User-Centered Requirements Analysis and Design Solutions for Chronic Disease Self-management

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Abstract. An aging population and the attendant growth in the need to care for people with serious chronic illnesses has created a demand for online support systems that can assist older adults to self-manage their illnesses. This could play a role in relieving some of the load on the healthcare system. Determining user-centered requirements of older adults for such systems is different from usual requirements analysis because older adults have particular needs, depending upon their chronic illnesses, their ability to manage technology, their access to appropriate technologies, and their cognitive abilities. This paper discusses in detail the use of the persona-scenario approach to elicit these needs from outpatients, informal care givers, and physicians. It proposes several suitable interface designs, depending on outpatient ability to deal with the proposed systems.

Keywords: Chronic disease · Self-management · Patient interface · Persona · Scenario · Design

1 Introduction

Due to the growing cost of healthcare, particularly because of the aging population, health self-management technologies may be able to play an important role in empowering patients to be more active in managing their own health and reducing healthcare costs. Internet use for communications, self-monitoring, and accessing online health information has led to a recent surge of interest in online health self-management of chronic illnesses. They are the leading cause of death in western nations (heart disease and cancer account for 48 % of all deaths in the U.S. [1]). Few people are unaffected by chronic conditions. The likelihood of developing a chronic illness and experiencing its resulting impact on quality of life is greatest for the socio-economically deprived, who may also suffer poverty because of disabilities resulting from chronic illness [2].

Interest in chronic disease self-management is considerable for older adults, who tend to develop chronic diseases as they age. Unfortunately they are also less adept

with technologies, and their cognitive abilities decline with age, making it more difficult for them to take advantage of such technologies [3]. Chronic illnesses are often caused or exacerbated by lifestyle risk factors, including low levels of physical activity, poor nutrition, obesity, tobacco use, and excessive alcohol consumption [1]. Risks from chronic illness may be reduced if patients improve their lifestyle behaviours [4].

Most recent research in online support for disease self-management has shown some success [5] in improved health outlook. Self-efficacy encourages patient activation (i.e. knowledge, skill, and confidence for managing one's health) of their self-management process, resulting in improved health outcomes [6]. Interventions specifically for outpatients with certain chronic conditions may enhance activation levels even more [7].

Although results from online chronic disease self-management are promising, there are still major underlying gaps: (1) long-term sustainability in terms of patient recruitment, continuation, and operating cost, (2) keeping patient self-management motivation high, and (3) dealing with psychosocial patient characteristics such as social isolation, loneliness, depression, avoidance coping and low self-efficacy. In addition, (4) older adults are likely to have more chronic illnesses than younger people, and are less likely to be able to use technology effectively for health self-management [3]. It may therefore be necessary to provide alternative support mechanisms for these individuals.

1.1   Objective

The objective of this study is to address the gaps noted above through an innovative approach to promote patient adoption and continuing participation in health self-management. An effective self-management system should support outpatients in a manner that fits into one of three categories proposed by Schulman-Green et al. [8] for patients who need to self-manage chronic illnesses: (a) Illness Needs; (b) Activating

Table 1. Self-management supports and categories [8]

Support	Category	Description
1	(a)	Educate patients about chronic illnesses and related comorbidities
2	(a); (c)	Train patients about chronic illness self-management approaches (e.g. monitoring blood pressure, heart rate, weight), problem-solving, coping techniques, and decision support
3	(a); (c)	Modify lifestyles (regularly exercising, smoking cessation, etc.)
4	(b); (c)	Provide links to counseling, advice and other support services
5	(b)	Help personal caregivers, such as spouses, to assist patients in managing their chronic illnesses
6	(b); (c)	Access community health, social resources, family, and friends to combat social isolation and loneliness
7	(a); (b); (c)	Motivate patients to adhere to self-management regimens, using creative mechanisms
8	(a); (b); (c)	Engage patients through effective user-friendly interface designs

Resources; and (c) Living with a Chronic Illness. Eight supports that our system provides appear in Table 1, along with the three equivalent Schulman-Green et al. [8] categories.

