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Linköping University Post Print



N.B.: When citing this work, cite the original article.

Original Publication:

Jan Aidemark, Linda Askenas, Jan Martensson and Anna Strömberg, Challenges for Heart Failure Patients Self-Care Systems Analysis of Patients Needs, 2014, CENTERIS 2014 - CONFERENCE ON ENTERPRISE INFORMATION SYSTEMS / PROJMAN 2014 - INTERNATIONAL CONFERENCE ON PROJECT MANAGEMENT / HCIST 2014 - INTERNATIONAL CONFERENCE ON HEALTH AND SOCIAL CARE INFORMATION SYSTEMS AND TECHNOLOGIES, 1256-1264.

<http://dx.doi.org/10.1016/j.protcy.2014.10.141>

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<http://www.sciencedirect.com/>

Postprint available at: Linköping University Electronic Press

<http://urn.kb.se/resolve?urn=urn:nbn:se:liu:diva-122078>

CENTERIS 2014 - Conference on ENTERprise Information Systems / ProjMAN 2014 - International Conference on Project MANagement / HCIST 2014 - International Conference on Health and Social Care Information Systems and Technologies

Challenges for Heart Failure Patients' Self-Care Systems – Analysis of Patients' Needs

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Abstract

Self-care is important for heart failure patients. However, what are the views of patients on their situation when it comes to realizing self-care? The aim of the paper is to investigate the self-care needs of HF patients, by understanding the issues they embrace in their self-care processes. In this paper we make a review of 17 interviews and make a classification of what the needs are for possible information technology support systems. Based on the analysis of these interviews, we identify the diversity of needs in support of activities related to different background conditions and the dynamics of change of learning and changes in the heart failure condition. The contribution of the paper is a framework for understanding the diversity of needs and the specific situations of this group of patients.

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Peer-review under responsibility of the Organizing Committee of CENTERIS 2014.

Keywords: Heart failure, self-care, user needs; information systems support, planning model.

1. Introduction

Many countries worldwide, especially in Europe and North America, have invested great resources in the development of patient-based e-health. There are high expectations on a government level that this development will bring better care to patients, simplify and increase access to care, and reduce the need for care of the patients who are expected to take greater responsibility for their own health and self-care. However, studies have shown quite

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moderate or no changes in health benefits among patients who have access to various health-related e-services compared to those who receive usual care [1]; [2], [3]. The projects that have shown positive results have focused on patients with chronic diseases with a large degree of self-care, such as diabetes, heart failure or asthma [3]. The projects that have major programs involving changes for healthcare organizations geared towards self-care and collaboration also show positive results [4]. However, research is scarce when it comes to studying which of, why and how these information technology (IT) tools for e-health can support patients and their caregiving family members to improve self-care. The main features are that the technology supports communication and interaction between healthcare professionals and the patient and that patients should have access to symptom feed-back, medical records and lab results [5]. Developing e-services to patients is often associated with patient-centred care (PCC) [6], increase in patients' life values, shared decision-making between patients and professionals and patients' greater responsibility for their self-care [7]. PCC requires changes in the approach to what constitutes good care and creates value in the care process, both for the profession and the patients [8]. Studies have also shown that IT services based solely on the participation of the patients, where the professionals are not active users, tend to be not used at all [9]. The same is true when the systems are only designed to support a clinical perspective on self-care [10]. Other studies have found that what is often used are primarily electronic communication opportunities and access to reading professionals' notes, tracking referrals, and seeing test results [11]. Patients do not use the same degree of services that are designed to support their self-care, such as e.g. measurements over time, notes and care plans.

Here we would like to offer some first steps toward a working model for encouraging the development and use of an integrated support system for self-care for heart failure patients. Heart failure is a condition that has no cure. But by adhering to advice, life can be better and there are chances for expanding the range of things that are possible to do in the patient's everyday life. IT-based systems might play a role in supporting patients in improving their personal health care. However, it is necessary to understand properly how the IT system could contribute.

The aim of the paper is to investigate the self-care needs of heart failure patients, by understanding the issues they embrace in their self-care processes. To achieve this, we will first make an analysis of a series of interviews and gather different types of problem situations that could form the basis for developing a framework for this class of information systems. Based on the insights from this analysis, we present the diversity of needs and suggest a model for reflecting the situation of being a self-care giver. The paper eventually contributes with a framework for understanding the needs of this group of patients, with a clear focus on personal self-care support from the standpoint of the patient and on what is possible to do in everyday life.

