for patients when they are seeking dietary counseling from health care providers.

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Figure 1.
Picture Icons for Foods

Food with No Barcode

Figure 2.
Interface Screen Shots for Selecting Food Items

Figure 3.

Graphical Display for Daily Intake.

NOTE: In this figure, fluid, phosphorus, and potassium intake are well below the dietary prescription. Daily sodium consumption is close to the dietary prescription and the background appears in red. The individual has also consumed enough calories today but has only consumed half of the recommended amount of protein.

Table 1

Health Literacy Components Integrated into DIMA
 Components of Health Literacy Integrated into DIMA

Health Literacy Component	DIMA
Computer literacy	PDA with large icons
Information literacy	UPC scanner
	Picture icons
	Voice recorder
	Culturally sensitive food icons
Numerical literacy	Computes real-time totals for 6 main categories
Visual literacy	Graphical interface
	Graph background changes color when individuals have nearly consumed the prescribed intake of each dietary element.
	Pictorial labels