1.2 Research Questions Addressed by the Study

1. What are the needs, preferences, and abilities of people with chronic illnesses and their informal caregivers, and can disease self-management meet these requirements?
2. What are the needs and preferences of healthcare providers who work with patients utilizing health self-management solutions?
3. What is the most appropriate design solution to address the outcomes, satisfaction and sustainability of use among end-users?

2 Peripheral Arterial Disease

Because of the diversity in chronic diseases, this paper focuses on one such disease, Peripheral Arterial Disease (PAD), in order to develop a prototype system design that can demonstrate effective self-management of a specific chronic disease. PAD is a condition that involves narrowing and occlusion of non-cerebral and non-coronary arteries distal to the arch of the aorta [9, 10]. It is one of the most common chronic illnesses among people over 50 years old [9] – with an estimated worldwide prevalence of 10 %, growing to 15–20 % in people over 70 years of age [11, 12].

The most important risk factors associated with PAD are age, cigarette smoking (current and former), diabetes mellitus, hypertension, hyperlipidemia, obesity (body-mass index BMI) lack of physical activity, and history of cardiovascular disease [13]. Its strongest risk correlations are with smoking and diabetes, in that order [14].

3 Self-management System Design

For many self-management technologies, usability design is less than satisfactory, resulting in low rates of elective adoption. Three factors can improve adoption rates: (1) suitability and relevance, (2) perceived usability, and (3) anticipated benefits of using it [15]. Traditional information technology (IT) development may ignore specific user needs and preferences, and systems not personalized (as in our case) to an aging patient population [16, 17]. Several methods of interface design, including focus groups [16] and interviews [18] may help to engage users in interface design. Supported by user-centered design (UCD), we identified user healthcare needs and preferences; thus informing user requirements, interface design and implementation decisions.

The method we chose is called a persona-scenario exercise. It has been used extensively to engage users in the design of human-centred interfaces [16, 18, 19]. Our goals were to: (1) understand the preferences and needs of our users – clinicians, patients and their informal caregivers; and (2) to provide a service to meet their requirements.

3.1   Personas and Scenarios

Personas can help to define "hypothetical archetypes of actual users" [20]. This utilizes user information in an ethnographic approach that focuses on users' behavioral characteristics, animating them in the minds of designers, developers, and testers. Each persona involves a fictitious person who plays the role of a group of users who will potentially use the system. These personas are then allowed to play their roles in user scenarios, resulting in use cases and hence test cases for the proposed intervention [21]. A persona-scenario exercise helps to foster support and uptake of the resulting online system design. The persona-scenario approach has been used elsewhere in developing other healthcare applications [17, 22, 23].

4   Study Procedure

Data were collected from six persona-scenario discussion sessions with ten participants (n = 10). This gave enough data to estimate the final outcomes of the exercise fairly accurately. Our study process involved three main steps, as follows:

Step 1. Recruiting participants. The first step in developing a persona is to determine the user groups who should participate in the interviews. For patients who have developed a specific disease such as PAD, with treatment being managed primarily by specialists, the groups most commonly involved in patient support include:

1. Surgeon Specialists (Senior Surgeons and Residents)
2. Outpatients
3. Family Members: Informal Caregivers
4. Family Physicians

In this study, we focused on the first three groups, which were most extensively involved in the self-management process, in order to limit the scope of the work. Family physicians will be brought into a more extended self-management process design later. The relevance to our discussion with each group of participants was:

- Vascular surgeons who work regularly with and are very familiar with the needs of patients with PAD and comorbid illnesses
- Outpatients with PAD who were also potential users of the prototype MyPADMGT disease self-management system that was been in use for almost two years
- Informal caregivers who could help outpatients to perform self-management tasks

Recruiting was carried out through handouts given to outpatients attending regular vascular clinics. We interviewed a group of senior vascular surgeons and residents together, and separately outpatients and informal caregivers, either individually or in groups of two. All interviews took place at the Hamilton General Hospital and each interviewee received 40 dollars and parking expenses for participating. The study was approved by the hospital's Research Ethics Board.