2. Background Theory: Patient Perspectives and Self-care

There is a relatively clear consensus about the benefits of good self-care, at least on a general framework level. What exactly should be recommended is, on the other hand, very individual, depending on the total picture of the patient. Self-care is important for avoiding problems in connection with heart failure [12]. It may be viewed from different perspectives, but could, in general terms, include any activity that the patient performs in order to improve his or her situation which positively affects the outlooks for life expectancy and general well-being. More strictly, it could be narrowed down to the adherence to self-care advice, as provided by the healthcare system. In Sweden today (which forms the research context of the paper), there are clear instructions that self-care should be given as instructions based on healthcare personnel judgments on what is possible and safe for the patient. In Sweden, the issue of self-care is defined by law, covering on a general level [13] all forms of medical specialties. Here self-care is defined as health care activities that health care personnel have decided that the patients can perform on their own. The health care personnel should make an official decision on which care is needed, a plan for the conduct and a follow-up report on its effectiveness and then reconsider a continuation. This law ensures patient safety with regard to self-care [14].

Heart failure is a chronic illness, where the patient's knowledge and possibilities to perform self-care are highly important. A number of aspects on self-care have been identified. Ten factors are suggested including: experience, skill, motivation, culture, confidence, habits, function, cognition, support from others, and access to care [15]. Someone with a heart failure has to learn to live with the condition. This could mean for example changing one's lifestyle, eating certain food, taking medications, exercising etc. Although the instructions for self-care are known, there are problems concerning how to motivate heart failure patients. There are a number of things [16] that the

patient needs to have an insight into, namely the cause of the heart failure, symptoms, different treatments; indications, dosing, side effects of drugs, diet, exercise, immunization, travel, smoke, alcohol, drugs recommendations, sexual activity, sleep and breathing disorders as well as psychological aspects, contact with healthcare providers, and personal monitoring.

3. Empirical Study

The empirical study is based on 17 interviews with heart failure patients. The patients were strategically selected so that there is a variation of people with regard to age, gender, follow-up as well as the severity and etiology of the heart failure. The selected patients belong to Categories II-III, according to the New York Heart Association (NYHA). There is an equal number of female and male participants and the age ranges between 66 and 95 years. The time that passed since the patients received their heart failure diagnosis varied between 6 months and 10 years. The educational backgrounds of the patients included 12 patients with elementary school education, 2 with college degrees, and 2 who had received university education. The causes of heart failure varied among the patients, in that 12 individuals had ischemic heart disease, two had dilated cardiomyopathy, and two had heart valve disease.

The patients were interviewed at their homes or at the hospital. The interviews were recorded and the recordings were transcribed verbatim using the language of the patients, including dialects etc. The interviews were guided by a number of topics, including:

- What heart failure is; symptoms; experiences of having a heart failure.
- What self-care was conducted, with examples, like diet, physical exercise, fluid restriction, symptom monitoring and adherence to medications?
- Contacts with the health care.
- Relatives and the social situation.

4. Analysis of Empirical Material

The statements are selected on the basis of the need of support that the patient seems to be expressing, not on how easy or suitable it might be to build a system for that need. The statements should be seen as indicators or possible leads towards what could make up a module of a system or as a starting point for an innovative process towards an IT solution. No consideration has been taken of whether an IS/IT solution is plausible. The sample of interviews is not in itself big enough to make a clear judgment about what is most important; it should be understood as possibilities for further investigations. An example of the analysis made of interviews is presented in Table 1.

Table 1. Example of a key sentence analysis

Interview	Key statements from the patient concerning important problems or possibilities	The statements indicate that support is needed in the following areas:
Interview 14 Male	" ... [about heart failure] I really have no idea ... " " ... sometimes I am out of breath ... then I cannot walk more than 20 meters, and then have to stop and rest... " " ... [about doctor] can sit and talk to him, joke around and I mean, it feels like you have confidence in him, and I have never discovered any strange words ... " " ... it is clear that you listen to those that you have confidence in ... " " ... all those damn pills that you are supposed to eat, and to remember what they are ... " " ... a feeling that there is something strange	- Support with easy, understandable information on heart failure, fitting for the patient's situation. - Support for creating confidence between patient and doctor for adherence to self-care advice. - Support with understanding and keeping track of medicines and when to take them. - Help with understanding body signals and feelings and how they relate to the heart failure symptoms. - Help with finding and organizing suitable ways of exercising - Help with motivation to exercise

with the body as such ... "

" ... I got myself one of those exercising bikes and it worked well until my knees started to hurt

...