Step 2. Interviewing process – personas and scenarios. Each participant signed an informed consent form and received a copy. Each interview lasted less than 2 h. Each

person received a tailored discussion guide, an introduction to the program components, and support from a facilitator (conversations were recorded and transcribed later). To design personas and scenarios, we conducted semi-structured interviews. In the first part, demographic information was gathered on interviewee characteristics, such as age, gender, education, etc. They were also asked to describe personas that represented their authentic needs. The second part focused on how they might deal with a system such as MyPADMGT, based on the persona that had been developed. Each participant or pair generated an experience of the self-management program by their persona with one or two "scenarios" that reflected their attitudes towards available information, measures, the possible frequency of usage, and how they might learn about and use the system. We needed to learn about their skills, what online technology they might be familiar with, wishes and expectations, and finally, in which situations they would use the system. Interviews were semi-structured; the interviewer was able to discuss any interesting topics that came up during the interviews. At the end of each session the patient or patient group had developed a persona and one or more scenarios.

Baseline patient and informal caregiver demographics are shown in Tables 2 and 3. All were 59 years of age or over. All patients had been diagnosed with PAD.

Table 2. Patient Demographics

Characteristics	Information
Gender	5 male
Age	59–77
Smoking status	1 smoker
	3 former smokers
	1 non-smoker
Duration of PAD	1 less than a year
	3 between one to two years
	1 three years
Experience of medical intervention	3 yes
	2 no
Existence of an informal caregiver at home	2 yes
	3 no
Access to the Internet	3 yes
	1 yes but not using
	1 no

Table 3. Informal Caregiver Demographics

Characteristics	Information
Gender	Female
Age	Between 70 and 80
Smoking status of the patient	Former smoker

(*Continued*)

Table 3. (*Continued*)

Characteristics	Information
Duration of PAD for the patient	Less than a month
Experience of medical intervention for the patient	Yes
Informal caregiver relationship	Spousal
Access to the Internet	Yes

Step 3. Analyzing the results. Summaries of the persona-scenario exercises were transcribed verbatim and coded for qualitative analysis. Based on themes found from the analysis, a system design was developed, including a design to-do list. It became clear that there were three distinctive groups of users and that we should create three personas. The first persona reflected the perceptions of users and/or caregivers who were comfortable with online technology, and usually own a home computer or smart phone. The second persona was a group of users with/without caregivers who were not comfortable with technology and needed a manual tool. They usually do not own a computer at home or smart phone. The third persona participants were similar to the first persona, but with limited access to the Internet, so they needed an offline manual tool. A fourth persona was developed to represent informal caregivers. Online patient personas and caregiver personas are in Tables 4a and 4b, and the surgeon persona is in Table 5. Due to lack of space only online personas are included.

Table 4a. Online patient persona

Name	Joe	Short introduction
Age	60	Joe is an active independent person, who is interested in learning more about his condition – walking difficulties and pain in his legs – and taking care of himself. He is also interested in participating because he believes it can help others as well. He can learn the application if somebody sits with him and teaches him how to use it so he can use it on his own afterwards. He prefers the online version
Education	High school	
Employment	Construction	
Caregiver	Spouse	
Smoking status	Smoker (trying to quit)	
Medical intervention	Yes	
Duration of PAD	1 year	
Knowledge about the disease	"I searched a little bit. I brought up a picture that shows what the disease does and what doctors do" "Doctors do not give you enough information. They just give you enough to get you by…Nobody really says what it is. It is cut and dried."	
Comfort with technology	"Computers yes! Smart phones, I know nothing about them! I have five computers at home" "I spend 10 to 12 h in a day on computers! I am retired, I have nothing to do…"	

Table 4b. Informal caregiver persona

Name	Rose	Short introduction
Age	77	Rose is an active social women who tries to take care of her husband to the best of her knowledge. If she knows she can do something to improve her husband's health she will do it. Her husband is not as active as she is, and he has different problems like back pain that stop him from being active
Education	High school	
Employment	Financial services	
Relationship to patient	Spousal	She will easily learn to use the online version with a little help for the first steps, and she will probably try to use it regularly. They have a big family, so there is always someone else to help
Patient smoking status	Was smoker	
Patient medical intervention	Yes	
Patient's duration of PAD	1 month	
Knowledge about the disease	"We look things up in the Internet. As I said we liked to know what it is, and have a general idea about what is going on." "I am not aware of the disease impact, characteristics and treatments. But I need to go online and read a little about it."	
Comfort with technology	"I use the Internet all the time and my husband has his own iPad. We both use the Internet. But my phone is just a regular phone because I am home all the time. I don't text because by type of the phone I have it would take forever to text. We research on the computer, we use Skype and face time with family."	

Table 5. Surgeon persona

Name	John	Short introduction
Age	50	John is an experienced surgeon who is interested in research because he believes he can make a difference. He is involved in several studies and gives a lot of talks as a specialist in his field. After many years of experience, he is pretty comfortable in his job. He believes that there is no real cure for PAD and technology is just a new Band-Aid, but he also believes it can be used for prevention which is the only successful trend in recent years
Education	MD, MSc, FRCS	
Employment	26 years in the hospital system	
Desires	Focused on clinical research and system level approach to patient care	
Attitude	Carefully optimistic – has lost his initial total optimism!	He is really interested in using the reports of the MyPADMGT system, which he believes will make his job much easier and provide patients with required information that they need. He will introduce it to the patients and follow up with them to ensure they use it correctly. He is also extremely busy and overwhelmed with the number of new technologies so it is hard to get his attention, so it is better to begin working with his residents

Table 5. (*Continued*)

Name	John	Short introduction
Hopes and fears about the disease:	"Very conservative after 15 years of seeing a lot of disasters with PAD" "More interested in prevention because it is the only successful trend in these years, rather than tackling the disease after it comes."	
Comfort with technology	"Pretty comfortable with existing and new technology"	

4.1   Design Themes

The results of the persona-scenario interviews were coded into 13 themes and 6 categories (Table 6).

Table 6. Design categories and themes

Categories	Themes
1. Technology	1.1. Patient or informal caregiver comfort in using the technology – prefer the online version of MyPADMGT
	1.2. Patient or informal caregiver discomfort with smartphones – no interest in mobile version of MyPADMGT
	1.3. Patient or informal caregiver discomfort in using the technology – prefer a manual version of MyPADMGT
2. Tool characteristics	2.1. How to introduce the tool
	2.2. Patient expectations
	2.3. Willingness (or not) to use the tool to communicate with other patients
3. Knowledge	3.1. Lack of knowledge about the disease, self-management, and willingness to learn more
4. Willingness	4.1. Patient willingness to improve lifestyle
	4.2. Patient willingness to use the tool
5. Support	5.1. Social communications
	5.2. Existence of informal caregiver at home
6. Barriers	6.1. Comorbidity existence
	6.2. Barriers to self-management

5   Research Outcomes

Following the detailed system design process our research outcomes included: (a) a complete health self-management system, based on the existing online prototype, upgraded through the results of the persona-scenario studies; (b) a comparison of the results from the categories of personas, in terms of their contribution to design quality; and ultimately (not included in this paper) (c) measures of success in end-user engagement and satisfaction, gathered from participant feedback questionnaires.

Three solutions were derived for self-management support systems.

1. Cellphones or smartphones [24] to monitor and record personal data directly through reminders and automatic devices such as weigh scales, heart monitors, cameras, etc. These can significantly improve the usability and effectiveness of a health self-management system through portability and automation of monitored measures. While this is the most effective approach, it is preferred by less than 40 % of older adults. The causes are that many older adults lack technological experience, or they may not have access Internet access or they may not be able to afford it.
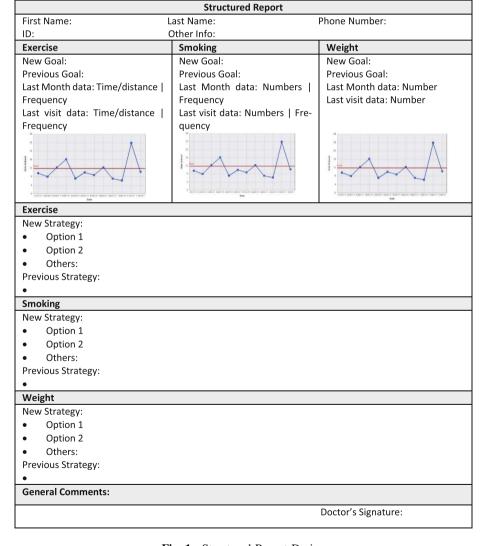
Structured Report		
First Name: ID:	Last Name: Other Info:	Phone Number:
Exercise	**Smoking**	**Weight**
New Goal: Previous Goal: Last Month data: Time/distance | Frequency Last visit data: Time/distance | Frequency 	New Goal: Previous Goal: Last Month data: Numbers | Frequency Last visit data: Numbers | Frequency 	New Goal: Previous Goal: Last Month data: Number Last visit data: Number
Exercise		
New Strategy: • Option 1 • Option 2 • Others: Previous Strategy: •		
Smoking		
New Strategy: • Option 1 • Option 2 • Others: Previous Strategy: •		
Weight		
New Strategy: • Option 1 • Option 2 • Others: Previous Strategy: •		
General Comments:		
Doctor's Signature:		