"... it is too easy to avoid taking a walk...I need some kind of whip"

5. Result: Planning Approach for Patient-centred Self-care Support Systems

The interviews show that, generally speaking, the areas of concern match the expected self-care areas as seen in the literature. Both pinpoint things that are not possible. Finding ways of avoiding problem situations and getting proper support are other important issues in most of the interviews. However, it also clear that the situation varies greatly among different participants, depending on the current symptoms of heart failure, the general state of the patient, as well as on age and on other illnesses.

5.1 Self-care activities

Many of the situations captured in the interviews are not exactly information problems; they could, however, form starting points for solutions, with the support system as part of a solution containing a number of activities. Here we aim for a broad classification of areas for self-care (Table 2) that could be targeted for development. It is important to constantly keep a clear focus on the situation that patients experience in their everyday lives.

Table 2. Areas of self-care support

Selection of areas	Needs of individual patients, examples from interviews	Examples of possible information support types
Exercising	Most patients try to do things they used to do, but in a different way. It is important to feel safe, having others around or being able to stop when necessary etc. (<i>"I got myself one of those exercising bikes and it worked well until my knees started to hurt"</i>)	<i>Finding</i> good and safe alternatives, <i>scheduling</i> of activities, <i>self-test and analysis</i> of abilities.
Battle against being tired, out of breath, or dizzy.	All the patients mention not being able to do what you used to do as a major aspect of living with a heart failure.	Support to continue with their interests, but maybe on another level.
Home services, cleaning, washing dishes, etc.	Some do their own housework but most have service help from public organizations or have relatives that help them. Just a few see this as a way to exercise.	<i>Stimulate</i> viewing it as an exercise by measuring everyday activities. <i>Finding</i> and <i>booking/payments</i> of services.
Relatives, family, involvement in care, understanding of heart failure	Here there are differences in the group, where some receive good help from their partners or from children that live close. Others have relatives that do not understand the situation or live far away. And some do not like to involve relatives – not wanting to have someone telling them what not to do.	Specialized information directed towards the needs of relatives. Giving access to relatives living far away.
Food, preparing, choice of diet.	Many mention diet as a way to take care of themselves, and try to lose or keep their weight, feeling that it is related to overall well-being. Others want to keep the good in life.	Information about recipes, learning about food preparation and nutritional facts. Support to make the right choices.

Trips, Transportation, Travels, service, cars, etc.	Most patients limit themselves to short trips (no trips abroad), some have their own car, others have partly financed public taxi service and a few use public transportation.	<i>Information</i> about available services, locally and internationally. Being able to <i>feel safe</i> , even if something should happen, on the trip and in a new location.
Social life, visits, parties, maintaining friendship	There are differences in how social they are. Many of them have a social life that makes it easier to get new contacts and others rely on an existing network and have a feeling that all the best friends have passed.	Support with finding and meeting with friends and making new friends through online services.
Anxiety, depression, fear of your own and your family's future.	There are different strategies with some focusing on making the best of life for themselves and for their family and others thinking that life is ending and that there is nothing to do about it.	Facts about problematic areas. Training of methods for fear control. Sharing experiences with those in the same situation.
Fluid restriction	Many patients mention that they keep track of how much they drink during the day (filling a pitcher of water and drinking from that), or feel it hard, as there are liquids in all food intake, while others are not aware of that.	<i>Scheduling</i> of intakes, <i>learning</i> methods for control. Help to monitor amount of liquids in diet and understand relationship with edema.
Self-monitoring, recognition of symptoms, weight, etc.	Many of them mention that they keep daily track of their weight and have experienced edema and shortness of breath when doing repeated activities. Some measure it, while others do not. (<i>"...a feeling that there is something strange with the body as such ..."</i>)	<i>Taking measures, making records of changes. Learning</i> , gaining understanding. <i>Stimulation</i> to take action because of the result and knowing what to do.
Facilitate life style changes	Many are not able to live as before. Those that have reduced their activities have more activities than those that need to start being more active. It is true for stopping smoking, drinking and reducing weight. Having a feeling that you make progress makes it easier. (<i>"it is too easy to avoid taking a walk ...I need some kind of whip"</i>)	<i>Facts</i> about the relation between action and outcomes, <i>Measurement</i> of progress.
Medications, taking the right doses, side effects	Medication is the major aspect mentioned. Many tell that they would like to restrict the use of medicine, but have experienced that the medicine is necessary when they tested to be without. Some have had problems with side effects or interference of medicine. Many know how they can titrate the medicine (<i>"all those damn pills that you are supposed to eat, and to remember what they are"</i>)	<i>Scheduling</i> of intakes, <i>Tracking</i> of causes and effects and improvements of health and symptoms. Sharing that with caregivers for possible titration of medicine. <i>Knowing</i> how to change ordination.
Knowledge of heart failure	Very few can give a clear view of what heart failure is or can tell about all aspects of self-care of heart failure. They mention that caregivers have talked about it, having seen a video, or obtained a brochure, but do not remember clearly what it is, but talking later about what they do for caring about themselves they mention many more aspects of self-care.	<i>Facts</i> , pedagogic presentation easy accessible when needed.