Fig. 1. Structured Report Design

2. Using Interactive Voice Response (IVR) systems to provide services in support of patient health self-management. However, findings consistently show that people in general and particularly older people dislike IVR systems [25].
3. The third method is the use of simplified manual systems that allow outpatients to record important lifestyle data and vital signs weekly or more frequently. The advantages of such systems are that they can operate at minimal cost, providing patient status and details to physicians during each patient visit to the clinic, and they are preferred by a majority of older outpatients.

5.1   Process Design

A flowchart was developed to guide developers and users of the revised MyPADMGT system process, accommodating both online and manual users (not shown here due to lack of space). Figure 1 shows an example structured report that would be generated by the system at the time a patient attends a regular appointment at the outpatient clinic. The report shows patient progress towards goals previously agreed with the patient's physician, and goals agreed for the next appointment (up to six months in the future). These graphics are for demonstration purposes only.

6   Discussion

In this study, we found that interviews with surgeons were very helpful in developing a deep understanding of different groups of patients. Most surgeons spend enough time with their patients to understand them very well. This makes patient segmentation much easier, and helped the interview process to be very productive in developing good solutions. Patient interviews were mostly focused on learning the details of patients' lives and understanding their needs, preferences, and capabilities. Surgeons more than patients were able to see usage patterns, since they interact with many different patients, and become familiar with different patient behaviours and needs.

The revised MyPADMGT system will focus on lifestyle changes, including addressing and monitoring, as appropriate:

- Education about chronic illnesses, so patients understand how to deal with related symptoms and problems
- Smoking cessation
- Walking and exercise programs
- Weight and heart healthy diets
- Taking medications for blood pressure, diabetes, etc., including regular reminders

In the first three sections of the structured report in Fig. 1, goals and strategies are set. In the next three sections (not shown here) of (e.g. blood pressure), patients and specialists have progress results to review. This application provides data to help doctors keep patients on track. In the smoking cessation section, patients have the option to note problems they have in quitting, like stress, family struggles, etc. This helps patients think about any barriers they have encountered while attempting to quit smoking.

6.1   Barriers

A major barrier to patient success with disease self-management is being able to educate patients in the nature of their diseases and how best to deal with related problems. MyPADMGT is designed to provide this type of support. A second barrier is that patients with PAD often have other serious comorbidities that require them to deal with several specialists (e.g. cardiologists and vascular surgeons) as well as their family physicians. Keeping personal patient records of their disease self-management activities and results in MyPADMGT can assist a great deal in guiding specialist care in many such situations.

Apart from a focus on patients with serious chronic illnesses, the lifestyle changes promoted by MyPADMGT also aid in preventive care through life style changes. This provides for a healthier and longer life for everyone who follows this approach, so this should be a consideration for anyone concerned about their health.

7   Conclusions

Our conclusions, based on findings from the patient persona-scenario exercises are as follows. In order to be adopted and used by our target clientele (physicians, outpatients with PAD and other serious chronic illnesses, and patients interested in preventive care) our system must be:

– Inexpensive
– Reliable
– Easy to learn
– Easy to use
– Adaptable to individual requirements
– Able to provide a link between outpatients and their providers as appropriate
– Help outpatients to understand and manage their chronic illness(es)
– Support both online and manual records for monitoring progress

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