(*"[about heart failure] I really have no idea."*)

Easy access to the health care organizations	<p>Important for many is to be able to get quickly in contact with a care giver they can understand and easily talk with. Others mention very sporadic contacts with caregivers and have no close experience of a caring feeling from health organizations.</p> <p><i>("[about doctor] can sit and talk to him, joke around and I mean, it feels like you have confidence for him, and I have never discovered any strange words")</i></p>	<p><i>Booking systems, contact information and possibility to make quick contact.</i></p>
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These areas are clearly a reflection of the views of the guidelines for the self-management of heart failure [16]. These in turn have guided the questions of the interviews and directed the attention of the patients. Still, the answers show that most patients have a mix of problems, strategies and successes in these areas. Since they differ in many respects, it is important to consider the dimension of needs when designing IT solutions. There are clear connections between many of these areas and, in practice, the support system must be developed with a notion and understanding of patients as individuals with their own goals and life expectancy.

5.2. Self-care process

The major aspects of the self-care process include the maintenance of self-care activities and the monitoring of changes in symptoms and progress. They also include knowing what to do when changes occur [15]. In the interviews and in the possible areas of support that have been identified there seem to be some important trade-offs to be made. On the one hand, it is important to keep active, do what is possible and go on with a "normal life". On the other hand, there is a need for getting help and having a good life that works in practice. There are a number of observable points that the development of possible support systems must reflect on. This situation could be translated into different generic strategies for self-care support which would fit into different life situations.

There is diversity in the background conditions of the patient. Before you start, you need to make a decision to be active and do self-care. The decision-making looks very different depending on the different conditions of patients' lives, which will affect their needs of support of e-health:

- There is an initial diversity in lifestyle before the heart failure is confirmed, which affects what, how and which self-care is needed. If the patient has been active in sports and been eating well, the issue then is to keep the healthy living and also to reduce the activity level so that it is suitable for the new condition. A patient who starts from a non-healthy lifestyle is a smoker or consumes a large amount of alcohol, requires much more action and decision-making.
- There is diversity in life situations, which affects how active they need to be (judging by the patients themselves or by their environment). For those who are employed, do voluntary work or very actively support their own family it is not only a question of changing their own life. Many others who need to understand the new situation may be involved in making changes and. This can make it either harder or easier to conduct the self-care, depending on the attitudes of the environment.
- There is diversity in the social situation in their lives. Some have an active partner, family or friends and/or are active in different associations, whereas others have just a few social connections that could inspire and help them. They also have different strategies for how to involve these in their self-care activities, with some of them unwilling to involve others. Some also take responsibility over other people's feelings about their situation. Those who are lonely tell about the loss of friends and the difficulty of finding new ones.

There is also diversity in the dynamic process of the patient over time.

- There is diversity in the severity of the illness (heart failure) and the patients' overall health condition, in how affected they are and what symptoms they have, which may vary from day to day, but also in the long-term. If they have fewer effects and symptoms they may be able to live as

before and are not as motivated to make major lifestyle changes. Having severe effects and symptoms may affect their ability to actually perform self-care themselves.

- Self-care does not come by itself. We can see a need of support of the learning process for the patient to conduct reflective self-care. The different individuals mention support of different types in their understanding of health care. Most of them mention communication and teaching from health care professionals, others documents handed out or video shows. There are also some who report of learning from doing and measuring different results in symptoms when conducting and testing different medication ordinations, self-care and other activities. There will be differences in the need for understanding between a newcomer and an experienced self-care giver. They report differences in how they learned self-management and gained understanding of their situation.
- Their life and social situation can change and thus the needs will change. There are also effects from the disease such as depression and cognitive impairment which affect their ability and increase the need for support.

There are different actors involved in the self-care process. There is diversity in who is conducting the care, from those that take care of themselves to those that get help by others, see Table 3. Depending on who provides the care, it will also change the role of the relatives and the professionals in care, and thus their need of support for e-health.

When professionals and distant relatives take more responsibility there will be a greater need for tele-monitoring solutions. Who does the care will also vary over the time, when situations change. It is important that role changes can be made as smoothly as possible.

Table 3. Different needs depending on patient strategies to conduct self-care

	Be active	Active relatives	Professionals
Home services	Understanding cleaning and similar activities as a way of getting exercise, knowing when it becomes too exhausting.	Supporting spouse to take greater responsibility. Family understanding and helping with harder issues.	Support in getting help, knowing the home situation, ordering service.
Medications	Support in remembering, trying out, experimenting and finding a personal balance between symptoms and side effects.	Helping in remembering, knowing how and when to get consulting, helping and becoming a partner in the discussion with health care professionals.	Support in supplying accurate drug prescriptions and ordination plan, knowing what the patient is taking according to the plan, and being interactive in titration and in consulting.
Understanding HF	Giving support to find out on your own, internet addresses, examples of literature, experience from individual documentation of symptoms and progress.	Support in understanding the situation and in how heart failure affects living.	Giving exact knowledge suitable for the individual, including simplified explanations in the specific context.
Training	Taking care of good old habits and acquiring a feeling of normality. Support in taking up new exercise alternatives.	Support in inspiring and accompanying the patient, in knowing what different exercises suit the patient.	Support in encouraging necessary actions to keep basic functions, support in offering safe group-training possibilities.
Relatives, friends	Making it easier to keep up with old friends and meet relatives in family parties, receiving support to find new acquaintances.	Support in understanding the importance of social life. Making it easier to travel and communicate at a distance.	Support in knowing how to find support in everyday life from friends/relatives for

			practical purposes.
Contacts with health care organizations	Support in knowing and deciding when and how to get care consulting.	Support in knowing and deciding when and how to get care consulting.	Support in supervision and active outreach to ensure that the right care is provided at the right time.
Diet, fluid intake	Support in knowing about connections between intake of drinks and food and symptoms for informed decisions about diet.	Support in helping to make the right choices.	Support in giving specific daily recommendations, deliveries of food, and measurement of liquid intakes.

6. Concluding discussion

Understanding the self-care situation from the patient perspective (cf. [6]) shows that there are more activities conducted than described in the guidelines of care (cf. [16]). How to adjust the ways patients with heart failure live as well as their professional and social lives to suit their new situation (including self-care activities) is a major challenge for them. Patient-focused solutions need to consider the major aspects of the patients' environment, in order to be helpful for them. It is also necessary to consider the diversity of the patients' needs, being able to support patients at different stages of their understanding of and practice in the self-care process. There is also a dynamic factor that must be considered, the increased or decreased abilities in conducting self-care over time, depending on patients' own understanding and learning of self-care, the progression of the illness and changes in their environment. There is the additional necessity to interact with and involve other actors that the patients feel are important in conducting the self-care, such as active relatives and their health care contacts in the solution, where the patients are empowered to choose who can share, take part, give support and make changes in the solution.

Future studies of this group of patients should take a clear step towards considering the everyday life of the patients. How can the design of patient-centred e-health take into account the diversity of patients' needs, the dynamic factor of those needs and the interactions with environment, relatives and health care givers?

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